

INSIDE

New research	2
Communities	4
Member Group profile	13
Thank you	14
Dates for your diary	16



the BEACON

Breast Cancer Network Australia's Magazine

Issue 52

Spring 2010

ISSN 1834-5921

Focus on:
Communities

The value of a 'community'

The term 'community' has different meanings to different people. Many of us might say that a real sense of community is rarer in our modern world with its multi-layered demands and our busy, hectic lifestyles.

Sometimes it takes a disaster, such as the horrendous Victorian bushfires of summer 2009, for a united community to really show itself and to appreciate the importance of working together to get in there and help those in need within its community.

In a similar way, for those of us who have had a breast cancer diagnosis, having a community rally around can mean so much, both in a practical sense and with emotional support. In my case, with two small children at the time of my diagnosis, my friends and neighbours delivered so many casseroles, we had to buy a freezer!

As we travel around the country presenting our BCNA Forums, the strong sense of community in rural areas is very apparent. Yes, city women often have a range of services close by, bringing more choice and better access to medical services. On the other hand, I have heard from many women living in capital cities who had no-one to readily lean on, no connection into their neighbourhoods – they were very lonely even



Connecting at BCNA's Townsville Forum

though they were smack bang in the middle of millions of people.

I am sure it doesn't always work in one's favour, but there must be so much benefit in knowing the people around you and in being confident that someone will come to your aid if you say the word. My sense is the community would jump at the chance to help.

Most women would certainly agree that they would never have opted to put their hands up to join the community of women with breast cancer! When I study the figures and see that our BCNA community is now 46,000+ strong, I feel sad that there are so many of us. Then again, I also feel comforted in the fact that, as a community, the potential is there to link people

together and to offer each other strength and encouragement.

Of course, BCNA cannot sit down with each of you individually, but our 275 Member Groups around the country offer the chance to physically hook up with others in a similar space. In an attempt to introduce the ability to connect with others in a different way, and especially for those unable to access a support group or to meet face-to-face with others, we have recently launched our BCNA Online Network.

Inside this issue of *The Beacon*, you will find directions for hooking up with us and others via BCNA's new website www.bcna.org.au. I hope you will consider joining our online network, regardless of whether you are in the city or on a remote cattle station!

The online network is also a tool that might be useful to the people around you, including husbands and partners. We know they often feel overlooked and have support needs which we struggle to address – this way they can connect with other blokes without attending any support group or showing their face to anyone!

*Lyn Swinburne,
Chief Executive Officer*



Breast
Cancer
Network
Australia

Exciting developments in radiotherapy

'The radiotherapy options for rural women are limited – either take six weeks away from family, work or farms ... or have a full mastectomy.'

Kerry

Imagine one single dose of radiotherapy instead of the six weeks of daily radiotherapy that is currently the standard treatment for many women with breast cancer. What a huge step forward that would be!

Exciting new research has shown that, for some women with early breast cancer, this may indeed be possible.

The research, called the Targeted Intraoperative Radiotherapy trial (TARGIT-A), has been under way for the past 10 years. In this time, researchers from around the world have been trialling a treatment which is a single dose of radiation given inside the breast during or just after breast-conserving surgery. The process takes about 30 minutes.

Western Australian breast surgeon, Professor **Christobel Saunders**, is one of the researchers involved. She told



Professor Christobel Saunders

The Beacon the trial outcomes have been positive, with women experiencing fewer radiation side effects. Importantly, breast cancer recurrence rates four years after the treatment are no higher than those in women who received six weeks of conventional radiotherapy.

'Almost without exception, women have been delighted when they've just had to have the one-off treatment,' Professor Saunders said.

'To be able to have radiotherapy treatment on just one day makes a huge difference to them, particularly for women who live in the country, run their own business or have a family to manage.'

Professor Saunders said that while it will be important to continue to follow-up trial participants to look at possible long-term effects and breast cancer recurrence, the results show that the treatment could be highly beneficial for women.

'I think we've got strong evidence that, for a certain group of women with low-risk cancers, this is at least equivalent to external beam radiotherapy,' she said.

Western Australian woman, Carol, participated in the trial and was pleased with the process and the outcome.

'I was happy not to have to leave home for six weeks of radiotherapy in Perth,' she said. 'The procedure was straightforward, with no side effects and only a little pain afterwards.'

For women like Carol who live in rural areas, a one-off radiotherapy procedure could increase breast cancer treatment options. We know that sometimes women elect not to have radiotherapy, even though it may be recommended for them, or choose mastectomy rather than breast-conserving surgery, to avoid being away from home for an extended period. This new treatment could make breast-conserving surgery a practical option for them.

The reduced side effects of the one-off treatment are another major benefit for women. The current treatment can cause fatigue, burns to the skin, breast tenderness and loss of appetite. An effective treatment that allows women to avoid, or reduce, these side effects would be greatly welcomed by women across Australia.

While the new treatment is not yet generally available in Australia, the trial is still open for eligible women in WA and Victoria. Women interested in participating should talk to a member of their treating team about it.

Our breast reconstruction survey – we need your input

BCNA is conducting a survey about women's experiences with breast reconstruction and we are looking for women who would like to participate.

Have you had a breast reconstruction? Do you have experiences you would like to share – good or bad?

Perhaps you would like to have a reconstruction but are finding it hard to access? We suspect many women are deterred by long waiting lists in public hospitals and high costs for private surgery.

BCNA is keen to tackle this important issue for women but

we need your feedback if we are going to be able to make an impact.

If you would like to help by completing our survey, please email your name, postcode and email address to policy@bcna.org.au by Friday 24 September. You do not need to have had

a breast reconstruction to participate.

The survey will be conducted online and should take no more than 20 minutes. It will be anonymous – we will email you a link to a website where you complete it via the internet.

BCNA's advocacy work on the net

As the peak national consumer organisation representing women with breast cancer, part of BCNA's work is to speak out on your behalf, to lobby government and to press for improvements in breast cancer treatment and care.

BCNA's Policy Team develops documents about issues that affect women, including position statements and submissions to government inquiries, to help promote our views.

You can find copies of these documents on the Advocacy page of BCNA's new-look website. They'll help to keep you informed about our advocacy priorities, campaigns we are running and other issue-based work we are doing.



BCNA's Policy Team: Michelle Marven, Katie Allen, Kathy Wells and Astrid Keir

The page can be found at www.bcna.org.au > About BCNA > Advocacy.

You can also join BCNA's Review & Survey Group by following the

speaking out link on the Advocacy page. Members of the Review & Survey Group participate in breast cancer surveys for BCNA and for researchers from

across Australia. They also review books, websites, DVDs and other items of interest to women with breast cancer.

Poor-fitting bras limit exercise options

'I generally avoid exercise that requires lifting my arms if I am wearing a bra because of the discomfort and annoyance of it riding up.'

Survey participant

It is well accepted that exercise provides a range of benefits for women with breast cancer. While some research has previously been undertaken into barriers to exercise, a study at the University of Wollongong is the first to look at whether a woman's bra comfort may limit her ability to exercise.

The first stage of this project, a survey of 414 women with breast cancer, most of whom are members of BCNA's Review & Survey Group, was recently completed.



Researcher Sheridan Gho tests an exercise bra with a BCNA member.

Nearly half the women surveyed (184) reported that the bra they wore for exercise was uncomfortable, with the band around the chest rated the most

uncomfortable part. Sixteen per cent of women (68) said their bra was so uncomfortable it prevented them from doing some types of exercise activity.

Wearing a prosthesis was also found to limit activity. Nearly 35% of women who wore a prosthesis said it restricted their participation in activities such as swimming, running, gym classes and team sports.

The researchers are now evaluating the results of the survey to determine their next steps, which may be to develop a 'purpose-built' exercise bra for women who have had breast cancer surgery.

To read more about the *Building Better Bras* survey results, visit our website at www.bcna.org.au > News > Resources > Research reports.

BCNA's online network linking together

By the time you receive this magazine, it will be four months since bcna.org.au had a major makeover. If you haven't visited recently, we recommend you take a look.

As well as a new look and feel, there is a new navigation structure. Having the information organised by topic and a more effective search function has made it much easier to find what you are looking for. We have also expanded the content to include more on living with breast cancer and secondary breast cancer, and added information specifically for people in rural areas, and for health professionals.

Online network

An exciting new component of the site is our online network. For several years people had been asking BCNA to provide a way for them to connect with others affected by breast cancer and to be able to communicate online. Research and overseas experience has shown that even when people with a cancer diagnosis have strong support from family and friends, they seek out and benefit from support from others – people they don't know but who have a deep and personal understanding of the cancer journey.

Online networking means that not only women diagnosed with breast cancer but their partners, families, friends and work colleagues can express their thoughts in the middle of the night and reach out to others thousands of kilometres away. For those familiar with the popular internet sites, BCNA's



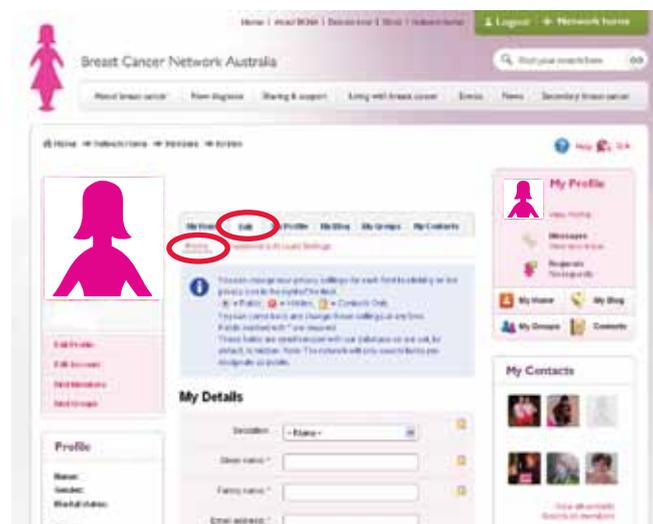
Joining the network is easy! Just visit the website homepage at bcna.org.au and click on the 'Join our network' button at the top right of the screen.

online network can be described as 'RSVP meets Facebook, specifically for people affected by breast cancer'.

My computer was my lifeline during a difficult time, my breast cancer diagnosis. I am very

passionate about linking rural women to information and services that our city folk have available, and the internet can do that for us.

Online network member from remote Australia



Completing your profile is important so that others within the network of similar interests and experiences can find and connect with you.

The network allows you to:

- Create a personal profile
- Tell your own story and maintain a blog
- Search for and find others with similar experiences
- Create and join online interest and support groups
- Choose who can access information about you and the content you create.

Joining the online network

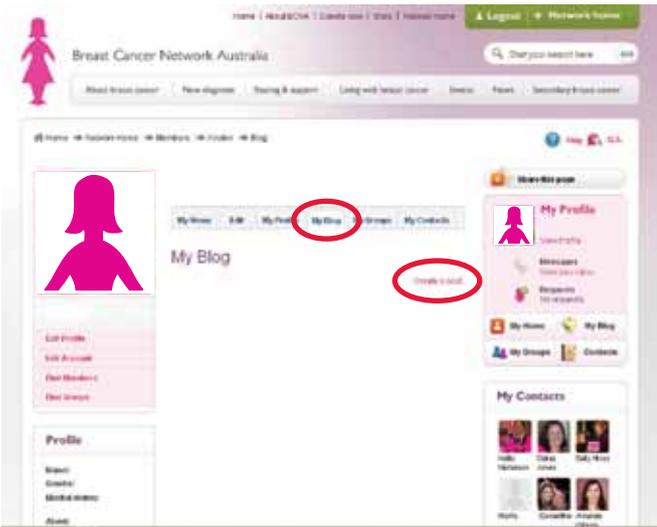
Joining the network is easy! Just visit the website homepage at bcna.org.au, and click on the 'Join our network' button at the top right of the screen.

We don't allow anonymous users in the online network, so you'll need to register to participate. Start by filling in your details on the registration page and follow the prompts. It's pretty easy, but if you get stuck you can go to the 'Help' page and download a simple user guide that has step-by-step instructions. If you are still stuck after that, call us at 1800 500 258 for some tips.

Once you have registered, you will receive an automated email message. Follow the instructions and the link in the email to complete your online network profile. One of the first things you should do is reset your password.

Your profile

When you're logged in and visiting the network homepage, you see a 'My Profile' panel on the right of the page. Click on your image or the 'View Profile' link to get into your profile.



To start your own blog, just click on the 'My blog' tab in your profile and create a post.

Completing your profile is important so that others within the network with similar interests and experiences can find and connect with you. Put in as much detail as you feel comfortable sharing, and use the inbuilt privacy settings (see box on the right) to control how much or how little others can see.

There's no need to share private or personal details, but the more information you share, the easier it will be for others with common interests and experience to find you via the search function.

Your online profile is also an easy way to keep your details up to date as it is connected to our database. Please do not remove, or delete details such as your address, especially if you receive our publications. Information, such as your diagnosis or family history also helps us know more about our members. If you want to make sure these are private, use the privacy settings.

Keeping a blog

The online network also gives you the option of keeping a blog, or 'online diary'. It can be a useful tool throughout your breast cancer journey because:

- it can be therapeutic to write about your experiences
- it is optional to share your experiences publicly, but your story may provide support and comfort to others in the same situation if you do share.

In the research we did last year, several people told us how they had used blogs and social networking sites to keep family and friends up-to-date with their progress and how they were feeling. They were able to direct people to the web page and avoid having to answer lots of calls or explain things over and over. Sometimes the blogs were written by a partner.

To start your own blog, just click on the 'My blog' tab in your profile, and create a post.

You can also send personal messages to other members and choose to be notified of network activity.

To find other members to add to your list of contacts, just click on one of the 'find members' links on your 'My Home' page.

You can then search by gender, age-range, breast cancer experience, location, etc.

We hope you enjoy using the network to connect with other women across the country.

I didn't realise this website and online network was so new! It is fantastic and a great way to communicate with others experiencing similar feelings. I have been involved in online learning for a number of years and the benefits of web-based social networking, which removes any geographical boundaries, is fantastic! Look forward to staying in touch!

Online network member

Privacy settings

One of the main features of the BCNA online network is the ability to control who can see your profile and the content you create.

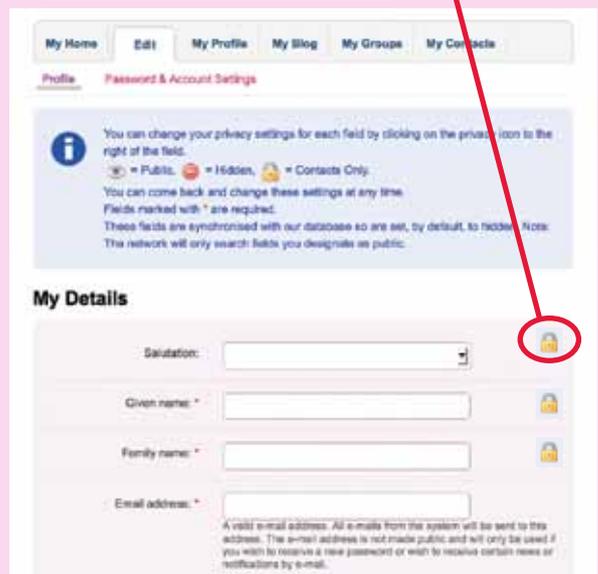
There are three privacy options for each piece of information:

- Public – visible to everyone
- Hidden – visible to you, hidden from everyone
- Private – visible to you and your friends

You can find the icon to change the setting at the right of every field.

When you first join the online network, the privacy option is set to 'hidden'. By changing the option, you can choose how much or how little information others can see.

Privacy icon



The more information you share, the easier it will be for others with common interests and experience to find you via the search function.

A community in need

Having survived a third bout of early breast cancer in eight years, I decided it was time to accept a different kind of challenge.

I volunteered with Australian Volunteers International (AVI) to work as an English Language Teacher Trainer with the United Nations Relief and Works Agency (UNRWA), the UN branch that supports Palestinian refugees.

In January 2009 I arrived at my new community, Yarmouk Camp, in Damascus, Syria, where I was to live and work for the next 18 months.

I worked with the UNRWA school English teachers, the majority of whom are Palestinian refugees.

I organised workshops, seminars and discussion groups for the teachers, and during one of the discussion groups I started to learn about awareness levels and attitudes towards cancer.

Shortly after arriving I found a cancer specialist, a professional and pleasant Syrian doctor.

My checkups with her and at the University Hospital were always



Denise with Noura, who she trained to speak out about breast cancer.

thorough, but of course there was a cost which for some would be prohibitive.

Through her I learned more about the community awareness and attitudes towards cancer. Cancer was thought of in a very negative way and 'death' was the first word that most people thought of.

A lack of awareness contributed to a certain secrecy surrounding this disease.

The current rate, which is not as high as in Australia, is increasing every year.

I obtained some funding from Australia (AVI and Planet Wheeler) to run a breast cancer awareness program.

The funding enabled the printing of brochures and posters, and the making of pink ribbons for distribution to the 12 Palestinian refugee camps in Syria. It also allowed

for a Community Awareness evening in the biggest camp, and a limited number of mammograms.

UNRWA also funded a 'Training of Trainers' (ToT) program and breast cancer awareness talks for all the camps in Syria.

My life became busy coordinating all facets of the program with the support of UNRWA staff, designers, translators, community workers and a team of specialist doctors.

I was thankful for my Community Liaison training which I had just completed with BCNA before I left for Syria.

The awareness talks, 'ToT' sessions and community evenings were mainly attended by women (and a few men) from the Palestinian community, but word of the program spread, so women from the Syrian community and other refugee communities, such as the Iraqi and Somali communities, were also welcomed.

The awareness program proved to be popular and was attended by many women, enabling the provision of information about 'when and how to check', 'changes to look for', 'ways to reduce risk' and 'statistics'.

At the final event a survivor approached me, told me her story and could not stop thanking and hugging me, an emotional end to the evening and the awareness program.

This was the beginning of a greater awareness and openness about breast cancer, in a community that I had grown to understand and love.



Women at Denise's Yarmouk Breast Cancer Awareness evening.

Denise, QLD

The joy of a new community

When you are diagnosed with early breast cancer, life changes, the way you see life changes and your needs change. There can be no rehearsal for what you are about to experience. It happens immediately and you can't say, 'Sorry, I'm busy at the moment, let's do this later.'

Luckily, I am blessed with many wonderful friends who helped get me through it without tears.

But in addition to my friends, it was also important to meet other women who had faced the same ordeal, because we all share something that words cannot really explain.

After my first surgery (I had two lumpectomies and a full mastectomy) my breast cancer



Irene

nurse told me that she had put me in touch with BCNA and to be prepared to receive a *My Journey Kit* in the mail.

It arrived a few days later and through the pages of **The Beacon** I read about so many women who had been through a

similar experience and were now living life to the full.

Some stories were extremely personal, courageous and gut-wrenchingly honest. The women wrote of their faith, love and high hopes; such emotionally charged stories that left me full of hope for my future.

Going through my various treatments I found it difficult to read a lot, but when each issue of **The Beacon** arrived I turned straight to the articles written by my new 'community' of women.

When the offer came to be trained as a Community Liaison for BCNA, I did not hesitate for a minute. I, too, wanted to be one of these strong women I had been reading about.

I had barely finished treatment

when I went through my training day with about 20 other women. What an exhilarating day!

Although some thought it may have been a little early for me, I felt confident that I could do it. And I did, filled with a wonderful sense of belonging.

When my treatment was finished and I was no longer spending most of my days with my medical team, I had a feeling of unexplained loss.

Just as there can be no rehearsal for the diagnosis, there is no rehearsal for the end of treatment, and so being part of a community of women who had been through it all gave me great comfort and the strength to cope with yet another unexpected feeling – my transition period.

Irene, VIC

Because of our communities

I live in a small town in a remote rural area in the middle of Eyre Peninsula, South Australia.

When I was first diagnosed with breast cancer at the age of 39, I wanted to keep it quiet. I wanted to go to my friend's 40th without everyone knowing what was going on. But when you live in a small community and suddenly you are not going to work and instead you are travelling to Adelaide every week for five weeks – a 1,300 km round trip – everyone knows something is up.

The support I received was extraordinary and unexpected. I had visits from other women in the community who had already taken this journey, including a young woman making it for the second time.



Paula with her daughters

I received cards and letters from former clients and care workers and colleagues from all over the Eyre Peninsula. These sat in a prominent position in my living room so, on a bad day, I could be

reminded of how many people cared for me.

I had my groceries carried out to the car for me when I went to the supermarket and if I decided to walk somewhere and

fatigue suddenly hit me there was always someone who would offer to take me home. There are advantages to everyone knowing everyone in a small community.

My experience with breast cancer opened my eyes to what had always been around me but I had never noticed or truly appreciated – a community that helps and supports one another, sometimes quietly and behind the scenes, and sometimes more openly, but when times are tough they are there.

Sometimes those of us living in isolated areas are actually less isolated than someone in the heart of the metro area, because of our communities.

Paula, SA

The Chardonnay Club

I live on the beautiful Mornington Peninsula in Victoria with my husband and children. I am a midwife and breast cancer survivor.

The Mornington/Mt Martha area, although a growing area, still has a community spirit about it.

Our family has always been involved in kinder, school and Rotary committees and activities, and from these long-term friendships have formed.

A breast cancer diagnosis in 2003 led to surgery, chemotherapy, and radiotherapy, and opened up another world to me.

During treatment our local breast surgeon gathered a group of younger women together and 'The Chardonnay Club' was formed. We met at each other's houses, we laughed, we hugged, we cried; these were my first 'Breast Friends'.

They became an important part of my cancer treatment, as the



Jo

sharing of experiences made them more bearable.

This experience prompted me to co-found and co-facilitate 'Breast Intentions', a support group for younger women on the Mornington Peninsula.

The women I meet through this group continue to inspire me and each other.

The experience also led me to further education and I became a breast care nurse (as well as a midwife) at my community not-for-profit hospital. This enables me to visit women while they are in-patients and pass on information.

As a local gal (I have been here 25 years, so am almost a local!),

many people contact me to seek information, have a chat, or ask me to talk at a morning tea, school or group. Others are referred by hospitals, doctors, and nurses. Sometimes it is as a woman who has had a cancer diagnosis, sometimes as the support group facilitator, and sometimes as a breast care nurse. It can make for a busy life!

Through my cancer experience I have attended national conferences for both survivors and breast care nurses, stood in the *Field of Women – Live* at the MCG in 2005 and 2010, organised *Mini-Fields of Women*, and spoken at many functions.

I also joined Amazon Heart Thunder and rode a Harley Davidson motorcycle 2,000 km from Brisbane to Sydney along with 30 other breast cancer survivors in 2009.

I have plans for the future!

Jo, VIC

All bound by one thing ... breast cancer

Twenty eight years ago, when I was diagnosed with breast cancer, I believed that my life would be cut short.

I never thought that I would leave my daughters and the UK and follow my husband to Australia for work. I have since been involved in various aspects of breast cancer support, Encore, BCNA and more recently have become a passionate dragon boat paddler.

Little did I think I would join a composite team from the Mid North Coast of NSW, called the

Aussie Dragonflies, to compete in Peterborough, Canada, at the International Breast Cancer Survivors' Dragon Boat Regatta. I decided we could not leave Australia without a BCNA poncho. Thanks to BCNA that wish was fulfilled.

What a treat we all looked, when we visited Niagara Falls. People stopped us to ask where we had come from and what the meaning of the ponchos was. Needless to say we were the driest people on the Maid of the Mist boat, when drifting towards the Falls.

Many of the international survivors wanted our ponchos as they kept us dry on the first day of the Regatta, when it rained heavily. The ponchos also acted as a ground sheet when we watched the Flowers on the Water ceremony. Finally, on the last day of the regatta, we were ready to part with our ponchos and they were swapped for tee-shirts, pins or were just given away. Now they can be seen in Canada, USA, Italy, South Africa, New Zealand and the UK.

It was a privilege to be among 2,000 breast cancer survivors, including two men. What an inspiration they all were. So much laughter, tears of joy, singing, love and friendship came from everyone, including all the wonderful people of Peterborough.

Our team came 24th out of 75 teams and we were delighted with our result. Finally thank you BCNA for the ponchos. Without them we would have become the Aussie Drowned Rats and not the Aussie Dragonflies.

Marion, NSW

Celebrating caring communities

When life throws its greatest challenges at us it is so often the support of our friends and families that sees us through.

My experience of being diagnosed with breast cancer less than three years ago has shown me how true this is.

It has also given me the gift of being embraced by communities of people who not so long ago were strangers to me, but who have reached out and walked with me side by side through the months of diagnosis, treatment and beyond.

The importance of community was brought home to me by my rather unusual situation.

I had joined my husband, Paul, on a four-year posting with the British High Commission in Canberra just two months before the fateful morning when, idly spreading body lotion on my breasts, I felt a lump.

What happened after that is a story familiar to thousands of women – the seemingly endless tests, surgery, chemotherapy and radiotherapy. What was different for me was that my family, including my 16-year-old son, and my friends, were, quite literally, on the other side of the world.

So many different people supported me. Individuals who took the risk of picking up the phone, of saying those wonderful words 'I am here for you; let me know if there is any way that I can help'.

I was happy to talk about my breast cancer to anyone who was interested in listening, in the hope that this might reduce



Bosom Buddies Sarah and Marilyn promote BCNA in their community.

in some way the fear of the unknown should it affect other people.

I was rewarded a thousand fold by the warmth and responsiveness of those I told.

People I had met only once or twice came with flowers, books, phoned me, made me laugh and sat with me while I cried.

Strangers rallied round, and what a wonderful thing that was.

It is amazing how strangers can become friends in such a short time when a crisis occurs!

I finished radiotherapy nearly two years ago and have gradually become increasingly involved in breast cancer support work.

My background is as a nurse – most recently running a lymphoedema clinic in England. Although I was not eligible to nurse here in Australia, I have been able to put my experience on both sides of the breast cancer experience to work.

I underwent training to give foot massages to women undergoing chemotherapy and now am a regular volunteer.

It seems to give particular reassurance to patients when I am able to tell them that two years ago I was quite literally where they are now and they tell me how much it means to meet someone who has been through the treatment and who looks and feels so well.

As well as being a BCNA Community Liaison, I am also involved with Bosom Buddies, the very active ACT Breast Cancer Support Group.

We have a team of volunteers who respond to requests passed to us by the breast care nurses to visit women in hospital who have undergone surgery for breast cancer. Many of them request a follow-up phone call, and from this and other contacts we provide a service which, as our name implies, provides friendship and support for women going through treatment.

Sarah, ACT

My two special communities

BCNA remains such a source of support for me, my family and friends, and it has been a blessing and a privilege to become a Community Liaison. My direction in life has been given a new road to take.

When diagnosed with breast cancer in 2005 BCNA was my lifeline to information, and the Community Liaison women I met were inspirational.

I am now proud to be a BCNA Community Liaison myself. I have sat down for a quiet chat or coffee with a woman who feels alone. I have tried so hard to voice positive support over the phone to a woman I am yet to meet. I have taken part in many local community events, all with the beautiful common thread of raising awareness and providing selfless support to our local world of seemingly increased

numbers directly or indirectly affected by breast cancer.

I see my community of Hampton in Melbourne as a haven on earth, and through its support, and mine in return, our local community has wide-open arms for those in need of support.

The young generation at my children's local primary school are all aware of the 'Pink Lady' – her symbol provides comfort to us all.

Along with an amazing group of volunteers, including breast cancer survivor **Michelle Adams**, I am privileged to have been part of the Pink Lady Art Exhibition initiative, now an annual event in my local area.

The event supports visual arts, community spirit, breast cancer survivors and volunteers, while raising awareness and funds for BCNA.



Lisa's artwork

Personally, I have taken up visual arts and am working on an oil painting called 'You'll never walk alone'. It reflects my recent incredible experience at the *Field of Women – LIVE* event at the MCG.

It will be an item in the silent auction at the next Pink Lady Art Exhibition event in Melbourne on October 23 and 24. For more information, visit www.pinkladyart.com.au.

Lisa, VIC

Pink Ladies to grow support among the blooms

BCNA is delighted to be a key charity partner of Floriade 2010, an annual event held to celebrate spring in Canberra. Floriade is the largest floral festival in Australia and takes place in Commonwealth Park, beside Lake Burley-Griffin, from Saturday 11 September to Sunday 10 October 2010.

More than 400,000 people from around Australia are expected to visit Floriade 2010 to view the one million spring blooms that will be on show.

A BCNA *Mini-Field of Women* will also be a feature of Floriade this year.

Breast cancer survivors, ably led by BCNA Community Leader **Kerrie Griffin**, will be present at the *Mini-Field* from Saturday 11 to Monday 13 September to talk to visitors about BCNA and its work.

A simple ceremony will be held at 11 am on Saturday 11th to pay tribute to women and families affected by breast cancer. The *Mini-Field* will remain on display for the remainder of Floriade.

For further information, visit www.floriadeaustralia.com.

A Mini-Field of Women will feature at Floriade 2010.



The sharing of hope

It was with great pleasure that, together with a number of other women, I recently met with former Hawthorn AFL football players Shane Crawford and Rayden Tallis.

Shane is preparing to embark on his 'That's what I'm walkin' about' run from Adelaide to Melbourne beginning on 5 September 2010 (Father's Day).

Each of us had been invited to share with Shane our experiences of being diagnosed with breast cancer.

Lyn Swinburne and **Raelene Boyle** spoke not only of their own journeys with breast cancer (in Raelene's case together with ovarian cancer), but also the genesis and evolution of BCNA.

Rayden shared some of his thoughts and feelings from the time his mother was diagnosed.

To find out more about Shane's run, visit www.bcna.org.au

Two young women aged in their early twenties spoke eloquently of their experiences in coming to terms with the news of the diagnosis, and of the huge adjustments to be made physically, socially and emotionally.

Other stories were shared by those recently diagnosed with breast cancer and I was able to speak about living with secondary breast cancer.

Shane listened attentively during our time together, seeking clarification from time to time as each of us spoke about the range of past, current and trial treatment methods we have been subjected to.

While we spoke about our differing fears, tough times and the many challenges that need to be confronted, we were unanimous when talking about the importance of hope.

All of us agreed that while breast cancer certainly slowed us down, each of us has continued to lead fulfilling lives, even if we are still accessing treatment.

I found the time spent sharing our experiences with Shane valuable. It reminded me that breast cancer affects so many different people. It does not discriminate based on age or culture, and its impact is far reaching as it also affects loved ones, such as Rayden.

I appreciated that Shane was clearly interested in finding out the reality of living with breast cancer, rather than just reading about it.

I would like to recognise that Shane's journey is not dissimilar to that of a person newly diagnosed or relapsed breast cancer. Neither knows in advance what they are truly capable of, but both know that there will be an immense need for strength, focus, resilience and often laughter.

As he undertakes this massive task, Shane has been charged by all of us to carry with him our hope, and the hope of all those whose lives have been touched by breast cancer.

We wish Shane the best on his journey and thank him for supporting our cause with great respect.

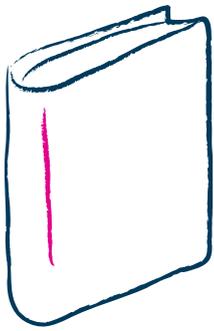
Barbara Oakes, VIC

'To live without hope is to cease to live.'

Fyodor Dostoevsky



Shane Crawford (centre) meets BCNA members for inspiration.



Review

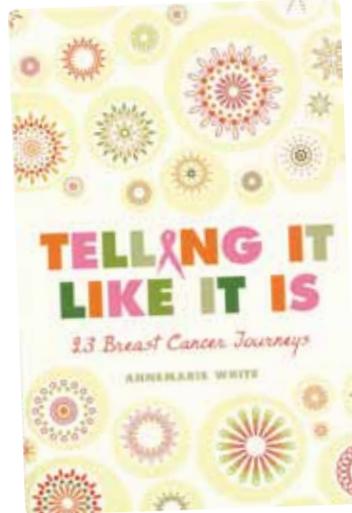
Telling It Like It Is: 23 Breast Cancer Journeys

by Annemarie Winter Harper
Collins 2009 270 pages, RRP \$32.99

This book chronicles the journeys of a diverse group of Australians (22 women and one man) diagnosed with breast cancer.

The author, a Queensland journalist, has included her own story of coping with breast cancer, and shown that while many experiences are common, there are also many different ways of coping with them.

The negative aspects of some journeys are written about as honestly as the positive. The contributors show, on the whole, an amazing optimism but, at the same time, their apprehension and fears.



As a reader who has experienced breast cancer, I felt heartened by some of the anecdotes and sentiments expressed throughout the stories. It reinforced for me that feeling teary, scared, and alone was not unusual.

The stories told of both the happy and the sad times and overwhelmingly relayed the amazing resilience of those affected and their supporters.

Telling it like it is could be useful for those newly diagnosed in giving them the confidence to question important aspects of their treatment. It would also help those around them.

I wish I had been able to access the book at a time when I felt that I must have been the unluckiest person in the world.

After reading the book I actually felt heartened that others had experienced tough times too and had pulled through and were so optimistic about the future.

I felt the email entries of the author were inspiring and showed the regard and concern that she held for the feelings of those close to her during her journey. She surely put at ease all those who received her updates. She and the other contributors and their supporters certainly showed the height that the human spirit can aspire to.

*Bronwyn Karapetcos,
Review & Survey Group Member*

Thank you

Thank you to all those readers of **The Beacon** who sent in donations and cards as a result of the letter in our previous issue.

Knowing that this magazine means so much to many Australians is a great feeling for us.

Linking together

Over the past 10 years a key part of BCNA's mission has been to **link together** Australians personally affected by breast cancer.

Local breast cancer groups around Australia that come under the BCNA umbrella as Member Groups are essential in linking women together.

We welcome the following new groups, which brings the total number of BCNA Member Groups around Australia to 275:

- Maitland Women's Cancer Support Group, Maitland, NSW



- Nyngan Cancer Support Group, Nyngan, NSW
- Warialda & Community Support Group, Warialda, NSW
- Bosom Buddies Gympie, Gympie, QLD
- Bribie Anglican Support Group, Bribie Island, QLD
- Innisfail Breast Cancer Support Group, Innisfail, QLD
- Malanda Cancer Support Group, Malanda, QLD
- Tully & District Cancer Support Group, Tully, QLD
- Women's Cancer Support Group, Rockhampton, QLD
- Benalla Breast Cancer Support Group, Benalla, VIC
- Moving Ahead, East Bentleigh, VIC
- Eastern Health Breast Cancer Support Group, Ringwood East, VIC
- Young Women's Breast Cancer Support Group Frankston, VIC
- Collie Breast Cancer Support Group, Collie, WA
- Young Women's Cancer Group – Geraldton, Geraldton, WA

You can visit our website to find a Member Group, including support groups, in your state or territory at www.bcna.org.au > Sharing & Support > Find a support group.

BCNA also now has more than 46,000 individual members across Australia.



Profiling our Member Groups

Women Touched by Cancer

In 2007, my friend Marg Mason and I formed the Women Touched by Cancer group in Swan Hill, Victoria.

We felt passionate about having an active cancer support group in our area. The group now has 20 members – all women who have been diagnosed with cancer.

We are a busy group and very involved in our local community.

We are well-connected with the local hospital and bought a fridge for the chemo unit that we keep stocked with drinks and ginger lollies.

Marg attends regularly to sit with the women for their first chemo.

Our wig library, which has more than 30 wigs, is popular. Many women feel they are 'on show' when they lose their hair, so appreciate the use of a nice wig. We have a qualified hairdresser who maintains, fits and styles the wigs for us. We provide women with a pamper pack that includes a wig, wig stand, shampoo and scalp massaging oils.

We are active in raising awareness of our group – what we stand for, what support is needed and how much that support is valued by women and their families.

As a result we are fortunate to have a community that is eager to help us. Local businesses organise pink golf days and pink afternoon teas to raise funds for our group.



Donna, centre front, with members of Women Touched by Cancer

Recently the Swan Hill Women in Racing donated its whole race day to us, with a race named after us and our pink logo on a pink saddle cloth in every race.

The day raised \$40,000, which will be used to support the wig library, the chemotherapy ward, other cancer therapies in the Swan Hill area and the work of BCNA.

Both Marg and I do quite a bit of public speaking. I've been trained through BCNA's *Seat at the Table* program and Marg is trained as a Cancer Council Cancer Connect volunteer.

I have presented at local events such as Lake Boga's Biggest Morning Tea and Inner Wheel (wives of Rotarians). A recent talk at the local football club about BCNA's Pink Footy Day got them keen to be involved in 2011.

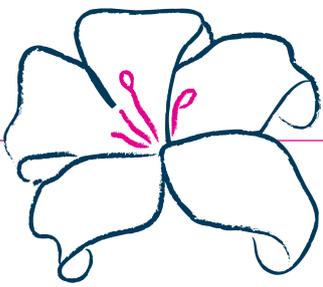
For several years I have spoken to third-year nursing students at the local TAFE college, to give the important perspective of a breast cancer survivor. I talk about how to care for their breast cancer patients and how important it is for women to know about the *My Journey Kit*.

We were excited to be nominated by the hospital and community for the Victorian Minister for Health 2010 Health Volunteer Awards, and we won the regional award!

We enjoy working with BCNA. Every year we get involved in the Bakers Delight Pink Bun Campaign and run a *Mini-Field of Women*, and I always have a *My Journey Kit* on hand.

Nothing is achieved without hard work. However, with determination to promote our group and what we are about, our community now wants to help us at every possible opportunity.

Donna Rullo, VIC



Thank you

We appreciate the financial support given to us by individuals, clubs, organisations and companies around Australia. We would especially like to acknowledge the recent help of the following outstanding supporters:

- ANZ
- Anthony Biggs, NSW
- Art Est. Art School, NSW
- Belinda Thompson and team, QLD
- beyondblue: the national depression initiative
- Bicheno Golf Club, TAS
- Brenton Yon, NSW
- Caroline Grimmeisen, NSW
- Caulfield Grammar School Auxiliary, VIC
- Daniel Deason, VIC
- De Lambert Largesse Foundation, NSW
- Delaware North Companies Australia and New Zealand
- Diane Grady, NSW
- DLA Phillips Fox
- Eaden Sleepwear Pty Ltd, VIC
- Epworth Eastern Hospital, VIC
- Ernst & Young
- Evans Family Foundation
- Freehills
- George Castan Family Charitable Trust, VIC
- George Malliaros, VIC
- Greg Waters, VIC
- Helen Douglas, WA
- Holy Family Primary School, ACT
- Ian Drysdale, QLD
- IOOF Holdings Limited



Anthony Biggs ran in this year's Sydney Morning Herald Half Marathon, presented by Colonial First State. He raised \$8,300 for BCNA, in honour of his aunt Anna. Congratulations and thank you Anthony.

- Jenny Craig Weight Loss Centres Pty Ltd
- Jo Fisher, VIC
- Joan Staples, NSW
- JRB Shopfitting Co Pty Ltd, VIC
- Kwong Teo, VIC
- Lumo Energy Australia Pty Ltd
- Macquarie Group Foundation
- Mandy Mitchell, VIC
- Margaret Illman, SA
- Mary Crickett, VIC
- Maureen Chan, ACT
- Mercedes-Benz Barloworld Motor Brighton, VIC
- Merlvic Schrank Pty Ltd, VIC
- Michael Swards, VIC
- Monash University, VIC
- Morgan Stanley Smith Barney
- Myer Pty Ltd
- Nissan Motor Co. (Australia) Pty Ltd
- Pacific Brands
- Pantan Hill Football Club, VIC
- Paul Brasher, VIC
- Peter Madsen, ACT
- RACV
- Robelene Cruickshank, VIC
- Roger David Stores Pty Ltd
- Ron Bonighton, VIC

- Roto Oil, SA
- Sacred Heart Parish School, VIC
- 7 Grams Café, VIC
- Sizzler Australia
- St Kilda Football Club, VIC
- Supagas, VIC
- Taryn Lupton, VIC
- The University of Melbourne, VIC
- Toshiko Budgen, QLD
- Trudy Harris, NSW
- Viewgro Capital, VIC
- William Clarke College, NSW
- Yvonne Carrick-Allan, NSW

Memorials

We pay tribute to the lives of:

- Beverley Wright
- Carolyn Spurgeon
- Dianna Polimeni
- Frederick Stock
- Marie Grege
- Marissa Buckley
- Mary Sherwood-Kay
- Patricia Deeny

Celebrations

Thank you to those who celebrated a special occasion and asked for donations to BCNA in lieu of gifts:

- Carmel Danks
- Gaynor Suckley
- Grace Cipriani
- Jennifer and Dean Beevor
- Paul Lostia
- Susan Crawshaw
- Vera Kostovski

Getting pink in October

October is Australia's Breast Cancer Month – a month marked by breast cancer survivors, those who care for them, and by many companies and organisations who want to show their support for all those affected by the disease.

Here are some options for getting involved this October.

Attend a local *Mini-Field*

Mini-Fields of Women, held in local communities around Australia, are a feature of BCNA's October calendar.

Each event features our Pink Lady silhouettes as a way to pay tribute to the local women and families who have been affected by breast cancer.

Every *Mini-Field* is unique and special to the community. They can be promoting local support services, a way for family and friends to gather and remember all those affected by this disease, as well as a way to raise money for BCNA.

If you are looking for a way to celebrate October, find out where *Mini-Fields* are being held in your local area. Visit bcna.org.au > events > mini-fields-women or phone us on 1800 500 258.

If shopping is more your scene then:

Head to a **Sussan** store and buy our exclusive pin with three Pink Ladies (right).



2009 Mini-Field of Women in St George, QLD

Friends, family or colleagues can wear the pin as a show of support.

While you are in the store you might want to introduce yourself and thank the Sussan team for their ongoing support. They love to meet BCNA women.

Also ask the Sussan team about the specially designed clothes and accessories supporting BCNA this October.



Sussan has been in partnership with BCNA since 2006.

Berlei has designed a bra to 'pink up' October and raise funds for BCNA.

The bra is part of the popular 'Barely There' range, which can be found at leading retailers. Five dollars from the sale of every bra goes to BCNA.

We are grateful to Berlei for its ongoing commitment.

Hammamas has designed a beautiful pink sarong that will look terrific on the beach this summer. It makes an ideal Christmas gift, and \$10 from the sale of each \$39 sarong will be donated to BCNA. To purchase, visit www.hammamas.com.au.

There is so much happening in October. To keep up to date

visit our events pages at www.bcna.org.au > events or phone 1800 500 258 for activities in your local area.



BCNA gratefully acknowledges our partnership with Bakers Delight.





Dates for your diary

September 5 – 16: 'That's what I am walkin about'. AFL champion and Footy Show personality, Shane Crawford, runs from Adelaide to Melbourne to raise money for BCNA. To see how you can get involved go to: www.bcna.org.au

September 7: BCNA will hold a forum in Dubbo, NSW. The topic will be 'Living Well after Breast Cancer'. There is no cost to attend and survivors, family and friends are invited. www.bcna.org.au will have all the details or call 1800 500 258 to register your interest.

September 10 – 12: The 2nd National Conference for Young Women Affected by Breast Cancer. An opportunity to learn, network, share, raise awareness and further advance the needs and issues of young women in Australia. Radisson Hotel, Gold Coast, QLD. For more information www.ywcaustralia.org.au

September 11 – October 10: *Mini-Field of Women* display at Floriade, Canberra. For more information visit www.bcna.org.au

September 11 (Saturday): BreaCan will present a one-day forum about treatment opportunities for women with advanced breast cancer at Queen Victoria Women's Centre, 210 Lonsdale St, Melbourne. For information or bookings phone 1300 781 500.

September 14 (Tuesday): Supporting Sisters and Aunties to Survive! Breast cancer summit for Aboriginal and Torres Strait Islander women. The Mangrove Resort Hotel, Carnarvon St, Broome, WA. 10am – 3pm. Free. To register, contact Hannah Nancarrow at NBOCC on (02) 9357 9479 or hannah.nancarrow@nbocc.org.au

September 19 (Sunday): Blackmores Sydney Running Festival. Choose from four different events. Register to participate in the event and fundraise for BCNA at www.sydneyrunningfestival.com.au

October: *Mini-Fields of Women* will be held around Australia. Visit our website www.bcna.org.au to find a *Mini-Field* near you or to register your own.

October: BCNA will hold a forum in Mt Gambier, SA. Visit www.bcna.org.au for details or phone 1800 500 258 to register your interest.

October 3 (Sunday): Combined Church Service for people affected by breast and prostate cancer, St Michael's Uniting Church, Collins St, Melbourne, 2pm.

October 17 (Sunday): Combined Church Service for people affected by breast and prostate cancer, St James Anglican Cathedral, King St, Sydney, 2pm

October 25 (Monday): Australia's Breast Cancer Day

October / November: BCNA will hold a forum in Broken Hill, NSW. Visit www.bcna.org.au for details or phone 1800 500 258 to register your interest.

November: BCNA will hold a forum in Gippsland, VIC. Visit www.bcna.org.au for details or phone 1800 500 258 to register your interest.

November 8 (Monday): COSA Consumer Forum – 'Beyond Cancer – It's about living'. While not breast cancer specific, this cancer forum may be of interest, particularly to women with secondary breast cancer. Topics include managing pain and maintaining emotional wellbeing. Melbourne Convention and Exhibition Centre, 1pm – 5pm. Free. To register, visit www.cosa2010.org.

December 5: Sussan Women's Fun Run 2010, 5 km and 10 km run or walk supporting BCNA, Catani Gardens, St Kilda, VIC. For details and online entry, visit www.supersprint.com.au

2011

November 10-12: 16th Reach to Recovery International Breast Cancer Conference, Taipei, Taiwan. For further information go to www.reachto_recoveryinternational.org.

Seeking stories from older women

The Autumn 2011 issue of **The Beacon** will highlight issues that particularly affect older women with breast cancer.

Were you diagnosed as an older woman? What were the problems you faced? Perhaps you live on your own and would have liked more support. Maybe you are a carer and your diagnosis added to the pressures you already faced. Did you have trouble finding appropriate information about your diagnosis and treatments? Perhaps there were some surprises – you may have made new friendships or found a caring support network.

We would also be happy to hear from people who care for an older woman who has been diagnosed.

Please email your story of 200 – 300 words (about half a page) to beacon@bcna.org.au by the end of December 2010. Please include a high resolution digital photo, or post your photo to us and we can return it to you.



Layout: SUBStitution

BCNA

293 Camberwell Road,
Camberwell, Victoria 3124

1800 500 258 (freecall),
(03) 9805 2500

beacon@bcna.org.au or
www.bcna.org.au

If you wish to unsubscribe to *The Beacon* or *The Inside Story* please contact BCNA.

Printing kindly supported by Vega Press

