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HOURS OF OPERATION
Monday 10am-2pm
Tuesday 10am-2pm
Thursday 10am-2pm
(Closed Public Holidays)

The Bridge of Support at The Royal Melbourne Hospital operates on alternate Tuesdays (12-4pm) and Thursdays (10am-2pm).

BreaCan
GYNAECOLOGICAL
& BREAST CANCER SUPPORT

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BreaCan is a service of Women's Health Victoria, a statewide women's health promotion, information and advocacy service.



BreaCan acknowledges the support of the Victorian Government.



A Decade in Review
2003-2013

10 YEARS BreaCan

“I believe the satisfaction I feel with my treatment is largely attributed to the information and support I got from BreaCan.” *Jeanette*



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

“A place of tremendous unspoken caring...” *Carole*



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COVER: Like a patchwork quilt,
 BreaCan is more than the sum of its parts.

QUOTES: Please note that some names have
 been changed to protect people's privacy.



FOREWORD

THE HON. DAVID DAVIS

Minister for Health and Ageing, State Government of Victoria

In the words of anthropologist and writer Margaret Mead:

“Never doubt that a small group of thoughtful, committed people can change the world. Indeed it is the only thing that ever has”.

Many years ago, a group of passionate, determined and committed women who had personally experienced breast cancer had a vision for a consumer-run support and information service. I believe their vision has been fulfilled in BreaCan. The Victorian Government is very proud to have supported the establishment and development of this unique, award winning service.

BreaCan has been supporting people affected by breast cancer for 10 years. Since its establishment in 2003, BreaCan has responded to the needs of women, their families and loved ones. Today the service has been expanded to people affected by a gynaecological cancer in recognition of the unique needs of this population.

The founding tenet of BreaCan was, and still is, a service *run by women for women*. At the heart of BreaCan are the volunteers, many of whom have been part of the service since it began. BreaCan's volunteer training and support model is unparalleled. These wonderful volunteers are the 'frontline' of BreaCan's Resource Centre and forums, and have touched the lives of many. Their lived experience of the cancer journey has enabled them to generate innovative programs that respond to unmet needs, such as the *Bridge of Support* program – a hospital-based 'in-reach' program for women receiving treatment.

BreaCan has a strong commitment to reaching women across Victoria, including those from culturally and linguistically diverse backgrounds. In recent years BreaCan has provided 'virtual support' by offering podcasts alongside community forums to rural service users and will soon add vodcasts and Skype. BreaCan's strength as a community based care provider is recognised across the cancer sector.

I commend BreaCan volunteers and staff for delivering an exceptional, high-quality service to those affected by a gynaecological or breast cancer and wish the service all the very best for the next 10 years. I am proud to support BreaCan with funding to continue its valuable activities, including more than \$630,000 in the 2013-14 State Budget.

Madly doing the doggy paddle

MAY'S STORY

It was almost a month after I turned 40 when I was diagnosed with ovarian cancer. My family is no stranger to cancer, as my Mum passed away from it five years before my diagnosis when she was only 60 years old.

I did what most women in my position would do, put my faith in my wonderful medical team and had treatment, which included surgery to remove the tumour, chemotherapy and a radical hysterectomy. And so, almost three months after my 40th birthday, I was childless with no prospect of having children, bald, as I had started chemotherapy, and the owner of a six-inch scar running down from my belly button. I am very lucky to have a supportive family. My husband, Dad and brother were there with me all the way, as were my girlfriends. On the outside I was fine, but inside I was madly doing the doggy paddle – physically my body had changed, but my emotions were still trying to catch up.

While I was having chemo, I was invited to Breacan to an event for women with from gynaecological cancers. Being generally inquisitive and with time on my hands, I decided to attend. The trip to the city was a good excuse to get out and a nice break from my daily routine at that time. The moment I walked through the door I felt warmth from the genuine smiles that greeted me. Even now, six years later, I still get this feeling of acceptance when I visit. And from that point on, I waited eagerly for the quarterly newsletters so I could mark off and book in for the myriad of sessions. From Sashiko to art, music and word therapies, to reflexology, to medical and psychology information sessions, I relished the opportunity to heal by accepting a helpful guiding hand, which is what Breacan was and still is for me. Along the way, I met many beautiful women who have become my friends. We connected while writing lyrics at a music therapy session and stitching during Sashiko, we shared a knowing glance, a coffee and a few laughs (and tears) and we can now support each other through life, not just our cancer experiences.

There are images of what Breacan means to me, a big sister or me as a baby in a mother's womb insulated, loved and protected at a most vulnerable time in my life. By providing information and emotional support, Breacan gave me the chance to enrich my mind, understand and work with my circumstances, gave my emotions a lift and offered gentle assurances. Breacan also gave me the strength to find my inner resources and to have hope for the future. Thank you Breacan, you have touched many lives.

“On the outside I was fine, but inside I was madly doing the doggy paddle – physically my body had changed, but my emotions were still trying to catch up.”



A Decade in Review 2003–2013



Official Breacan launch 11 April 2003

TOP: Helen Shepherd, Di Missen, Lyn Swinburne and Sue Lockwood with the first group of peer support volunteers



In February 2002, Women's Health Victoria (WHV) and the Breast Cancer Action Group (BCAG) led a consortium of women's health services tendering for a three-year project to pilot a consumer-focused breast cancer resource centre. That tender was successful and on 11 April 2003, the then Minister for Health Bronwyn Pike launched Breacan, an innovative information, support and referral service for women with breast cancer, their families and friends.

The idea behind Breacan came from a group of women who, because of their personal experiences, understood the need for women diagnosed with breast cancer to receive high quality, accurate, up-to-date information and importantly to have the chance to meet other women who had survived and understand what they were going through. These women felt very strongly that such a place needed to be away from treatment centres and in a nurturing, women-friendly environment. A decade on and we have become an award-winning service for women living with breast cancer or a gynaecological cancer. The service has supported, connected and informed thousands of women, their partners, carers, friends and family and helped them all to deal with the challenges of a cancer diagnosis.

Breacan has been established, shaped and supported by individuals and organisations committed to quality supportive care and by the

women who have used it. This *Decade in Review* is a testament to the value of Breacan and its unique and effective model of information and support for women affected by breast and gynaecological cancers and their partners, families and friends. At the heart of this model has been the extremely successful peer support volunteer and training program. As a consumer-centred, responsive and innovative service, our impact on the lives of women living with cancer and those around them can be clearly seen through the personal stories, quotes and images included here.

The next decade promises to be as innovative and supportive as the first. Increased awareness, early detection and better treatments have meant more women are being diagnosed and living well with cancer. The need for quality, consumer-focused information and support is more important than ever. We are focused on ensuring that every Victorian woman diagnosed with breast or a gynaecological cancer is supported to live well during treatment and beyond.

“The current idea is for a central place where women, their carers and partners come for information on breast cancer. A centre run by women for women which was independent of hospitals and other medical services, and that volunteers, ie. women who have breast cancer, would be the key to its success.”

SUE LOCKWOOD, 2002

“Sue Lockwood, fellow Committee member and I lobbied long and hard over a number of years to have a drop-in centre established in Melbourne and were delighted along with Marilyn Beaumont, also a member of the Committee and CEO of Women's Health Victoria, when we achieved that goal, and Breacan as it was later named, came into existence.”

LYN SWINBURNE, former CEO and founder of Breast Cancer Network Australia and Chair of the then Breast Services Enhancement Program's Implementation Advisory Committee of the Department of Human Services, 2013

Manager's Message

LEE KENNEDY BreaCan Manager



As the new kid on the block, I'd like to thank my predecessor, Alison Amos, whose undeniable energy and passion have been much appreciated by all. However, at this important milestone, I think it's also fitting to acknowledge the work undertaken by BreaCan's founding manager Di Missen, who has led the implementation of the BreaCan idea from its humble beginnings to a robust and award-winning service. Also important has been the contributions from all staff who have helped establish the service and shape the warm and supportive culture of BreaCan. The commitment, consideration and care demonstrated by all these women have been extraordinary and provide a very high standard to aspire to.

One of the highlights of my new role is that it has introduced me to a great band of inspirational women who are the volunteers of BreaCan. Without exception, these resilient women demonstrate skills and abilities that cannot be taken for granted. On a daily basis these talents are used to ease the confusion, fear and concern of women who make contact with the centre as well as their friends and families. Their commitment to continued learning and for some, their long association with the service (our retention rate is very high), means whenever I am out and about at meetings, forums or conferences I'm always accepting compliments on their behalf because their work is so highly valued. It really is a privilege to work with and for these women.

In May we were able to provide a small token of our appreciation for some of our longest serving volunteers at our National Volunteer Week celebration. Georgie Crozier (Parliamentary Secretary for Health, Parliamentary Secretary for Mental Health, MLA for Southern Metropolitan Region), presented our 10-year volunteers (Heather, Sandra, Ellen, Rhonda, and Mary) with framed service certificates. Ang, Betty and Janine weren't able to make it on the day, but have also received theirs.

We also continue to work in partnership with a range of individuals and organisations that share our goal of empowering women with cancer to live well. In partnerships, we bring our unique peer support model to the table and we work closely with organisations whose skills and experience complement this. Our work with the Royal Women's Hospital, The Royal Melbourne Hospital and Western Health on a pilot project for women at the end of active treatment typifies this. We assist in bringing a consumer lens to the process as well as play a role in evaluation.

Looking to the future, the State Government provided some funds for us to extend our reach through the use of new and emerging communication technologies. We're looking forward to being able to use Skype and video conferencing for women unable to get to the city because of distance or illness. In addition, we have some iPads that will help us connect women to online digital resources both in the Resource Centre and at the *Bridge of Support*.

Moving with the times is a challenge for us all as we balance the need to hold on to what we value and what works well, while responding to the new realities around us. Just as treatment for women with breast and gynaecological cancers has come a long way in a decade and will no doubt continue to improve in the next one, so shall BreaCan.

"Start small and do it well."

DI MISSEN, BreaCan Manager (2002–2011), 2003



"Congratulations to BreaCan on achieving a great milestone. From humble beginnings as a pilot project to the vibrant and growing service that it is today, BreaCan provides a stunning example of the value of peer support. There are so many achievements to celebrate through the provision of this unique service and the safe and nurturing environment that it creates for women, carers, family members and friends to receive compassionate support, to be informed and empowered to live well."

ALISON AMOS, CEO Ovarian Cancer Australia and former BreaCan Manager (2011–2012), 2013

Sharing my story

TRISHA'S STORY

I have always kept busy with family and other interests. Like most of us, I took my body for granted. Then one day in December 1999, wow what a New Year that was, I had the shock of someone telling me, "Sorry, but you have breast cancer". Thank goodness for family support, Breast Care Nurses and my lovely friends, they got me through.

I faced it full on because I wanted to get on with life. But then I was diagnosed with another primary cancer and my journey started all over again. I gathered together all the information I could find and joined the G.R.A.C.E (Geelong Regional Activities/Caring and Education Group) Breast Cancer Support Group in Geelong, which I've been in touch with since 2003. I have also talked to many other women, as I really believe it helps to share our stories.

In my search for information, I did visit BreaCan, as well as Breast Cancer Network Australia. When you first get diagnosed you are given so many papers, books and info sheets. I'd look at them and think I'll read them tomorrow, as it's all too much, or put them in a drawer until I needed them. I read what was relevant to me at the time and that's how I have dealt with each stage.

When I realised breast cancer is so widespread I wanted to help others. I knew there was such a lot of information to tap into through BreaCan and there are so many lovely ladies to talk to if you go down to any session. You can ring for a chat or go down and sit with a cup of coffee and you realise you're not alone. Reading *What's On* each time it comes out means you can see what there is for you to go down to Melbourne and be a part of.

My favourite session with BreaCan was the art one where we explored all the emotions we had experienced. It was an amazing session where we went through and talked about our journeys. Wow, how we are all so different in what our goals are, our ages and our different needs, but sharing stories can be a great healer.

My thanks are for my very patient husband, bless him, my family, and my photography. I love being out and about looking for wild orchids or travelling along the coast, looking over cliffs for the southern right whales. To sit or stand and get close to one of these wonderful creatures takes away my fears of what's ahead as I know my cancer is not finished with me yet. I pray I get to see them or my seasonal wild orchid again next year; that's how I deal with my breast cancer.



"Wow, how we are all so different in what our goals are, our ages and our different needs, but sharing stories can be a great healer."



Our History in Highlights



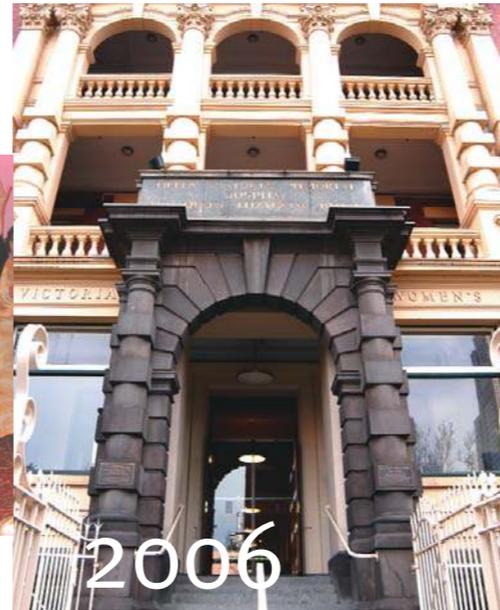
2003



2004



2005



2006

Our History in Highlights



2007

About Us

BreaCan is a unique information and support service for people throughout Victoria who are affected by a gynaecological or breast cancer. A service of Women's Health Victoria, we are committed to providing a women-focused service that is shaped by what women say. Since 2003, we have provided high quality supportive care through our city-based Resource Centre and in communities across Victoria.

We are focused on ensuring that every Victorian woman diagnosed with breast or a gynaecological cancer is supported to live well during treatment and beyond.

2002

Recognising a need for support and information outside of the hospital setting, women living with breast cancer lobby the government to establish a consumer-focused drop-in centre.

A model of supportive care is developed based on a framework designed by the Ontario Cancer Treatment and Research Foundation, but incorporating a unique model of volunteer face-to-face peer support.

2003

15 women begin the peer support training program with 12 women completing the course, and they are now ready to provide support when the service opens.

11 April, the then Health Minister Bronwyn Pike launches BreaCan, and the doors to the service open for business on 14 April.

In July, the Feel Good Gentle Exercise Program commences, providing fortnightly exercise sessions specifically for women with breast cancer.

2004

Identifying a gap in service provision and recognising the unique needs of women with advanced cancer, BreaCan establishes the *Making Connections* program for women living with advanced disease/secondaries.

A second group of peer support volunteers are trained, and this group includes a woman living with advanced cancer.

2005

BreaCan secures recurrent funding from the Department of Human Services after a comprehensive evaluation of our service shows its significant impact on the wellbeing of women living with breast cancer.

BreaCan incorporates creative therapy programs like *A Chorus of Women*, which provide extended opportunities for expression while impacting on personal confidence, empowerment and growth.

2006

Experiencing rapid growth, BreaCan moves to the ground floor of the Queen Victoria Women's Centre. We launch our 1300 number, so that people in rural Victoria can ring us for the cost of a local call.

A third intake of women completes the eight-week peer support training program, increasing the number of peer support volunteers to 30.

With funding from the Cancer Council, BreaCan fills an information gap, creating a multimedia resource for young women diagnosed with breast cancer. *Young Women Talking* is sent all over the country.

2007

BreaCan expands to providing support and information to women with uterine, ovarian, cervical and other types of gynaecological cancer.

BreaCan's value is publically acknowledged through winning a Victorian Public Health Care Award for Innovations in Models of Care.

Acknowledging the increasing body of evidence showing the effects some complementary therapies have on providing relief to women living with cancer and the side effects of treatment, BreaCan introduces a free reflexology program.

"I was diagnosed with breast cancer 20 years ago. This was an era when breast cancer-specific support groups were non-existent, advocacy groups were unavailable, and there was limited recognition of the differing support needs of newly diagnosed women. Women were not actively encouraged to seek information about their diagnosis and treatment options, support for family and carers was minimal and breast cancer information was very basic and lacked detail. How far we have come!"

AVIS MCPHEE, Consumer Advocate, 2013



Our History in Highlights



2008

2010

2012

2008

Breacan establishes an advisory group to provide advice, guidance and support for service development and deliverables.

The pool of peer support volunteers extends to include two women living with a gynaecological cancer.

2009

Breacan launches its stand alone website including access to podcasts of key information sessions.

Funding is secured from Cancer Australia to focus on identifying and addressing the needs of women from culturally and linguistically diverse backgrounds.

2010

The *Bridge of Support* pilot project begins at The Royal Melbourne Hospital, taking volunteer peer support to where the women are during their diagnosis and treatment.

Taking more services to where the women are, Breacan develops and trials *Steps for Fun and Fitness*, a five-week group exercise program delivered within local communities.

Breacan implements a Rural and Regional Expressions of Interest Program to increase access to information and support for women living in rural and remote areas.

2011

Breacan records the highest number of contacts in a financial year (2,446), 300 more than the previous year.

2012

A collaboration is established with the Breast Service at Royal Melbourne and Royal Women's Hospitals, Western Health, and the Inner North West Medicare Local as part of the Victorian Cancer Survivorship Program, to improve the care for women at the end of active treatment.

Volunteer participation in Breacan's strategic directions is strengthened by establishing the Breacan Volunteer Reference Group.

2013

14 April marks 10 years of providing quality information and support to women living with cancer, their friends and family.

We continue to grow, with the development of different and innovative ways to create access to information and support particularly through the use of new and emerging technologies.

Don't walk alone

MARIE'S STORY

Attending my regular breast screening in 2007, I was shattered to be told that my screen had come back with some inconsistencies. I sat in the consulting rooms of the specialist in North Melbourne with thoughts racing around my head at 100 miles an hour.

I was thinking about how this could be happening to me, I am a healthy woman with no signs of illness, no symptoms and no pain, so how could this be happening? I thought of my children and my husband and how this will affect them and I sat there afraid of how my future was going to change. As humans we always fear and think of the worst scenario... will I survive?

Things progressed extremely quickly for me. Before I knew it I was being advised that I needed to have surgery. My mind stopped – I could see the doctor's mouth moving and I could hear the words coming out of his mouth, but I didn't want to believe what he was saying. There was a roller coaster of emotions: fear, sadness, anger, confusion and an abundance of hurt. Waking up from my surgery feeling excruciating pain I could see my children and husband surrounding me. I looked towards them for answers and reassurance. My family and friends were a great support, however I found that during the course of my treatment I was not able to share certain things with them.

It was 12 months after my initial diagnosis and my course of chemotherapy that I remembered my initial meeting with Kate Cardigan that I'd had before my surgery. She'd provided me with an abundance of information for the support that would be available to me, and she was gentle and had offered reassurance. But at the time of the surgery and in the time that followed I was in no state of mind to accept or be open to external help. However, as the months rolled on I realised that I needed help.

Looking back now I feel that it was the most positive decision I made. The people who I met through Breacan have been supportive, empathetic, kind, warm and above all understanding and non-judgemental. The services that have been provided to me – relaxation course, reflexology and many other things – have been a positive contribution to the course of my recovery. The only way I am able to sum up my experience with Breacan is that it has become my second home. I am and will always be eternally grateful for all their help and support.

I strongly encourage others who find themselves in a similar position to reach out and take the help that's available to you. No one is able to take away the personal pain that you are going through, however having someone to hold your hand or walk beside you during this trying time makes the journey a little easier!

“No one is able to take away the personal pain that you are going through, however having someone to hold your hand or walk beside you during this trying time makes the journey a little easier!”



Statistical Snapshot

Contacts

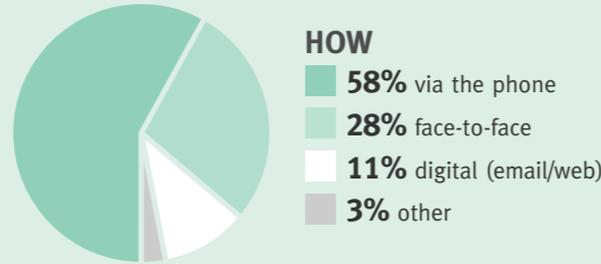
Over the decade we have touched the lives of many through our direct services.

20,554

contacts

Data period: April 2003 – June 2013.

9,212 one-on-one contacts



Contacts data period: April 2003 – June 2013.
How and Outcomes data period: July 2008 – June 2013.

8,882 Group attendees

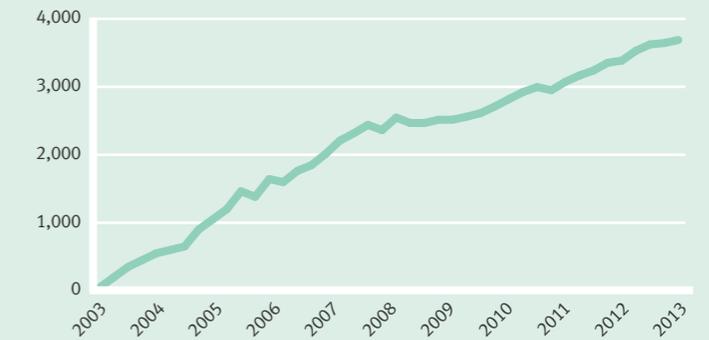


Data period: April 2003 – June 2013.

802 Bridge of Support contacts

1,658 Health professional contacts

Mailing list contacts

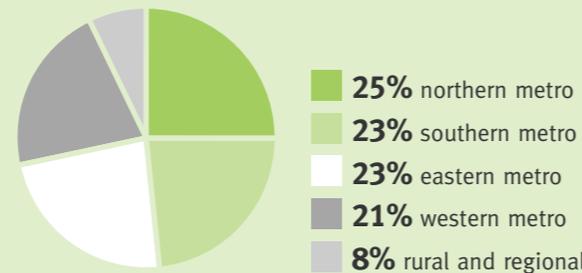


People

Geographic origin

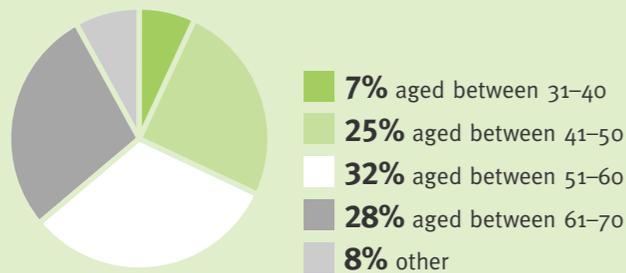


Group and individual contacts where country of birth has been identified. 24% (compared with 17% in the Victorian population).



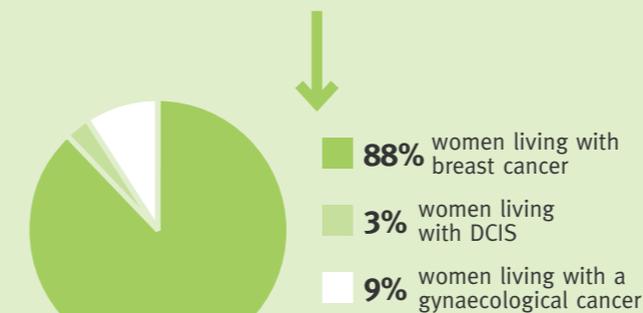
Group and individual contacts where postcode is known.
Data period: July 2008 – June 2013.

Age range



Group and individual contacts where age is known.
Data period July 2008 – June 2013.
Range: 0–20, 21–30, 71–80 & 80+ omitted.

Nature of diagnosis



Group and individual contacts where diagnosis and status is known.
Data period: July 2008 – June 2013.

Volunteers

In the Resource Centre

6 x 40 hour volunteer training program = 71 trained Peer Support Volunteers = 2 volunteers x 4 hours per session = 8 x 3 sessions per week = 24 x 48 weeks per year = 1,152 hours x 10 years =

11,520 hours of trained volunteer peer support

Peer support commenced in April 2003.

Bridge of Support

1 BoS training program = 9 hospital trained peer support volunteers = an average of 1.5 volunteers x 4 hour session per week = 6 x 48 weeks per year = 288 hours x 3.25 years =

936 hours of peer support in a hospital setting

Bridge of Support commenced in April 2010.

Supporting Women

We recognise that every consumer's experience of breast cancer is unique and must be seen in the broader context of their lives.

We will share experience. We will provide a welcoming, accessible and safe environment.

Over the past decade we have learnt that a cancer diagnosis touches every aspect of a person's life. Giving people time is fundamental to supporting them during treatment and beyond.

Each woman's experience of cancer is different and influenced by a multitude of factors. Breacan focuses on providing a service that is tailored to the needs of each individual for as long as their need exists. We support women to identify and manage the areas in their lives most impacted by a cancer diagnosis.



One-on-one Peer Support

82% of all one-on-one contacts received peer support

We are committed to empowering women to make informed choices about their care and treatment. For many women, especially in the early stages of diagnosis and treatment, one-on-one contact is a critical form of support.

The establishment of the Breacan volunteer peer support program has been fundamental to the provision of quality one-on-one supportive care. The recruitment and training of volunteers has been comprehensively undertaken and ensures that the support provided either face-to-face, via phone or email is not only carried out by women with a lived experience of cancer, but by women trained to listen, support and inform.

The volunteers are a group of diverse women and the training program requires them to frame their own experiences and refine their communication skills in a way that equips them to share their experiences with other women affected by cancer without providing advice.

In the past decade 82 per cent of all one-on-one contacts received some form of support in their interaction with the service. For many women, hearing the experiences of others validates their own and provides strength, insight and an opportunity to reflect. Connecting and communicating with people who have been there gives a genuine and realistic view of life after a cancer diagnosis, while at the same time alleviating the anxiety of 'what next'.

We will continue to develop the trained volunteer peer support program along with expanding our ability to connect with women one-on-one, both in the physical and digital world.

"By sharing my feelings with others, it helps take some of the fear out of having a cancer diagnosis and enables me to move on with my life."

Jennifer, 2005

Supporting Women

Extending to Women with Gynaecological Cancer

Over 1,200 Victorian women are diagnosed with a gynaecological cancer every year*

The success of the Breacan service model in supporting and informing women with breast cancer was acknowledged by the Department of Health in 2007. At the same time, the model was perceived as having significant transferrable potential to other cancers, most specifically to women with a gynaecological cancer. It was agreed that as part of ongoing service delivery, we would extend our service to include women living with uterine, ovarian, cervical, vulval, vaginal and placental cancers.

We have worked hard over the past five years to provide supportive care for women living with a gynaecological cancer, their friends and family. The library, *What's On* information sessions, *Making Connections* program and most importantly the volunteer peer support program have all expanded to provide for the support and information needs of women living with a gynaecological cancer. We have taken several steps to establish partnerships in the sector and create awareness around our

expanded role. Women who have accessed the service have felt welcomed and had their needs met, however we recognise that there are still a vast number of women diagnosed with a gynaecological cancer who are unaware of our service and would value support.

Our dedication and commitment to providing information and support to women with a gynaecological cancer will continue as we look at new and innovative ways to communicate our service to the sector and the women diagnosed.

*Note: Canstat, Cancer Council Victoria 2010.

"You never know what a place will be like when you first walk in the door. But Breacan... it has just felt so welcoming and comfortable."

Toni, 2007



Peer support volunteers Kirsten and Aaltje at jointly hosted Breacan and OCA forum for women living with gynaecological cancer

Massage and Reflexology

567 free reflexology appointments = 375 Hours = \$22,440*

During the past decade there has been much research done on the potential health benefits of complementary therapies for people living with cancer. There is now growing evidence that some complementary therapies such as reflexology can offer relief to some women living with cancer and the side effects of treatment.

Since 2007, we have been offering free 40-minute reflexology appointments to women with breast or a gynaecological cancer and most recently to those who have connected with the service through our *Bridge of Support* program at The Royal Melbourne Hospital. Reflexology has been an effective and gentle entry point into the service for many women. Internal evaluations of the sessions showed us that 94 per cent of women who responded stated they found the session relaxing, and 50 per cent said the session had prompted them to seek out other forms of relaxation and self care.

By offering more than just a place where women can connect, we give women the opportunity to experience other forms of support that they may not have come into contact with. Reflexology, massage, meditation and other therapies are essential elements in the provision of holistic supportive care and aid in the development of self-care management strategies.

*Note: Session is 40 minutes in duration at a cost of \$60 for the period May 2007 – Jun 2013.

"After treatment the body and self are a bit battered and being in such a positive place (reflexology session) enhanced my feeling of self worth and esteem."

Sue, 2008



Supporting Women



Feel Good Gentle Exercise Program

231 sessions 2,401 participants*

Similar to complementary therapies, significant research has been undertaken to substantiate and quantify the benefits of exercise after a cancer diagnosis. Among this research is increasing evidence that physical activity not only contributes to general wellbeing, but may also reduce the risk of recurrence after a cancer diagnosis.

Many women face significant physical and emotional issues as a result of a cancer diagnosis. Surgery and treatment can have such long-lasting effects that women feel that they have to reconnect to their physical self.



“The group remains an anchor and an inspiration, even as I am well recovered.”
Bridget, 2009

Our fortnightly Feel Good Gentle Exercise Program started in 2003 and Judy Sammut, a qualified instructor and breast cancer survivor, runs the program with the help of other support volunteers. It offers gentle exercise to tone the body and aids the lymphatic system. It also helps rebuild women’s trust in their bodies whilst in an environment where those around them are facing similar challenges.

The initial focus of the program was to assist women in transitioning back into their own community exercise programs and gyms. However, for some women the Feel Good Gentle Exercise Program has become a cornerstone of their support network. Our experience suggests that women value a community based approach to exercise that recognises their cancer experience and therefore their unique physical and emotional requirements.

*Note: Data period July 2003 – June 2013.

The Future of Support

The future of support is very exciting. Improvements to broadband infrastructure and other technologies are creating new forms of face-to-face communication and interaction. Skype is an example of how we can interact with one person or a group of people, each sitting in the comfort of their home, many miles apart. The possibilities, especially for people whose ability to physically connect is limited, are boundless. We are committed to extending our access by taking the service to women through the use of new technologies and while retaining the Resource Centre, a presence within hospital settings and local communities.

Staying on track through exercise

HELEN'S STORY

I was diagnosed with breast cancer in 2002. Thankfully it was caught early through a routine mammogram when I was 50. I was totally shocked by the diagnosis and felt myself looking around the room to see the other woman the doctor was obviously speaking to! I had a lumpectomy, radiotherapy and Tamoxifen.

I started to read everything I could find on breast cancer and about a diet and healthy lifestyle that would aid in recovery and prevention. I needed to be able to make informed choices about further treatment and health goals. I had been treated in the Royal Women’s Hospital, so I went to their information centre where I borrowed reading material. They referred me to a new centre called BreaCan. I remember attending an art class there. It was a great feeling to find a centre especially set up for people who were going through breast cancer. The staff were very welcoming and friendly.

Later on I joined the Feel Good Gentle Exercise Program, and the fortnightly class kept me on track and exercise became a priority in my life! I felt inspired to continue exercising at home and I regularly go for long walks on our local bayside beach.

I have always enjoyed the exercise classes with Meryl our lovely volunteer and Judy Sammut, our amazing BreaCan instructor. She has always been a great role model, having gone through so much herself and coming out on the other side feeling fitter and stronger. I am so thankful to find this class that is tailored for us and Judy explains how beneficial the routines are for our flexibility, strength and lymphatic drainage.

Last year, nine years after my first diagnosis, I got a new primary breast cancer on the same side. Thankfully the BreaCan staff were there to answer my questions and calm me down, reassuring me of their support. Again it was caught early and after another lumpectomy, I am on Femara for five years.

I still attend the Feel Good Gentle Exercise Program, where I meet old and new friends every fortnight. We love our exercise and have lunch together afterwards. I made exercise a part of my life and I feel so much better for having done that. I don’t know what the future holds, but I know I will keep on exercising – it’s great for your health and peace of mind!



“I made exercise part of my life and I feel so much better for having done that. I don’t know what the future holds, but I know I will keep on exercising – it’s great for your health and peace of mind!”



Informing Women

We are committed to enhancing consumer's skills and capacity to make informed choices, as they wish.

We are committed to providing access to good quality information and support and to regularly evaluating its relevance to consumers, it's sustainability and effectiveness

For many people affected by cancer, providing clear information that is tailored to their needs and preferences is a valuable way of alleviating anxiety and distress.

A key focus of the service has been to assist people to navigate a path through the complexities of their treatment and enhance their capacity to make informed choices.

We have been able to do this by sourcing and creating free access to credible, consumer-friendly technical and medical information on a range of cancer and wellness subjects. We view information provision as a shared process – an exchange between the individual seeking the information and the person providing it.

"I believe the satisfaction I feel with my treatment is largely attributed to the information and support I got from BreaCan."

Jeanette, 2010

The BreaCan Library

We have over **650** library items

When women affected by breast or a gynaecological cancer, and their friends and family, feel informed, this gives them a sense of empowerment and control. Providing access to credible, reliable and quality information has been an essential part of what we offer. The establishment of the BreaCan library was one of the first outcomes of the development of the service.

The main section of the library is housed at our Resource Centre and has informed all the women and health professionals who have used it. Over 650 catalogue items, including books, pamphlets, journal articles, DVDs and CDs, are available for loan, and an information service is linked to the Women's Health Victoria (WHV) ClearingHouse. The link with WHV has helped BreaCan with support in researching and responding to complex issues and questions from women. We also offer to pay for the postage and return postage of library items to ensure that no Victorian affected by breast or a gynaecological cancer is at a disadvantage due to their financial or geographical circumstances.

The development and review of the library and its resources is an ongoing process. The future for information provision includes not only the cataloguing of and access to traditional types of media (books), but the inclusion of new media resource types such as mobile apps and e-books. In a first step towards modernising the way we provide information, the library will be made available online through a user-friendly interface on our website.



"This book has been an invaluable resource and has answered many of my questions that I was too afraid to ask."

Geraldine, 2004



Informing Women

The *What's On* Information Program

Over **4,700** group attendees to *What's On* Sessions since May 2003

The BreaCan *What's On* program delivers free information sessions that can make a difference to a woman's ability to manage her diagnosis. The program provides an opportunity to hear professionals from a range of fields speak on topics that increase a woman's knowledge of cancer and its management, will help them learn how to deal with the impact of cancer, and show how to take control of aspects of their life with a positive outcome. Women can also socialise, exchange ideas and discuss personal experiences during or after each session.

The *What's On* program began in May 2003, with a session on Lymphoedema, a session that is still conducted each year as part of the ongoing program. The spectrum of topics and approaches are representative of the holistic approach taken by the service, covering the areas of clinical treatment, psychosocial development, creative therapy and wellness. The program also recognises that women seek out and process information in various ways and at different points in the cancer journey. Sessions are run in a relaxed manner, which allows for significant discussion and interaction with the speakers.

As part of a responsive service approach, we have sought feedback from group participants in selected sessions to evaluate the relevance of the topic or session. The evaluation process has provided valuable insight into what women want and what works. This input has resulted in the service offering a range of unique sessions, including sessions that deal with end of life issues. Feedback has also shown that not everyone wants to receive their information in a group setting or has the ability to attend a session in person. Since 2004, we have been recording and making information sessions available in a CD format, and since 2009 they have been available on the website as a podcast.

Highly Attended Clinical and Psychosocial Sessions

- When There Are Long-term Side Effects
- Breast Cancer And Bone Health
- Your Immune System And Cancer
- Making A Choice: What You Need To Know About Breast Reconstruction
- Balancing The Scales – Nutrition And Cancer
- Now What? What Happens After The Treatment Is Over?
- Fatigue – To Rest Or Not To Rest?
- Lymphoedema
- Breast Cancer Chemotherapy And The Brain
- Anxiety

The Most Popular Creative and Wellness Sessions

- Sashiko (Japanese embroidery)
- Art therapy
- Music therapy
- Word play
- African drumming
- Dance
- Hana flowers
- Belly dancing
- Quilting
- Listening to music for energy, relaxation or creativity

"I feel that doing something creative was a different way of looking at all the pain, fears and anxieties, rather than just talking about it."

Leola, 2008

Informing Women



“Really purposeful to be able to direct rural women to the wide range of resources and services accessible through Breacan at different stages of their breast cancer experience.”

CATHERINE ENTER, McGrath Breast Care Nurse, Gippsland

Forums and Regional Visits

22 forums and regional visits attended by 547 women

Isolation can take many forms: geographic, cultural, linguistic, and social. Each presents its own special challenges. We have worked hard to extend our services to people faced by the challenges of distance, language and culture through innovative programs and partnerships. In 2004, the service worked with two regional health services to identify and trial ways of supporting women in rural areas. In 2005, we hosted our first busload of women from Shepparton on a regional visit to Breacan. Regional visits include an information session and provide women with an opportunity to gain high quality, up-to-date information while connecting with each other and the trained peer support volunteers.

Regional visits have been an effective way of connecting women into the service; however they require women to come to Melbourne. In acknowledgement of the difficulties people face coming to the city, in 2006 we conducted two regional forums in Wangaratta, one for women,

their families and friends, and the other for health professionals. Both forums were extremely successful and the design and make-up of the forum program has been replicated in other regional areas over the past seven years not only by Breacan, but also by other services.

We have taken the information and support forums and effectively translated them to also meet the needs of women connected through culture and language. We have conducted forums for women from a Vietnamese background in western Melbourne using interpreters.

The Future of Information Provision

Advances in information communication technology hold great potential in the exchange and dissemination of information. We are committed to using new technologies to open up access to our range of information services. Webinars, vodcast and mobile apps will have a place in our future provision of information alongside traditional face-to-face group sessions, workshops and forums. As we have learnt over the last decade, women access information differently and at different times in their cancer journey, and our commitment is to ensure that the channel they choose is open, in the language they prefer and when they need it.

Re-finding my place

JENNIFER'S STORY

My first breast cancer diagnosis was in 1996, and then in 1998 I had a diagnosis of bone secondaries. My two support groups (one a medication group for all cancers and the other a breast cancer group) were immensely helpful in bridging the health downturn with secondaries. Life for me and my family was turned upside down. We adapted with a lot of help along the way.

Despite being surrounded by great benefits – the hospital where I had my treatment, expert complementary health information and the resources of suburban life – I still felt groundless. Connecting with Breacan was the magic ingredient for me. As well as the information they provide, there is the ‘inexpressible comfort’ of joining something that has been carefully and expertly thought out. This is the gift of the Breacan staff. I didn’t have to explain about my slow and tired body and mind, they already knew.

One of the first sessions I went to had volunteers who were modelling and demonstrating bras and breast forms – real knowledge of how to manage in everyday life, combined with goodwill and good cheer.

Other sessions have brought me the privilege of being in personal communication with experts speaking on the latest topics. I love learning and being able to hear the questions, views and experiences of other women and carers. It is one of the ways I have been able to re-find my place in life.

Then, and this is something that really sums up Breacan, a friend with secondaries (we’d met in a brilliant secondaries teleconference program) asked: “What about programs for women with advanced breast cancer?” And Breacan was able to provide two information sessions (*Making Connections*) and a specialised support group format (*Here and Now*).

My friend and I joined the first *Here and Now* group. One of my memories of this time is that most weeks we arrived early (for those of you who know me ‘early’ might seem hilarious, but it’s true!). Breacan would let us in and we’d make ourselves morning tea. We were arriving for *Here and Now*, for help addressing and solving some difficult things, yet we were also able to have a detached, relaxed talk about other aspects of our lives – time to take a breath or two.

Now I’m a Breacan person. I can phone for help or information. I can join in and be welcomed. I’ve been given the space and time to swap between having to deal with the intensity of a health condition, and being able to find time for relaxation and letting things be, which means I can then return to living my life as it is, feeling lighter.

“I love learning and being able to hear the questions, views and experiences of other women and carers. It is one of the ways I have been able to re-find my place in life.”



Service Innovation

We will actively encourage consumers to participate in the development and operation of the service.

We are committed to establishing and maintaining high standards in all aspects of the service and to regularly evaluating its relevance to consumers, its sustainability and effectiveness.

Listening to the needs of women coming through the Resource Centre or ringing in is an essential element of our responsive, consumer-centred service. This has driven much of our service innovation over the past decade. We are committed to responding to the needs of women with a lived experience of cancer as they define them. Many of our successes have been in identifying effective solutions to a range of unmet needs.

Making Connections

12 Here and Now groups comprised of 91 sessions with 459 participants

Women with advanced cancer tell us that their needs are different to those with early cancer. They face issues such as living with ongoing uncertainty, communication with family, friends and service providers, coordination of care and dealing with financial, legal and employment concerns.

In 2004, the Department of Health provided additional funding to BreaCan to develop and trial a model of support for women with advanced cancer. Following a successful pilot phase, providing services to women with advanced cancer was formally added to our services list.

To meet the needs identified by women with advanced cancer, we run a separate program called *Making Connections*. This program consists of information sessions specifically of interest to women with advanced cancer, occasional social events to encourage women to connect with each other and, when numbers are sufficient, a six-week program called *Here and Now* to allow women to meet and share and reflect on matters of importance to them. We have always encouraged women with advanced cancer to become peer support volunteers, further supporting the needs of women with

advanced cancer. Women with advanced cancer are also able to access all our programs, including reflexology. Women tell us that coming together with other women who have advanced cancer provides support, comfort and a warmth of shared experiences that others find hard to understand.

Currently, 12 per cent of women accessing BreaCan are identified as living with advanced cancer. We know that for many women coming into the city to participate in programs is particularly difficult. We are preparing to offer technological options such as Skype and vodcasts to allow women with advanced cancer to participate in BreaCan activities from their home. Further consideration is being given to extending the services of BreaCan to all women with advanced cancer, regardless of their initial diagnosis. Primarily, this is due to the similarity of shared experiences of women once diagnosed with an advanced cancer and the lack of services available for women once re-diagnosed.



“I’ve realised that when a window of friendliness and acceptance opens in one area, the sunlight filters through to lots of places.”

Jane, *Here and Now* participant, 2005

Service Innovation



“It’s great to see a familiar face... a relief to have you there (at the hospital).”

Maria, 2010

Bridge of Support

1,248 hours of volunteer peer support

The *Bridge of Support* brings together BreaCan and the Breast Service of The Royal Melbourne and Royal Women’s Hospitals. This program was brought about by the number of women coming to us who said, “I wish I knew about this service earlier”, and after some consultation and research, a treatment centre was chosen as the best place to start. The *Bridge of Support* program aims to reach out to women in treatment by providing peer support at The Royal Melbourne and Royal Women’s Hospitals. A BreaCan staff member liaises with hospital staff and peer support volunteers visit the day oncology and surgery wards as well as the medihotel to provide support and information to women.

Since 2010, 802 peer support contacts have been successfully provided within the hospital setting, and many of these women, their partners and family members have been linked into further community based support. Awareness of BreaCan and other relevant services has been extended among hospital staff and patients of the Breast Service. In turn this has extended our reach to more Victorian women.

The *Bridge of Support* has been the first time that we have provided an outreach model of service provision in a hospital setting. This acute-community sector partnership has demonstrated how the medical and social models of health can work in harmony to provide a connected and high quality service for women at the time of diagnosis and active treatment for breast cancer. The three organisations, their cultures, expertise and skills have both influenced and been influenced by this work.

We are currently in negotiations with staff to extend the service to women affected by a gynaecological cancer at the Royal Women’s Hospital and are hopeful of finding sponsorship for a similar program to be run at Western Health. Work is also underway on developing a range of outreach models that might suit different treatment centres.

Service Innovation

Steps for Fun and Fitness – exercising in the community

61 women attended over five programs

Women have often expressed an interest in attending a regular exercise program close to where they live, where they feel confident that people will understand their physical and emotional circumstances following a cancer diagnosis and treatment and where they will be well supported.

It is increasingly well documented that exercise is highly beneficial for people diagnosed and treated for cancer, and in the case of breast cancer it seems that exercise has a positive impact on reducing the likelihood of recurrence.

In late 2009 through to mid-2010, through funding made available by Cancer Australia and in partnership with the North Eastern Metropolitan Integrated Cancer Service, we provided four, five-week exercise programs for women with either breast or a gynaecological cancer in a number of locations across metropolitan Melbourne.

The programs were conducted at Fernwood Fitness gyms by the inspiring Judy Sammut and consisted of a different focus of exercise each week so that women participating could experience different styles of exercise to broaden their knowledge about what might be suitable for them.

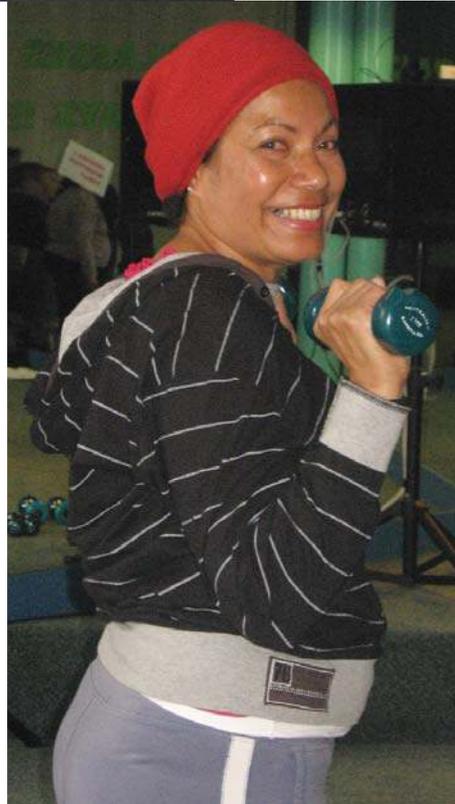
Overall, 78 per cent of women who provided feedback about the program felt that it was appropriate for their stage of health, and 100 per cent of these women also felt the program had improved their awareness of specific exercises suitable for them. At the completion of the programs, 100 per cent of the women had increased motivation to exercise and expressed an intention to continue to exercise.

In some instances we were able to coordinate running this five-week program with the YWCA Encore program so that women could have 13 weeks of supported exercise. This was seen as highly beneficial by the women who participated in both programs. Further programs were conducted with Nillumbik Community Health Service and Western Health in 2010 and 2011, with the Nillumbik Community Health Service continuing.

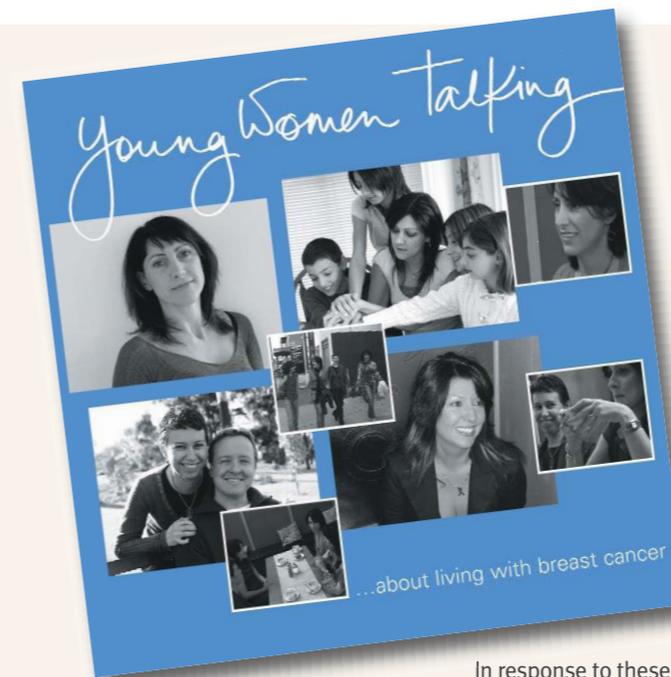
This program was highly successful in supporting women to exercise safely and confidently and women enjoyed being taught by the highly skilled exercise leader and the opportunity to exercise with a group of like-minded women. If funding becomes available, we would be delighted to conduct further programs in community locations. We are currently working in partnership with Breast Cancer Network Australia to develop a statewide Healthy and Active Living After Breast Cancer Program.

“Participating in this program (*Steps for Fun and Fitness*) has helped me both physically and emotionally.”

Dimitra, 2009



Service Innovation



Young Women Talking 5,000 copies printed and distributed

Women using Breacan identified that there are particular issues facing young women with breast cancer. These include greater emotional distress than older women when diagnosed, feeling socially isolated or stigmatised as a result of having breast cancer at a young age, and difficulty accessing age-appropriate psychosocial support, including peer support. In addition, epidemiological studies suggest that younger women with breast cancer have worse disease-free and overall survival outcomes.

In response to these issues we successfully worked in partnership with Cancer Council Victoria and Think Pink to develop an audiovisual package for younger women with breast cancer. This unique resource includes an informal discussion between a group of up to five women talking openly about the social, emotional, practical and psychological impacts of breast cancer on their lives.

The DVD and booklet is now widely available and is very accessible and easy to use. It enables young women to help normalise their experiences of breast cancer by drawing on the experiences of other women. Importantly, it contains very practical information and can be used as a tool to generate discussion and enables women, support groups and health professionals to use it in a range of ways.

The success of this approach has given rise to the idea that other target groups could also utilise a similar multimedia package and we are keen to identify suitable partners to undertake such projects with.

“If other young women can take comfort in knowing there are women – like us – who have been through it (breast cancer) and are living well... it makes sharing our stories and experiences worthwhile.”

Joanne, Mary M, Mary N and Rita

The Future of Innovation

The success of these innovative projects has demonstrated the power of consumer-identified solutions and the importance of a partnership approach. There are several projects in the pipeline that we hope will continue this successful process. These include:

- the use of Skype and video conferencing to reach women unable to come in to the city Resource Centre.
- the documentation and packaging of our successful peer support training.
- developing and documenting our approach to culturally safe and responsive service delivery.
- partnering with organisations that share our goal and mission.
- providing information and support wherever women live.
- extending the volunteer base into rural areas.

A partner's Story

COLIN'S STORY

Glenys was diagnosed with breast cancer in May and June in 2010. When it was initially diagnosed, the surgeon said that a lump mastectomy would be all that was needed to remove the cancer. But while operating, he found that there was an aggressive cancer in her milk ducts. So Glenys had to face a second lot of surgery for a full mastectomy.

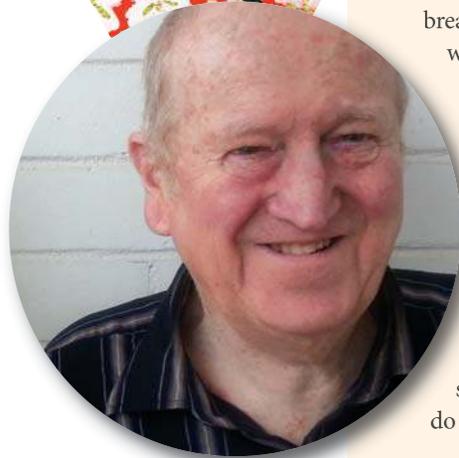
The trauma she experienced from one lot surgery was bad, but having to deal with two, the emotional effect on Glenys was great. Physically she was fine, and she was lucky not to need radiation or chemotherapy treatments, everyone was happy that she was cancer free and her church family really supported her, but she still found it hard to leave the house.

To see the one you love not coping and you not having the answers to help them brings tears to your eyes. We went to some of the support groups, but Glenys felt that she was not ready for them. She really struggled to cope with the loss of her breast. With her mother and sisters living in Perth, they were too far away to really support her, and with a history of mental unwellness to cope with as well, the breast cancer experience was too much for Glenys. She had trouble sleeping and needed medication, which meant that she rested a lot during the day. I tried to encourage her to find 'the new you', but it was hard. I didn't like leaving her on her own. I tried to draw on my experience of having prostate cancer over 10 years ago, which I know is different. I have just had two weeks of radiation; Glenys came with me every day, which was quite tiring for her.

Still, two and half years on, Glenys is still struggling to come to terms with the loss of her breast and she has spent some time in hospital and rehab. Glenys is now seeing a therapist who has had breast cancer and who is helping her deal with all her issues, both physical and emotional. Glenys is sleeping better now and becoming more active.

When we found out about the BreaCan *What's On* sessions early in 2012 we both decided to go to some of them and Glenys found answers to her questions. Being able to chat to the staff and volunteers about how she felt about her breast cancer experience has really helped her, as has chatting to other women about how they have coped surviving their cancer. The library of CDs and books that are available is also most helpful.

Every woman reacts and copes differently, but no woman wants to have cancer and no husband ever wants his wife to have cancer. But if it does happen to them, the sooner they come to BreaCan, the better it will be for them. They won't regret it, they do a marvellous job of helping women find 'their new you'.



"To see the one you love not coping and you not having the answers to help them brings tears to your eyes. We went to some of the support groups, but Glenys felt that she was not ready for them."



Innovation – The Feel Good Gentle Exercise Program

JUDY'S STORY

In the beginning, Sue Lockwood declared, "I have a dream... we need a drop-in and resource centre for women with breast cancer", and she sought support from those of us with experience in the ever-widening field of breast cancer. "Make a list," she said, "of what you would like to see in this centre."

Having run the treadmill of breast cancer in 1992, including a mastectomy and implant reconstruction, which then became infected and had to be removed, then a TRAM flap reconstruction followed by another mastectomy, followed by six months of chemotherapy, I reckon I've experienced many breast cancer challenges.

During the two-year recovery period I discovered the importance of specific exercises to stretch my chest wall, relieve the tightness that resulted from the auxiliary clearance, regain my range of movement and restore my damaged body to wellness. One of my sons, a physical education student, and I created a series of relevant exercises that provided the ideal recovery outcome.

I then discovered the YWCA Encore program, a land and warm water pool exercise program that was new to Australia, and I was so impressed with the huge benefits for women with breast cancer that I trained in the first group of qualified instructors prior to it becoming a national program.

My experience led me to joining up with other driven women to improve the paucity of services for breast cancer. So when Sue Lockwood said, "Make a list", mine included, among the many other features available today at BreaCan, an exercise program, of course! Di Missen and Helen Shepherd undertook with enthusiasm many hours of research and hard work and the enormous task of breathing life into Sue's dream, and then BreaCan became a reality. As the opening date for BreaCan approached, Sue said to me, "You wanted the exercise program – well go for it girl, it's all yours." So what else could I do but say OK? But where were we to hold this program? And what do we call it?

It was decided that we'd try out the Feel Good Gentle Exercise Program on a fortnightly basis and following a slow start, the numbers have increased noticeably – we've had as many as 21 participants in the donated gym space at some sessions.

Over the years many women have participated in the Feel Good sessions while coping with the dreaded emotional and physical rigours of breast cancer. It is very rewarding and gives me so much pleasure watching the camaraderie develop between them and the reassurance they feel of having appropriate exercises tailored to the limitations they experience following surgery. I love watching them move on, return to work, capture and restore their health and their lives, although sadly not all of them do.

I am privileged to be part of this unique service and watch as it continues to develop and expand under the professional and caring guidance of management and staff and of course the warmth of the empathetic volunteers.



"During the two-year recovery period I discovered the importance of specific exercises to stretch my chest wall, relieve the tightness that resulted from the auxiliary clearance, regain my range of movement and restore my damaged body to wellness."

PARTNERSHIPS

The success and relevance of BreaCan relies heavily on working collaboratively with a range of services in the cancer sector. Like many community based services, we believe the best level of care is achieved as a result of healthcare providers working collaboratively. We continue to play an important role in the development of quality models of supportive care and survivorship. We contribute to the sector's understanding through the services we provide, the productive collaborations we establish and the sharing of expertise and knowledge we have gained from the consumers themselves over the last 10 years.

We will continue to develop our services in consultation with key health and wellbeing stakeholders and look towards future opportunities to make a tangible difference to the lives of people affected by breast or a gynaecological cancer.

Key Partnerships Developed

The Victorian Department of Health has provided pilot funding followed by recurrent funding to establish and support BreaCan from its inception. Since 2003, the Victorian Department of Health has been very generous in supporting a range of projects all aimed at improving information and support to Victorian women with breast or a gynaecological cancer.

A number of health professionals support the training of peer support volunteers. With each of the six volunteer intakes, a number of health professionals give their time, professional expertise and experience to assist in the training of BreaCan volunteers. This support continues to ensure that our peer support volunteers are very well informed and trained to undertake their role.

We have participated in the Cancer Council Victoria's Clinical Network (formerly Victorian Cooperative Oncology Group) to understand current practice in oncology, promote the views and needs of consumers within these networks and pursue active relationships with other oncology practitioners.

Breast Care Nurses and other oncology nurses from across Victoria have supported women's access to BreaCan in so many ways. They give information, they encourage women to contact

the service, make referrals on behalf of women, organise bus trips to bring rural women to Melbourne, assist in organising forums across Victoria – in so many ways these amazing women support us so we can support others.

Cancer Australia has provided funding for a number of projects since 2008. These projects have been focused on extending information and support to people for whom access to these services is more difficult.

The Royal Melbourne Hospital, the Royal Women's Hospital and Western Health have been significant supporters and collaborators over the past decade. The Bridge of Support, Chorus of Women, increasing access to CALD communities and the current Victorian Cancer Survivorship project are some of our collaborative successes.

The Integrated Cancer Services across Victoria have supported and partnered with BreaCan to develop projects and share knowledge with the aim of supporting women to live well.

A shared value base and emphasis on reaching women with gynaecological cancers has brought BreaCan and Ovarian Cancer Australia together in a number of ways. Jointly running forums and information sessions, collaborating on projects and sharing knowledge and resources have been important components of this ongoing partnership.

Many researchers with ideas for projects or with projects already organised approach us to recruit participants. Where there is a sound ethics process and a clear benefit to women with cancer, we support the research. By contributing to research we know that we are supporting the best outcomes for women now and in the future.

PARTNERSHIPS

Current Partnerships

Survivorship

We are collaborating with The Royal Melbourne Hospital, the Royal Women's Hospital, Western Health, Melbourne Health and the Inner North West Medicare Local to implement and evaluate the Comprehensive Breast Cancer Survivorship Program for women completing definitive treatment for early breast cancer.

We committed to sourcing and supporting consumer involvement from the very initial stages of this project through a range of activities including:

- hosting a consumer consultation workshop involving women who have experienced breast cancer and are users of BreaCan.
- gathering feedback from women, e.g. the opportunity to brainstorm ideas and priority topics for a series of information navigation tools.
- active consumer representation on the Project Working Group.
- project communication and feedback, which has occurred through regular volunteer newsletters and more broadly through communicating with nearly 2,500 service users via quarterly *What's New* updates.

The perspectives of women who have experienced breast cancer have been integral to the success of this project and we have been well placed to facilitate the meaningful involvement of consumers throughout the project's planning, implementation and evaluation activities.

CALD Communities

This project, funded by Cancer Australia and in collaboration with Western Health, aims to increase information and support for Vietnamese women with a breast or gynaecological cancer to create a comprehensive best practice community model of information and support that can be implemented into other communities by:

- developing and integrating sustainable approaches to engaging diverse groups, commencing with Vietnamese women in the Western Health community.
- building and strengthening linkages for women affected by breast and gynaecological cancers within the Victorian Vietnamese community to develop culturally appropriate, quality information and support resources including mechanisms for improved access to community support.
- developing a best practice culturally appropriate community service model that engages consumers, the acute sector and the local diverse community to respond to local needs.
- drawing on the best practice community based model to translate to other cultural groups.

"BreaCan has been a welcome addition to the support services we are able to offer to women experiencing breast cancer and their carers at the RMH. Personalised contact with women whilst in hospital has been a great initiative to bring community based support into the hospital setting. We have also welcomed the collaborative role with BreaCan in the development and evaluation of a survivorship project."

KERRY SHANAHAN, Breast Care Nurse,
Royal Melbourne Hospital



OUR PEOPLE



Working at Breacan is not like a normal job. It demands a lot of you, but it also gives a lot back. Like many Victorians, some of the women who have worked for us over the years have been touched by cancer in some way and are passionate about improving services for women affected by cancer. Some simply want to work in a place that has strong values and can 'walk the talk'. Regardless of their reasons, the commitment and dedication of many of the staff has been exceptional – working long hours to meet deadlines and often going the extra mile to translate the needs of women living with cancer into tangible services.

Breacan Staff (current staff in bold)

- 2002** Di Missen, Manager (July 2011)
Helen Shepherd, Services and Volunteer Coordinator (March 2012)
Gina Mancuso, Project Officer (October 2003)
- 2003** **Justine Dalla Riva**, Project Officer and later Communications & Information Management Coordinator
- 2003** Trisha Murdoch, Information Officer (2004)
- 2004** Josie Scott, Advanced Breast Cancer Project Officer (2007)
Pip Brennan, Casual Information and Support Worker (2010)
- 2006** Nicole Wilton, Information and Support Officer (2011)
Sascha L'Huillier, Project Officer (2008)
Gabrielle O'Brien, Administration Officer (2008)
- 2007** Janette Liebelt, Information and Support Officer (2008)
- 2008** Brigitte Gerstl, Project Officer (2008)
Katherine Bradstreet, Administration Officer
Wendy Pullan, Information and Support Officer and later Programs Officer
Fiona McRae, Project Officer and later Team Leader, Breacan Programs
- 2010** Rebecca Tipper, Project Officer (2011)
- 2011** Alison Amos, Manager (2012)
Kellie Holland, Information and Support Officer and later Volunteer and Consumer Participation Coordinator
Jenny Rigby, Information and Support Officer and later Programs Officer
Robin Curwen-Walker, Information and Support Officer and later Programs Officer
- 2012** **Annemarie Ferguson**, Diversity Project Officer
Mary Macheras-Magias, Programs and Training Officer
Lee Kennedy, Manager

OUR PEOPLE



Breacan Advisory Group

Sally Fawkes, Chair
Lyn Allison
Helen Coleman
Christine Evely
Bronwyn Flanagan
Jane Fletcher
Frederika Laurie
Jane McNeilage
Penny Sanderson
Beth Wilson
Katy Weare

Former Advisory Group Members

Annabel Pollard, Chair (2008–2011), member until 2013
Heather Beanland (2007–2013)
Claudia Ginn (2009–2012)
Angela Hill (2007–2009)
Jenny Macindoe (2007–2009)
Suzanne Phillips (2007–2009)

From the Advisory Group Chair SALLY FAWKES

It has been a decade since Breacan was launched to help women 'live well' and actively participate in their care following a diagnosis of breast cancer. The essence of Breacan continues to be a powerful combination of compassion, experience, skills and knowledge of both volunteers and staff of the service. Over its 10 years of operation, the service has expanded its emphasis to include women with gynaecological cancers, but has remained true to the notion that women who have had challenging life experiences are uniquely placed to help other women. And they must be supported to do so.

As a Women's Health Victoria Council member since 2007, I have had the opportunity to see Breacan grow under the stewardship of three committed managers and with the devoted contributions of many skilled staff. Last year, I had the honour of coming on-board as Chair of the Breacan Advisory Group (or 'BAG' as we call it). Its role is – and has always



been – valuable for ensuring that Breacan can navigate the community, political and financial environments in which it operates, and that it can thrive by making best use of opportunities to respond to the needs of diverse groups of women in meaningful ways. The voices of consumers are central to the Advisory Group. These are complemented by the experience, views and fields of influence of women who work in health and other professional roles in our community and health organisations. On behalf of the Breacan Advisory Group, happy tenth anniversary Breacan!

OUR VOLUNTEERS



“It’s about what we can share, having been through this ourselves.”

Mary, Breacan Volunteer

Program Support Volunteers

Barbara
Bev
Cheryl
Claudia
Dorothy
Elizabeth
Jewels
Jocelyn
Judy
Kim
Maree
Maureen O
Maureen T
Naideen
Patricia
Sandra B
Sue E
Susan
Lois

Our volunteers are the lifeline of our organisation and the secret to our success! We rely on their time and good spirits, which they generously contribute.

The volunteers at Breacan are very much a team, having enjoyed a sense of camaraderie and friendship over the years. They are united by their shared experiences of cancer and their desire to give back and make a difference in some way.

Our volunteers support the organisation in the areas of exercise, mail-outs library support, program support, peer support, the Breacan Advisory Group, graphic design, admin support, the Volunteer Reference Group and are the backbone of Breacan. Without their commitment, Breacan would have been unable to support the thousands of women who have used our service.

The principles of compassion, reassurance and supportive care provided in a non-judgemental atmosphere have been modelled by the pioneering peer support volunteers who strongly influence the peer support volunteer team today.

Breacan volunteers bring integrity, compassion, laughter, knowledge, experience, authenticity and empathy to Breacan. They have shaped and continue to inform who we are as a service.

Peer Support Volunteers (current in bold)

2002 GROUP 1: Ang, Betty, Christine, Ellen, Heather, Janine, Liz, Mary, Pas, Rhonda, Rosemary (deceased), Sandra

2003 GROUP 2: Pauline, Meril, Rita, Cate, Julie (deceased), Lea

2006 GROUP 3: Florence, Joy, Christine, Jenni (deceased), Angela, Michele (deceased), Toni, Ojdana, Teresa, Chris (deceased), Frederika, Pam, Khim

2008 GROUP 4: Carolyn, Meena, Paula (deceased), Grace, Kirsten, Christine, Leola, Dianne, Annette, Aaltje, Heather (deceased), Cindy, Jules

2011 GROUP 5: Bridget, Cindy, Joan, Barb, Jill, Georgina, Julie, Ange, Suzanne, Ellie, Nikki, Helen, Sue P

2013 GROUP 6: Belinda, Coralie, Janice, Jewels, Khim, Lianne, Lilyana, Lois, Naideen, Sue G, Sue S, Susan, Toula, Wendy

*Please note photos 2003 and 2006 contain a mix of volunteer intakes and do not include all trained peer support volunteers from those years.

OUR VOLUNTEERS



Volunteer Reference Group

The Volunteer Reference Group (VRG) provides a voice for volunteers. It is open to all volunteers and meets quarterly. It’s a mechanism for feedback and input from volunteers and offers discussion of key issues, challenges and opportunities facing the service. We hope it’s an avenue for suggestions for future directions and for ways to add value to the service, and we try to ensure a two-way forum for sharing information and discussion. Another important element is that volunteers have an opportunity to have input into planning and shaping the direction of volunteer activities and programs and to discuss training needs. We have also found that the Reference Group provides an opportunity for volunteers to take on a different role that may assist in maintaining their interest and provide a new challenge particularly for those who have worked with the service for some time.

Consumer Reference Group

The objective of the Consumer Reference Group (CRG) is to provide advice from a consumer perspective in relation to our current and future service provision.

It is made up of 10 service users who come from a range of backgrounds including metro and rural, breast and gynaecological cancer, early and advanced cancer. The group meets face to face twice a year, but also has input into projects throughout the year.

The CRG provides a regular mechanism for consumers to feed back into the service to inform service delivery, service planning and service evaluation. The CRG enables the organisation to formally utilise and integrate consumer knowledge and experiences when developing new services or resources.

“Peer support was a very new concept in 2003. The idea of women talking to women about their cancer experiences was not well understood. Breacan volunteers took a huge leap of faith and committed themselves to complex training to ensure the professionalisation of support could evolve. Service quality at Breacan was high, with volunteers supported in their challenging role and managing their own health vulnerabilities to send a strong message to more recently diagnosed women – ‘you too can live well after cancer’.

HELEN SHEPHERD, founding Breacan Volunteer and Services Coordinator

OUR VOLUNTEERS



“All Breacan volunteers know what it is like to live with cancer. They provide a message of hope to help others with cancer to live well.”

KELLIE HOLLAND, Breacan Volunteer and Consumer Participation Coordinator



Paula

Paula & Rosemary

Breacan peer support volunteer Paula died in December 2012. Paula provided so many women with hope, reassurance and understanding and was always a warm and vibrant presence for all who came into contact with her. We miss her and remember her.

At the time of writing this publication we were informed of the death of Rosemary, one of the first Breacan volunteers. While she had not volunteered for many years, her contribution will forever be remembered, as she will be in the hearts of those she supported.

In memory of the Breacan peer support volunteers who have died since 2003.

Julie, Jenni, Michele, Chris, Heather, Paula & Rosemary

– we continue to remember you and give thanks for your contributions to Breacan.

The Beginning

SANDRA'S STORY

I was so excited to be selected to be part of the first group of volunteers for Breacan in 2003. The training was intense and very professional. Breacan's manager and our volunteer coordinator took part in the training program with us. Their enthusiasm and support was contagious. They shared their vision of what Breacan could become.

We were determined not to fail the trust and belief placed upon us. The future of this service was in our hands, and we became very close as we shared our own journeys with breast cancer, and our own fears and concerns for our own futures. We finished our training period with 12 volunteers ready to take up the challenge.

On a personal level I have grown as a person through Breacan. I was 63 years old, two years post diagnosis having had bilateral mastectomies when I was selected to be a volunteer. Breacan undoubtedly encouraged me to look within myself and to take on some things I had thought about but never tried. I took part in the exciting *Chorus of Women* program and performed with nine other women in two productions telling our story with words and music. Sadly one of our *Chorus* members died soon after our performances. Now eight years later we still meet regularly as a support and friendship group.

This program reawakened my desire to learn to play the piano. Purchasing a keyboard and finding a wonderfully patient teacher, I had lessons for three years. I can now read music and play many of the main themes of my favourite pieces, which I call my 'Musical Snapshots'. This experience with words and music led me to taking part in a Breacan creative writing *What's On* session. I now write poetry and short stories and hopefully will soon have some poems selected for publishing in a poetry anthology. I have won a Commended Certificate for a short story with the Society of Women Writers Victoria and had some stories published on websites receiving favourable comment. Writing is my new passion.

Life changes after a cancer diagnosis, but it can be wonderful and fulfilling and I believe Breacan's unique service, which now also helps women with gynaecological cancers, plays a huge part in supporting women to reach out and grab life with both hands and never let go.

“

Life changes after a cancer diagnosis, but it can be wonderful and fulfilling.”



2012–2013 In Brief

“When I think of BreaCan I think ‘a service for women that is unique and has innovative responsiveness to the needs of clients, staff, volunteers, government and external services with a can-do attitude’.”
Bronwyn Flanagan, Breast Care CNC, 2013

We continue to go from strength to strength. Our core work providing support and information to women has continued in a range of settings and we continue to attract project funds to allow us to concentrate on areas of unmet need. The work is not without its challenges though and financial constraints have been a significant challenge this year. The death of Paula, a peer support volunteer, late in the year affected many staff and volunteers. Another change in manager was an unexpected event, but as with most things, we at BreaCan took it in our stride and continued to provide excellent support and information to women.

The work with our partners has been a great pleasure this year, especially our partners in hospitals. A range of health professionals work with us on committees, in referral and on projects aimed at helping women with cancer to live well.

As the recognition of the importance of supportive care grows, more and more women are able to have their needs met in a more complete way that acknowledges them as a whole person rather than just someone with a diagnosis of cancer. The role these partners play as our champions cannot be underestimated and their knowledge and networks assist us in our work every day.

The BreaCan Advisory Group has had a change of emphasis – with a renewed focus on the strategic objectives of the organisation. These dedicated women have found the time to assist us in achieving some of our more aspirational goals and their efforts have helped us define the best use of our limited resources.

Of course it’s the volunteers who have been the means of the year’s achievements. Whether it’s those who have just notched up 10 years’ service or the new recruits from the 2013 intake, these are the people whose efforts really count as they continue to make themselves available on the roster for the Resource Centre, the Bridge of Support program, the library, speaking engagements, forums or the mail-outs.

“BreaCan is unique for so many reasons including the dynamic nature of the service, the core role of staff and peer volunteers in supporting women with breast and gynaecological cancer and its commitment to making sure that quality, compassion, sensitivity and care is critical to the service. This has been an essential ingredient to the success and growth of BreaCan and will be important as we look to extend the model to reach more women across Victoria in the future.”
Rita Butera, Executive Director, Women’s Health Victoria

Highlights

- Presentation at the Inaugural Victorian Integrated Cancer Service Conference on our role as a partner in one of the Victorian Cancer Survivorship Projects.
- We launch our Facebook and Twitter accounts, providing information and connection to women in the virtual world.
- The Bridge of Support pilot project report is lodged and a poster presentation is accepted at the Clinical Oncology Society of Australia (COSA) conference in Brisbane.
- In partnership with Ovarian Cancer Australia (OCA), BreaCan hosts a successful one-day forum for women with ovarian cancer focusing on the needs of women once diagnosed and treated.
- A fact sheet is developed and published by BreaCan and OCA for women with a gynaecological cancer.
- BreaCan partners with the Royal Women’s Hospital and Cancer Council Victoria to present a Living with Cancer Day specifically for women living with a gynaecological cancer and their partners, family and friends.
- Recruitment of a sixth intake of peer support volunteers is completed.
- April marks our tenth year in operation.
- During National Volunteer Week, eight peer support volunteers from the very first intake who continue to volunteer with BreaCan were presented with certificates of appreciation for their dedication and commitment to supporting women with breast and gynaecological cancer.
- To formalise the contribution of service users, a Consumer Reference Group was established in 2013.
- As part of a project funded by Cancer Australia, BreaCan, in partnership with Western Health, held a free information and exchange day for Vietnamese women living with breast or gynaecological cancer.

Key Statistics 2012–2013

- An average of 16 people attended each of 73 group sessions. (See Table 2.)
- 68 women received reflexology offered in 19 sessions across the year.
- Of the service users for whom cancer status was recorded:
 - 91 per cent have experienced a form of breast cancer and nine per cent have a gynaecological cancer.
 - 12 per cent reported their cancer as ‘advanced’.
- 25 per cent of service users (where country of birth was identified) were from a non-English speaking country (compared with 17 per cent in the Victorian population overall).
- Our website recorded a nine per cent increase in the number of visits. The number of podcast page views increased by 52 per cent.
- 30 podcasts of information sessions were available to download via our website, including eight that were recorded in the 2012–2013 period (an overall increase from 25 in 2011–2012).
- Our mailing list has grown by five per cent to almost 3,700 individuals (2,804 service users and 861 service providers).



Parliamentary Secretary for Health, Georgie Crozier (third left) with the first intake of BreaCan peer support volunteers (L-R) Heather, Sandra, Ellen, Rhonda and Mary (absent: Betty, Ang and Janine)

2012–2013 In Brief

Table 1: BreaCan contacts

Contact type	Number of contacts
Individual contacts – Resource Centre	826
Individual contacts – <i>Bridge of Support</i> at the Royal Melbourne Hospital	250
Attendances at group sessions	1,185
Service provider contacts	177
Total	2,438

Table 2: BreaCan Group Session Overview

Session type	Number of sessions		Number of participants*	
	2011–12	2012–13	2011–12	2012–13
<i>What’s On</i> Info Sessions	36	36	768	659
Feed Good Gentle Exercise	23	21	376	371
Information forums, regional visits, workshops	8	5	165	75
<i>Making Connections</i> info sessions for women living with advanced cancer	7	7	81	58
<i>Here and Now</i> group program	8	4	32	22
Total	82	73	1,422	1,185

* An individual may have attended more than one session.

Finding normality

CARMEL'S STORY

I was 59 years old when I was diagnosed with stage 3 ovarian cancer. It had spread beyond the ovaries to all my reproductive organs, spleen and appendix and beyond. I had been travelling in Europe when I felt nauseous and bloated – these were my first and only symptoms.

After six months of surgery and chemotherapy, I gradually regained my health. Unfortunately, within a year I had a recurrence and it was so advanced that surgery or radiotherapy were not possible. I am now on a trial of Arimodex, which is gradually reducing the tumours. During the three years since diagnosis, I have been in good general health and at this time, I am perfectly well.

In the terrible shock after the diagnosis, my daughters 'hit' the internet. They found Breacan and enrolled me in every session they could find. They came in with me in the early days to the fitness program, reflexology, and some of the other sessions. My husband also deeply appreciated the welcome accompanied by homemade shortbread. The reflexology sessions were such a nurturing experience – just what you need in your hard times.

Breacan has been an enormous support to me since I developed cancer. It has given my life a structure – apart from doctor's visits in the early days. I went from being general manager of a large organisation to a sick person. Breacan has helped restore my normality. I have attended the Feel Good Gentle Exercise Program regularly for over three years. My fitness is now better than ever and I still find it valuable. The interaction with the participants provides enough 'support' while fulfilling the important need to be fit. Similarly, the information sessions have also been enjoyable, and the sessions on current research are always a highlight for me as I appreciate the evidence-based approach. And I have rediscovered the city after a life of living and working in the suburbs.

I am learning to live with cancer as hopefully a chronic disease. I will always hope and pray for a cure. I have taken an integrated approach to my health, but in the words of my Chinese medicine practitioner, "someone has to be the leader of the team", and that is my oncologist. I will always value and keep in close contact with Breacan because I always benefit in so many ways – knowledge, wellbeing, fun, health – in my spirit.

"I went from being general manager of a large organisation to a sick person. Breacan has helped restore my normality."



Our Supporters for 2012–2013

We are extremely grateful to the following people and organisations that contributed to the service in 2012–2013. Donations were received in memory of Joan Langmaid, Paula Drum and Margaret Willimot.

Kevin Ayrey
Elizabeth Brown
Colin Carty
Kathy Collins
Jim and Jan Crowe
Diamond Valley Foodshare Inc
Janet Elovaris
Sue Ewin
The ladies from Fernwood Mornington
Margaret Fisher
Teresa Fusca
Pauline Gibbs
Mary Goldsmith
Lynette Hunter
Jenny Leeson
Marylyn Matheson
Bernice and Ewen McRae
Andrea Molloy-Drum
Heather Moran
Fred and Sylvia Pieteron
Emy Pinneri
Thelma Pudney
Aggie Purcell
Simpson Family Foundation
Lois Smith
Janice Sutton
Douglas Tempy
Heather Wearne
Pamela Williams
Rona and Graham Wilson
Kenneth Woolard

IN-KIND DONATIONS
Franca Agresta
Belinda Astl
Monique Baldacchino
Joy Buchanan
Mitchell Chipman
Caro Clarke
Michael Green
Naideen Hillier
National Australia Bank volunteers
Avis Macphee
Jane McNeilage
Ingrid Mitton
Libby Oldfield
Leanne O'Sullivan
Meron Pitcher
Michelle Temminghoff
Naomi Thomas
Yvonne Zwar

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Genesis Fitness, Lonsdale Street
IT Strategic
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Squisito

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Jo White
Beth Wilson
Sandra Wilson
Nicole Wilton
Marg Wyatt
Matt Young
Yvonne Zwar

Thank You

We would like to say thank you to all the people and organisations who have donated time and/or resources over the last decade. Without this support we would not have been able to provide such a high level of quality information and support to the thousands of people affected by breast or a gynaecological cancer.

We would also like to thank all the women, their families and friends who have used the service over the past decade and been involved in helping it continue to provide a quality service through their comments, feedback and stories.

A special thank you to those people and organisations instrumental in the establishment and early development of the service.

There are of course too many to mention, each of our valuable contributors have made the service what it is today. So to those many organisations and individuals we thank you and to those no longer with us we remember and acknowledge you.

A special thank you to our funding body and the staff at the Department of Health, Elise Davis, Kathryn Whitfield and Spiridoula Galetakis.

There were also donors who wished to remain anonymous.