Your voice matters

As we approach our 20th anniversary in 2018, we are looking back over our history and at the origins of our organisation.

In the very first edition of The Beacon published in the summer of 1997/1998, our founder Lyn Swinburne wrote of the need for a national voice for those affected by breast cancer.

For our network and our voice to be truly national, she implored readers from all around Australia to share their experiences and raise the issues that affected them.

Her message remains at the heart of BCNA today and is reflected in the theme for this issue of The Beacon – your voice matters.

Before BCNA, breast cancer was not often talked about publicly. It was discussed in whispers, and many women spoke of a feeling of shame at diagnosis.

We have come a long way since then, and the voices of our members have led to many of our proudest achievements.

By speaking up and sharing your story, you help us to understand your experiences so we can provide better support and more information and ensure our advocacy work focuses on the issues that most affect you.

Thank you to everyone who has had their voice heard by participating in our Member Survey – your feedback is greatly appreciated. More than 8,000 people have completed the survey to date. Anyone diagnosed with breast cancer is encouraged to take part. The survey will close on 30 June. Visit bcna.org.au/membersurvey.

In the last edition of The Beacon, we introduced our exciting new State of the Nation project. As well as showing how far we've come in the past 20 years, this project is helping us to see where the gaps in treatment and care are and who is missing out.

By connection to support services after a diagnosis, to reconstruction waiting times and access to lymphoedema services, our State of the Nation work has already identified areas where we can help. This has highlighted to me how important it is to provide a platform for women and men to share their experiences and concerns.

Our advocacy work isn't just about achieving a better journey for Australians diagnosed with breast cancer in the future, nor is it just focused on large-scale issues. Over the years we've raised many concerns. They aren’t all necessarily issues of great science, discovery or clinical understanding, but they are real issues, faced by real women and men.

As a person-centred organisation, we value every one of our more than 120,000 members. We speak out on behalf of individuals and press for immediate improvements for communities. We want all of you to receive the very best support, information, treatment and care.

If you don’t raise your issues, they won’t be heard by those with the power and influence to bring about improvements.

As Lyn said in our first issue all those years ago – use your voice!

Christine Nolan
Chief Executive Officer

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Mammographic breast density

You may have seen discussion in the media recently about the role that breast density plays in breast cancer. Mammmographic density, which is also sometimes called breast density, describes how breasts look on a mammogram. It isn’t a measure of how the breasts feel and it cannot be detected in a clinical exam by a doctor. Breasts are made up of several kinds of tissue, including fat, glandular tissue (the milk ducts and lobules) and connective tissue (which helps hold everything in place). Glandular and connective tissue are denser than fat, and this difference shows up on a mammogram.

A woman is said to have a high mammographic density if her mammogram shows her breasts have a lot of glandular and connective tissue and less fatty tissue. Mammmographic density varies from woman to woman. It is thought that about 50 per cent of women undergoing a mammogram will have a mammographic density of 51 per cent or greater. Of these, around 10 per cent are thought to have ‘extremely dense’ breasts, which means their breasts are made up of more than 75 per cent dense tissue.

Researchers think that a woman’s level of mammographic density is determined when her breasts first form, and that it is largely due to genetic factors. However, breast density can change a little over a woman’s lifetime due to factors such as body weight, age and hormonal changes after menopause.

One of the main concerns with mammographic density is that there is a greater chance of breast cancer not being seen on a mammogram. This is because small cancers can be hidden or ‘masked’ by glandular and fibrous tissue. Because of the masking issue, some women with high mammographic density may be recommended to have extra screening, such as a breast ultrasound or MRI.

Research is also beginning to show that having dense breasts can itself be a risk factor for developing breast cancer. Women with high mammographic density are one to two times more likely than average to develop breast cancer. This risk is even greater if you compare the two ‘extremes’ of mammographic density. The 10 per cent of women with extremely dense breasts have a four to six times greater risk of developing breast cancer than the 10 per cent of women with mostly fatty breasts. These risks should be taken into account alongside other known breast cancer risk factors, such as being over the age of 50, having a high body mass index or having a strong family history of breast cancer.

At present, breast density is still not generally used in Australia to assess a woman’s risk of breast cancer and there are no guidelines on the best way to screen women with dense breasts. Most breast screening clinics in Australia also do not routinely advise women of their mammographic density.

More research is needed to understand why mammographic density is a risk factor and to find out whether the risks could be reduced through treatments or lifestyle changes.

There are also problems with the methods currently available to radiologists that help them measure mammographic density. Although radiologists can use scoring systems to rate mammographic density, most of these scores depend on how radiologists interpret what they see in the woman’s mammographic images. This means that a woman’s mammographic density score can vary from one radiologist to another.

There are also new technologies that use computer models to help give a more reliable measurement of mammographic density. However, these technologies are more expensive and not widely used at present.

Currently, the BreastScreen Australia national screening program is the ‘gold standard’ for identifying breast cancer early in women. Biennial mammograms are still the only screening method proven through clinical trials to reduce the risk of death from breast cancer in women over the age of 45. However, alternative screening methods – including breast ultrasound, breast MRI and breast tomosynthesis (each used in combination with mammography) – are now being studied to learn whether they improve detection in women with dense breasts compared to mammograms alone.

If you are interested in knowing about your mammographic breast density, you may be able to ask your radiology clinic, breast surgeon or GP.

If you have dense breasts, you may like to talk to your breast specialist about the best follow-up screening protocol for you. This may include adding ultrasound and/or breast MRI to your regular follow-up mammograms, although MRI is not currently covered by Medicare for this purpose. This means there can be significant out-of-pocket costs.

We have information about breast density on our website, bcna.org.au. You can also read our position statement on the advocacy pages of the website. Mammographic density is an issue that will continue to evolve as new evidence comes to light. We will keep our members up to date as new knowledge emerges.
Ask the Expert: Radiation oncologist

Associate Professor Susan Pendlebury is Director of Radiation Oncology at North West Cancer Centre, Tamworth. The Beacon asked Susan to tell us about new developments in radiotherapy.

When is radiotherapy treatment recommended for women with breast cancer?
Radiotherapy should be considered for all women diagnosed with early stage breast cancer who have undergone breast conserving surgery (also called lumpectomy or wide local excision). There is also a role for radiotherapy for women who have had a mastectomy and are at intermediate or high risk of experiencing a recurrence of breast cancer, for example if cancer cells are found in a number of lymph nodes in the axilla (armpit) or if the breast cancer is large.

A recent randomised clinical trial has shown that there are benefits also for women when cancer cells are found in only one to three lymph nodes. So radiotherapy should be considered in this situation too, especially if there are other risk factors such as a high-grade cancer, a large tumour or unfavourable biological subtypes such as triple negative cancers.

What does it involve?
Radiotherapy involves delivering small increments of radiation to the breast and/or armpit after breast surgery to kill any remaining cancer cells. It reduces the risk that the cancer will come back in the breast or go on to spread as later-stage disease.

For women who have had a mastectomy and are receiving radiotherapy to their lymph nodes, evidence indicates that radiotherapy should be delivered over a five-week period. For women who have had breast conserving surgery, evidence suggests that radiotherapy can be delivered over a shorter, three-week period. This shorter course is known as hypofractionated radiotherapy.

Evidence also shows benefits if an extra boost of radiotherapy is given to women aged under 60 at the end of their course of radiotherapy. Technology now allows us to incorporate the boost treatment into the three-week or five-week course.

The Cancer Australia Influencing best practice in breast cancer statement states that some women should be offered hypofractionated radiotherapy. Can you explain what that is and who may benefit from it?
For women who have had breast conserving surgery where we are treating just the breast with radiotherapy (i.e. not the lymph nodes in the armpits also), there is evidence to suggest that radiation can be delivered over a three-week period, with a boost treatment delivered during that three weeks. This is called hypofractionated radiotherapy. There are significant benefits, especially for women in rural areas who may have to travel long distances to and from treatment every day or move to another town or city for their treatment. Hypofractionated radiotherapy offers the same benefit in terms of destroying cancer cells, but with 20 per cent less toxicity, so a reduction in the extent of fatigue, skin redness and peeling women may experience.

At the present time, radiation given over a five-week schedule is standard treatment for women who have undergone mastectomy and for whom radiation treatment includes the lymph node area, such as the axilla. Research is underway to help determine if the hypofractionated course is also suitable for these women.

What is intraoperative radiotherapy, and is it something women should talk to their radiation oncologist about?
Intraoperative radiotherapy involves delivering radiation at the time of surgery through a machine that is inserted into the cavity formed when the cancer is removed. Because radiation is delivered at the time of surgery, it is convenient. On the downside, the clinicians will not yet have the pathology results, so women may require more surgery and possibly more radiotherapy at a later time. There is also an increased risk of infection, though the risk is still low.

Intraoperative radiotherapy requires close interaction between surgeons and radiation oncologists. It also requires a different set-up of the operating theatre, so is not available at all centres. The research suggests it is good, but not better than treatment with an external beam.

What is the deep inspiration breath hold technique?
Deep inspiration breath hold is a technique that lifts the chest wall up and away from the heart. It has been developed to minimise the dose of radiation to the heart, so is primarily for women who have breast cancer in their left breast. There are a number of techniques for achieving this but, essentially, as you breathe in the lungs inflate and the ribs expand upwards and outwards so that the expanded lungs act as a buffer to keep the chest wall away from the heart. As technology advances, it is likely we will have other ways of minimising the dose to the heart.

Where can we find more information about radiotherapy?
The Royal Australian and New Zealand College of Radiologists website targetingcancer.com.au and the Cancer Australia website canceraustralia.gov.au are both good websites.

I also suggest my patients talk to their breast care nurse. Breast care nurses are often very good at answering questions or pointing women in a local direction to have their questions answered.
A day in the life of a breast care nurse

Breast care nurses can support women in many ways through their breast cancer journey. They can coordinate care, help with managing side effects, translate difficult medical terminology, explain treatment options and advocate on behalf of an individual woman to make sure her voice is heard. The Beacon spoke with Monique, a breast care nurse at Royal Melbourne Hospital, and Lauren, one of the women she looks after, to learn more about a day in the life of a breast care nurse.

4.45 am: I like starting my day with an hour-long walk. I know how important exercise is and it’s something I talk a lot about with the women I support. My walk is my time to focus on me: it is important to look after myself when so much of my day involves caring for others.

Morning: Every day is different, but most mornings I do rounds with the breast surgeons. I talk with the women who had their breast surgery the previous day, assess their needs, help them prepare for discharge with things such as drain care and lymphoedema prevention, and discuss the next steps.

Women having chemotherapy start arriving at the oncology clinic. I make sure they know I am here for them. This can be a struggle, as chemotherapy is on a different site, but the women just have to ask for me if there is anything they need and I can pop over and see them.

Some days I attend an interdisciplinary team meeting or run the breast clinic. This allows me to support, advocate for and educate newly diagnosed women.

Another big part of my mornings is coordinating care. Yesterday I sorted out an urgent dental appointment to treat a dental abscess for a woman scheduled for chemo today. I try to make things run as smoothly as possible for the women.

Lunch: I respond to emails while I eat.

Afternoon: I have one-on-one appointments. If a woman is getting ready for surgery, I check she has a good understanding of her surgery and discuss her pre- and post-op care. I make sure she has a My Journey Kit and, if she’s having a mastectomy, I fit her for a My Care Kit bra. I ask some questions to find out what her needs might be. For instance, questions around sexuality and body image, or how the family is going to manage at home. It is important that she knows I am here to have these conversations.

In our one-on-one chat, we might discuss breast reconstruction and go through some pictures of how other women look after their surgery. I sometimes put a woman considering reconstruction in touch with another woman so she can ask questions or suggest she come along to a breast reconstruction awareness (BRA) session so she can meet others who have been through it.

Sometimes I do a survivorship care appointment for a woman at the end of her treatment. We discuss any concerns and develop a care plan so she knows what to expect in terms of her follow-up care.

After the appointments are finished, there is always paperwork to catch up on. My pager will be going and queries from outpatients will need answers. I try to catch up with other inpatients as well as seeing our post-op patients. I triage new referrals. If it’s a Tuesday, I’ll attend another breast clinic, and if it’s a Friday I’ll run my nurse-led nipple tattoo clinic. Helping women with this step at the end of the journey is a positive way to end the week.

5.00 pm: I visit the women in hospital I haven’t had time to see today. My thoughts turn to tomorrow – I try to forward plan, but our priorities are changing all the time.

Evening: On a good day, I’ll leave at six, sometimes it’s closer to seven.

The most important thing for women to know is that they can ask me anything. Whatever they need I will do my best to be there for them, but I do struggle with the knowledge that as hard as we try we cannot always be everything to everyone.

Lauren’s experience

I was diagnosed with breast cancer in October last year at the age of 30. I’m now in the middle of my chemotherapy treatment and have surgery coming up at the end of June.

A typical treatment day for me starts a lot like a day at work – I take some medication to help with chemo side effects and then catch the bus into Peter Mac for my chemo treatment. Because I am relatively well right now, Monique my breast care nurse doesn’t pop into every treatment, but it is a real comfort to know she is only a phone call away. Monique’s an intermediary between me and the medical world. She translates the medical jargon and explains my choices to me. I’ve often checked with Monique when I’ve been confused. She is there for me if I have a strange reaction to a treatment and am wondering if I need to freak out or if it’s nothing to worry about!

Monique is a master in making my appointments flow smoothly. When I was diagnosed I tried to take control of the practical things, but there are so many different appointments to coordinate. I have some fatigue and memory issues, so Monique’s help is important to me.

Monique sees who I am as a person and is a great support through the emotional impact of diagnosis and treatment. She helps connect me to any additional services I need. She is a consistent face and voice through a tumultuous time. I can’t fully express how grateful I feel for how much support she provides.
Palbociclib approved for sale in Australia

Many thanks to those of you who have signed BCNA’s online petition to have the new breast cancer drug palbociclib (Ibrance) made available in Australia and listed on the Pharmaceutical Benefits Scheme (PBS).

As at the end of April, more than 25,000 people had signed our petition! Thanks to you all. Please ask your family, friends and colleagues to sign the petition too. The more signatures we have, the more likely the Australian Government is to listen. It’s not too late to sign our online petition – visit our website, bcna.org.au, to show your support.

Palbociclib is a new type of drug used to treat hormone receptor positive, HER2-negative metastatic (secondary) breast cancer. An international clinical trial found that giving palbociclib in combination with the hormone therapy drug letrozole doubles the length of time before the cancer spreads, from 10.2 months for women who took letrozole only to 20.2 months for women who took both drugs.

BCNA has been working with stakeholders to have palbociclib made available to women in Australia. As this issue of The Beacon went to press, we were very pleased to learn that the Therapeutic Goods Administration had approved palbociclib for sale in Australia. BCNA understands it will be available from mid-May, however it is likely to cost several thousands of dollars per month as it has not yet been listed on the PBS.

Getting palbociclib listed on the PBS is the next step so that all Australians who may benefit from it can access it on an affordable basis, not just those who can afford it. Unfortunately, the Pharmaceutical Benefits Advisory Committee (PBAC) has recommended against listing it on the PBS. Our experience with other drugs such as Herceptin, Kadcyla and Perjeta is that eventually, with public support, new drugs are listed. Therefore, it is important to keep promoting the petition to friends, family and the wider community.

BCNA has also called on the drug company that manufactures palbociclib, Pfizer, to open a patient access program in Australia. Patient access programs allow people who might benefit from new drugs not listed on the PBS to obtain them at a greatly reduced price or, in some cases, free of charge.

We will keep you updated on any developments through The Beacon and our website.

An application has also been made to have a drug similar to palbociclib made available in Australia and listed on the PBS. Ribociclib (Kisqali) is also used to treat hormone receptor positive, HER2-negative metastatic breast cancer. Given with a hormone therapy drug such as letrozole, it has been shown to increase the length of time before the cancer spreads to 25.3 months.

BCNA is supporting the listing of this drug on the PBS also. You can read our submission on the Submissions page of our website, bcna.org.au/submissions.

BCNA’s metastatic advocacy manifesto

BCNA’s mission is to ensure all Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs. An important part of our work is to ensure that people living with metastatic (secondary) breast cancer have access to services that improve both their quality and length of life.

In March, BCNA held a roundtable meeting with women and men living with metastatic breast cancer to discuss the issues affecting them and how BCNA could help. Key priorities were identified and, along with findings from our 2014 research with people living with metastatic breast cancer and interim findings from our 2017 Member Survey, used to develop an advocacy manifesto on behalf of all Australians living with this disease.

The manifesto includes the following key messages:
• Metastatic breast cancer is largely misunderstood by the Australian public.
• We are living with, not dying from, breast cancer.
• More awareness is needed about information and support resources available.
• We need accurate metastatic breast cancer statistics, not estimates.
• The focus on survivorship and cure makes us feel we are the silent minority.
• The financial impact of our disease is profound and ongoing.
• More support is needed to help us remain in the workforce.
• Our disease impacts the whole family – more supports are needed for them.
• Specific services are needed for young women living with metastatic breast cancer.
• Hope is always important.

BCNA will use this manifesto to inform our advocacy efforts and progress our vision to ensure a better journey for all Australians affected by breast cancer.
Making a difference: BCNA National Summit 2017

Every two years, BCNA holds a national summit where we bring together peer support leaders and community champions in our network from across Australia to help build their skills, knowledge and connections.

In March, nearly 200 members attended our seventh summit on the Sunshine Coast, with the theme ‘Making a difference.’ We wanted delegates to share knowledge and experiences, and develop skills to support them in making a difference in the lives of people affected by breast cancer.

It was a busy two-day program. Summit delegates heard from inspirational speakers, including David Bortolussi, Chief Executive Officer of Pacific Brands (which includes Berlei), medical oncologist Dr Catherine Shannon, Juliette Wright, founder and Chief Executive Officer of GIVIT and Dr Vivienne Milch from Cancer Australia. Presenters spoke about the importance of improving outcomes for all Australians affected by breast cancer, including addressing the needs of Indigenous women, people with metastatic breast cancer, and survivors.

Delegates attended workshop streams that expanded on their areas of interest:
• effective peer support
• communicating with impact
• community events and fundraising.

Delegates have returned home re-energised and inspired, and with a clear plan to engage in new ways with their communities. We will continue to monitor and support their initiatives.

The women and men who attended contribute enormously to supporting people affected by breast cancer in their communities. We thank them for reaching out to others, for sharing their experiences and for spreading the word about what BCNA does.

BCNA acknowledges the Australian Government’s support in contributing to funding for the summit through the Supporting Women in Rural Areas Diagnosed with Breast Cancer program.
A new journey for BCNA

BCNA held its first Aboriginal and Torres Strait Islander Think Tank at our National Summit in March. Forty-eight Aboriginal and Torres Strait Islander women representing every state and territory made up the group, which met over three days. The women included breast cancer survivors, Aboriginal health workers and representatives from some of Australia’s major cancer hospitals.

The Think Tank allowed the women to come together to share their stories and lived experiences as survivors. Together, the group worked to develop and prioritise future actions to improve support and care for Aboriginal and Torres Strait Islander women diagnosed with breast cancer.

The group agreed it was important to establish partnerships between BCNA and national Aboriginal and Torres Strait Islander health organisations to develop resources and provide information and services to improve pathways for women returning home after treatment.

On the final day of the Think Tank, cultural projects were shared in yarning circles. A Stradbroke Islander weaver presented her beautiful work and discussed how remaining culturally strong and focused saw her through her cancer treatment when she was most unwell.

A possum skin cloak project was shared from Victoria. The presenter discussed the cultural significance and history of the cloak.

The group agreed to develop some locally based cultural healing projects to allow breast cancer survivors to connect and support each other in culturally safe spaces. A weaving project in Queensland and a possum skin cloak project in Victoria will be undertaken and used to support the training of health professionals in local culture and knowledge.

A BCNA National Aboriginal and Torres Strait Islander Reference Group will ensure the work discussed at the Think Tank continues.

A video is being produced to share the stories of Aboriginal and Torres Strait Islander women affected by breast cancer.

New Queensland State Development Manager

Sadly, in January, we had to accept the resignation of Margaret Jolly, our first Queensland State development Manager, due to new family caring responsibilities.

Margaret did a great job and we will miss her.

In March, we welcomed our new Queensland State development Manager, Michelle Farquhar.

Michelle has worked in marketing and journalism for almost 30 years, including ABC Radio and Channel 9. She is passionate about expanding our reach in Queensland.

Michelle was delighted to have the opportunity to meet a number of our members at both the summit in March and our Cairns information forum in April. She is settling into her new role and is keen to connect with and hear from BCNA members and supporters.

Her email is mfarquhar@bcna.org.au.
Giving back through my medication

After seeing a news story on TV, I asked my GP about Letrozole FBM. She had never heard of it. When she looked up brands of letrozole on her computer, the FBM brand was not listed as an option.

I rang the chemist where I get my Sandoz brand of letrozole each month for $28. They hadn’t heard of For Benefit Medicines. After a bit of back and forth, they discovered yes, it was available, but I would have to order it in, so I did.

I picked it up a few days later, and it wasn’t till I got home that I saw I had been charged $38.80, a difference of more than $10. I rang FBM and spoke to John, one of the directors. He is an amazing person who is ‘retired’ and taking on the big pharmacy suppliers for purely humanitarian reasons … talk about the next Australian of the Year!

I learnt that chemists can only charge a maximum amount ($38.80) for most items on the PBS, but they are allowed to discount. So when a big chain buys lots of drugs from a company, they can afford to discount those quite dramatically. The same might not happen for smaller suppliers (like FBM).

Armed with my new knowledge, I rang back my chemist and said I was shocked at the price difference between the two products. They said the higher price was because it wasn’t a product on their ‘list’, and they had to go to a lot of trouble ordering it in. However, they would be happy, as a favour to me, to give me the FBM brand for $30.

Given that I would be on this drug for 10 years and would be buying it from them every month for those 10 years, I asked if I could get it put on their ‘list’.

The answer was ‘no’.

John at FBM actually implored me to stay on the Sandoz brand, because the last thing he wanted was for patients to be out of pocket or inconvenienced. I felt my heart twang at that comment.

I don’t want my experience to deter people from chasing up Letrozole (or Anastrozole) FBM, in fact, the opposite. Once you know a little bit about it, it is easy, but you have to be persistent. Ask for it, and keep asking.

I will continue to put my order in every month, negotiate the price and pay that $2 extra, for the next 10 years. Because in the long run, I think it is the best thing to do. I get my medicine, and the profits go back to BCNA and cancer research. And when John, having donated his retirement to help others, is up on the dais being recognised for his altruistic generosity, I’ll be applauding.

Jane, VIC

Help with travel insurance

When you have the opportunity to take a break from breast cancer treatment, or when your treatment ends, a holiday can be just what you need. However, we still hear from women who have trouble getting travel insurance because of their breast cancer diagnosis.

It might help you to know that BCNA has two fact sheets that can answer some of the most common questions we hear about obtaining travel insurance after breast cancer. There is a fact sheet for people who have had early breast cancer, and a separate fact sheet that covers information for those diagnosed with metastatic breast cancer.

The fact sheets include information to help you decide whether you need travel insurance, the questions you should ask about your travel insurance (including finding out what is and what isn’t covered), the definition of pre-existing conditions, and a list of countries where Australian travellers are covered by those countries’ health systems (reciprocal health care agreements).

There is also a fact sheet that provides information on the process to follow if you want to make a complaint about your travel insurance provider.

To download or order a copy of these fact sheets, visit the resources page on the BCNA website bcna.org.au.
Pink Bun 2017

Since 11 May, Bakers Delight bakeries across Australia have been awash with pink for the annual Pink Bun campaign. Once again, we are overwhelmed and delighted by the generosity of Bakers Delight and its customers. The proceeds from every finger bun sold has come directly to BCNA. As the campaign draws to a close, we encourage you to visit your local bakery to thank them for helping BCNA continue to provide free information, programs and services to women and men when they need it most. Follow us on Facebook and keep an eye on our website, where we will soon announce the final tally!

Reaching out to our members

We know that a breast cancer diagnosis can turn your world upside down. Many people don’t know where to turn. Whatever concerns or challenges you’re facing, BCNA is here to support you every day, from day one.

Some of you who have recently received a My Journey Kit may have received a call from us. Over the next 18 months, we will stay in contact through phone calls. We’ll also send emails from time to time about what is happening at BCNA and how to get involved with us.

This extension of our Helpline service aims to better support members recently diagnosed with breast cancer by letting them know about the information and services available to them.

With more than 120,000 members around Australia, unfortunately we can’t call everyone. However, no matter where you are in your breast cancer journey, from 10 days to 10 years post-diagnosis, your voice matters to BCNA.

If you need information or support, contact our Helpline team. We will always welcome your call. Call 1800 500 258.

A partner’s perspective

There’s no way I can truly understand what my wife has been going through, from the moment she found a lump in her breast, through tests, diagnosis, surgery, treatment, scares and medication side effects. It’s difficult to express my feelings, which may be insignificant in the scheme of things, but I’m sure there are plenty of men in similar shoes.

My wife was fortunate that she bumped into a screen door left ajar and hurt herself, because that’s when she discovered the lump in her left breast. At first she thought it was from the injury, and she kept the knowledge from me until we visited our GP. It was diagnosed as an aggressive cancer, but small because, fortunately, it was discovered early. I couldn’t believe the roller-coaster ride from there. It was a scary and emotional time.

The hardest part for me still is watching helplessly while my soul mate of over 40 years suffers. It’s now three-and-a-half years since her diagnosis and she has constant pain in her joints, aggravated by what we believe to be the unwanted side effects of her medication. We hope the pain eases when she comes off her medication.

I have mixed emotions. Sexual intimacy is mostly a distant memory for us, but we’re still close. She’s hurting and I’m afraid I might hurt her more. I love her and support her in every way I can, but am frustrated because I can do nothing to take her pain away. It’s her journey, but I can be there with her, and will be while I have breath in my body.

David, QLD
The positive side of prosthetics

I had cancer in my left breast. It was quite large and I only wore a B cup, so a left mastectomy was recommended. I thought I could do surgery, chemo and radiation only once, so I asked for a double mastectomy, envisioning my fabulous C cup reconstruction down the track.

The day after surgery, my breast prosthetic consultant came to see me, zipped open her case and said, ‘Well Cath, what size breasts would you like?’ Since then, I pretty much have been hooked.

Thank you Medicare for paying for them – there’s now no reason why any of us can’t have great boobs. I now have a fabulous C/D cup – no need for any more Wonderbras.

You can have different sizes for different occasions – small for the gym so they don’t get in the way, large for a lovely dress and big night out, everyday size for work, or nothing at all – surprisingly liberating.

When I get home from work, there is nothing I like better than taking off my breasts and throwing them on the bed, until the next day.

I honestly don’t miss my real breasts. They did their job and fed my baby, but I honestly can say in the two years since surgery I rarely think about it, I just enjoy all the positive things about prosthetics.

My most recent discovery is perhaps the best, I have discovered that my swimming boobs also double as a flotation device. With some trepidation, I went snorkelling for the first time in over 20 years and discovered I couldn’t have drowned even if I wanted to. My breasts provided extra buoyancy, much like a child’s Floaties. I was much better at snorkelling than people 30 years my junior.

Will I have a reconstruction? I doubt it, I have too much choice now and who knows what new discovery I will make next about them.

Cathy, QLD

My second time around

I’m a two-time breast cancer survivor. The first time, in 2011, I had just retired at the age of 63. A small, aggressive tumour was found by a routine mammogram. This led to a lumpectomy, chemo and radiation.

I managed through all the side effects, including hair loss, with help from my husband, family and friends. Throughout the years after, I had the usual check-ups and felt fit and healthy. I was confidently looking forward to my ‘five-year clear’ milestone. I though I had beaten it.

After my next check-up, I was devastated to find it had reappeared in the same breast, in the same place, five years to the day after my first lumpectomy. This time it meant a mastectomy and chemotherapy again. I was very lucky to be offered the ‘head freeze’ or ‘cold cap’ treatment during the chemotherapy sessions. Last time I lost all my hair to chemo and managed with wigs, hats, scarves etc., all of which I gave away to charity several years ago. I was not looking forward to all that again.

The head freeze treatment was a little uncomfortable and took more time, but was pretty easy and very successful for me. I kept all the hair on my head, so recommend others to give it a try.

I have chosen to have a breast implant. As a keen swimmer, I couldn’t imagine water sports while wearing a prosthesis.

So, now at the end of treatment and 2016, I’m fairly fit again, with a full head of hair, looking forward to celebrations with my family and getting back to ‘normal’ living.

Treatment after diagnosis happens so quickly, you almost don’t believe it until your hair falls out. That is when you realise it is serious – it is cancer. This realisation hurts more than the loss of hair. I feel better this second time around. I know I’ve had cancer, I’ve lost one breast, but I have my hair and an implant and I’ve beaten cancer again.

Christine, VIC
Your voice matters

Forward without fear

I was diagnosed with early stage breast cancer in 2013 at 58. My diagnosis didn’t come as a big surprise, because my sister had been diagnosed with breast cancer five years earlier.

The day I was diagnosed I was very calm and I was thinking about how difficult it must have been for the doctor to tell me. Once told, the first words that came out of my mouth were, ‘How will this affect my daughter?’

I had the lump removed and then had seven weeks of radiation therapy. For a long time I felt like a bit of a fraud when I read other stories about women who have endured more intense treatments and are left with emotional scars. I got away with breast cancer relatively unscathed – all I have to show for it is a 6 cm scar on my left breast.

I kept my emotions in check all the time because my husband, who has depression, was upset about the fact that I had cancer and I felt I had to be the strong one. However, I would not have been so strong if he wasn’t there by my side the whole time. He was at the diagnosis, he went to every treatment with me and he is with me when I have my annual visits with the specialists.

For a long time after the treatment ended, I was very paranoid about the slightest twinge in my breast or a pain that had just occurred. With the assurances of my specialists, that paranoia has subsided. For all those out there who have felt like I do – you are not alone. I now look forward to the day when they say, ‘You are five years clear and we don’t need to see you again!’

Sandy, WA

Not a ‘journey’ – an ‘education’

Ever since I was diagnosed with breast cancer, I keep hearing about people’s different cancer ‘journeys.’ With due respect, it’s not like we were seduced by some clever advertising and thought, ‘Ooh, let’s go have all these invasive tests and find out if we qualify for this trip of a lifetime. If we do, let’s spend lots of time in a modern hospital where they have great drugs, remove parts of your body, then possibly poison you or irradiate you, (or both if you’re really lucky!)’

No, I certainly didn’t sign up for any of this. Instead, (in my early sixties) I feel like a small child who has been told it’s time to start school, and there’s nothing I can do about it. I’ve figured out from talking to some students in higher grades that this is a school of hard knocks, and I’m torn between admiring them for their progress so far, and dreading what lies ahead.

Right now I’m about nine months into an open-ended course called ‘How to Cure Your Cancer.’ I’ve been promised that if I obey the rules and pass all my assignments, I will eventually graduate. (I know there’s some fine print in there somewhere, but I’m not looking too closely.)

So, what’s in this course? There are several complicated modules and just perusing the syllabus is enough to give you information overload. If you’re very lucky, you get to skip some of the modules, but the following is an outline of the course that I’ve been forced to attend so far:

• Diagnostics (I passed with top marks, unfortunately)
• Homework (loads of texts that do not make for light bedtime reading)
• Advanced Surgery (one breast and many lymph nodes removed)
• Medical Jargon 101 (scary stuff)
• Advanced Chemotherapy (includes Fatigue, Depression and Needles 101)
• Beauty Class (at least this was fun)
• Radiation Therapy (I’m currently a weekly boarder because of distance)
• Self-paced Learning (digging deep into the meaning of life, the universe and everything)
• Hormone Therapy (will take years to complete)
• Breast Reconstruction (optional).

Alison, NSW

Alison and her daughter

Sandy and her daughter
Staying positive and keeping active

I was 73 when I was diagnosed with breast cancer in May last year. A couple of weeks after a routine check-up, I received a letter to attend BreastScreen. When my diagnosis was confirmed, I was shocked, but I knew I must remain positive. Radiation treatment was recommended.

At the time, I was very busy. The AFL's Indigenous Round was being renamed in honour of my father, Sir Doug Nicholls. I was too busy to worry about myself having breast cancer, as at the time the football round was more important to me. I just carried on doing what I needed to do at the time and then after the footy I focused on my treatment and recovery.

I was supported by my family, friends and work colleagues, but what helped me the most was staying positive throughout my journey, which I continue to do to this day.

I had taken up exercise more than 20 years earlier at the age of 50, and completed my first triathlon when I was 59. I didn't want to let my breast cancer stop me from maintaining my healthy lifestyle.

I kept exercising, as I knew this would help in my recovery and reduce my risk of recurrence. This year I will be taking part in my 20th Mother's Day Classic fun run.

I haven't let my breast cancer slow me down and I continue to live a busy life as a Yorta Yorta woman and an Elder of the Victorian Aboriginal community. I worry that some Aboriginal women feel shame and are not confident about going to mainstream breast cancer screening services. It is our culture to share among ourselves. I think the community would benefit from having specialist Aboriginal breast cancer services.

I think it's important for Aboriginal women to connect with others who have faced the same challenge. I would be very happy to speak with any other Aboriginal women who are facing this journey.

Aunty Pam, VIC

You don’t know what you’ve got ’til it’s gone

None of us is satisfied with the hair we were born with. We dye it, cut it, straighten it, curl it. We torture it – until the day we lose it. Then we appreciate that it is more than looks that is important. Rather, it keeps our head warm in winter and cool in summer. It stops you getting a sunburnt head. It is the perfect insulation.

When I knew I was going to lose it, I got my hairdresser to shave it off. It was one thing I could control. That was in the cold of August, so I found an old beanie; I wore it day and night. I know I looked daggy, but it kept my head warm and I wasn't going anywhere.

I also acquired a lovely wig, which was exactly the colour of my (dyed) hair and close to my usual hair style. I got some scarves and started tying them around my head, which was fine. I started wearing my scarves to go out instead of the wig.

It wasn't just the hair on my head that fell out, it was my eyebrows and eyelashes and other bodily hair. I tried to hide my sparse eyelashes and eyebrows with beauty products, but ultimately I had nothing to work with, so in the end I didn't bother, and nobody noticed.

Now my hair is growing back, very soft and white – like baby's hair. Only time will tell how it will end up. Last week I was showing my hair to my daughter and granddaughters. They were stroking it like a kitten. It felt so nice.

I missed my hair, but I think I will appreciate it more and I don't think I will torture it any more just to keep up appearances.

Glenda, VIC
Profiling our Member Groups

Oxenford Bosom Buddies

Oxenford Bosom Buddies is a social group that meets on the Gold Coast. The group combines friendship and emotional support with information and practical advice. Group leader and founder Lee Seery shares how the group began and how it provides support to the local community.

After my breast cancer diagnosis in 2011, I felt I could give support and encouragement to others. I trained as a BCNA Community Liaison in April 2013 and attended BCNA’s National Summit in Sydney later that year. When I returned home, I decided to start a support group in Oxenford.

Our group meets for two hours on the first Thursday of every month at Oxenford and Coomera Community and Youth Centre. We can get up to 26 members at a meeting.

People who came to the first meeting three-and-a-half years ago still attend, so something must work for them. We also have new members joining.

It’s a happy and upbeat group, with members of all ages, from women in their 30s to others in their 70s and beyond.

The group is very relaxed, with very little structure, as we find people are more inclined to talk and join in if there aren’t many restrictions. This approach isn’t for all support groups, but it works really well for us. After each meeting, many of the members then go out to lunch together.

We welcome anyone diagnosed with any type of cancer, as well as their families, carers, friends and supporters.

The group offers friendship and emotional support from others with a personal experience of cancer. Members also share tips and insights from their own cancer experience to help those who are newly diagnosed.

We have a guest speaker every month, such as a breast care nurse, a surgeon, a yoga instructor and a bra fitter.

I believe that peer support is invaluable after a breast cancer diagnosis, when people can feel isolated, alone and scared. I remember one day when an older woman arrived at our group and sat very quietly with her handbag on her lap, her head down, and she didn’t speak. I gently asked if she would like to share her story and, without any eye contact, she said she had just arrived on the coast, didn’t have any friends and her husband didn’t understand – she was very alone.

Support groups allow people to talk without judgement and provide a sense of belonging.

A few years later, this same woman is one of the first to arrive at our meetings, joins in, asks questions of the guest speakers, goes out to lunch with other members and is a terrific group member (and her handbag is no longer on her lap). She arrived friendless, but now has friends who understand what she went through.

Without being obvious and intrusive, the group was able to encourage her to talk. I believe talking is an extremely important part of the recovery process. Support groups allow people to talk without judgement and provide a sense of belonging.

We are lucky to have the support of our local community. Our local Bakers Delight bakery supplies our morning tea for every meeting at no cost to the group. The community centre where we meet provides the room at no charge. They even set up the chairs and tables for us and supply the tea and coffee.

If you would like to join Oxenford Bosom Buddies please phone Lee on 0439 754 180 or email lee@catsrule.com.au.

Support groups allow people to talk without judgement and provide a sense of belonging.

I believe that peer support is invaluable after a breast cancer diagnosis, when people can feel isolated, alone and scared.

Connecting people

A key part of BCNA’s mission is to connect Australians personally affected by breast cancer. We welcome new Member Groups to our network. They now total 288.

To find a support group in your state or territory, visit bcna.org.au. If you can’t find a face-to-face support group in your area, consider joining our online network. Connect with hundreds of others talking about:

- what it’s like to be newly diagnosed
- undergoing treatment
- breast reconstruction options
- living with metastatic breast cancer
- getting active and well again.

For more information, visit bcna.org.au, or phone 1800 500 258.

It is hard to explain to others what we are going through and how we feel, but it is such a blessing to know that all those on this forum ‘get it’ and are there for each other.

– online network member
Thank you

Thousands of generous supporters across Australia donate their time and money to support BCNA. We would especially like to acknowledge significant contributions recently received from:

- Elaine Reynolds, SA
- Hoang Nguyen, NSW
- Hopes 'n' Dreams – Pink Lady Barrel Classic – Gingin, WA
- Horsham Golf Club – Julie Obst, VIC
- Ildiko Tyler, VIC
- Leonie Gloster, VIC
- Leslie Spry, QLD
- Manly Art Gallery and Museum – Dallas Winnem, NSW
- Middy's Bellarine Peninsula – Elle Cox, VIC
- National Council of Jewish Women of Australia – NSW Division

- Pietrina Sassano, VIC
- Redlands Breast Cancer Support Group – Wendy King, QLD
- Rosa Sfameni, VIC
- Rosina La Terra, VIC
- Ruth Fox, SA
- Sandra Ashwell, VIC
- Tasmanian Breast Cancer Network, TAS
- Weight Watchers – Rhonda Smedley, SA

BCNA Tuscany Trek team

- Amanda Clark
- Ann Vitale
- Annette Cooper
- Bev Elward
- Brett Sammut
- Caitlin Cooper
- Deborah Hicks
- Gerard Martin
- Jane Delahay
- Julie Keding
- Kate Digney
- Katrina Dupree
- Linda Head
- Lynelle Watson
- Marg Papps
- Meg Charlwood
- Monica Hay
- Ruth Turnell
- Tania Smith
- Wendy Johnston

We are delighted to announce the eight lucky winners of our prize draw:

- Christine Foster, VIC
- Gabi Brie, NSW
- Joan Hatton, NSW
- Joy Martin, VIC
- Liz Dodds, QLD
- Mary-Ruth Dowd, VIC
- Pamela Browne, NSW
- Valerie Johanson, NSW

Celebrations

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

- Graeme Southwick, VIC
- Sharon Hunt, VIC

Sussan voucher winners

Thank you to everyone who participated in our Member Survey. If you didn’t fill in the survey, there’s still time. The survey will close on 30 June.

Suits and Women for Cancer

Thank you to the many people who requested gifts for cancer patients were their loved ones were diagnosed with breast cancer.

Winter Escape Pack

The best way to warm up your winter!

Pack includes:
- Vanilla Soy Candle
- Five Pen Pack
- A5 Pink Lady Notebook

Plus a special gift from BCNA, a silver-plated Pink Lady pin, free with every pack!

Limited number of packs available

For more items visit bcnashop.org.au or call 1300 020 650
Pink Lady Bequest Society

Earlier this year, we were very pleased to launch the Pink Lady Bequest Society. In the past, we have been fortunate to receive unsolicited bequests from BCNA supporters. We believe it’s time we recognise the contributions of these generous individuals and acknowledge their gift during their lifetime.

When a supporter decides to leave a gift of any amount in their will to BCNA, they will be invited to become a member of the Pink Lady Bequest Society. Members will share a unique bond and be part of a warm, caring group of individuals.

The group shares the vision for a better journey for all Australians affected by breast cancer, now and in the future. Pink Lady Bequest Society members will come together throughout the year to hear about BCNA’s future projects, which bequests will help fund.

To date we have held successful events in Melbourne, Brisbane, Canberra and Sydney.

If you would like further information about the Pink Lady Bequest Society, call Abby on (03) 9805 2580 or 0401 378 804, or email acormack@bcna.org.au.

Our 20th anniversary

In 2018, BCNA will turn 20. Following her own breast cancer diagnosis in 1993, Lyn Swinburne worked tirelessly to establish links between breast cancer groups across the country. This work culminated in the first National Breast Cancer Conference for Women, held in Canberra in 1998. The launch of BCNA by Raelene Boyle followed, at the inaugural Field of Women on the lawns of Parliament House. We will celebrate our 20th anniversary with a range of events and announcements in 2018. Keep an eye out on our website and in coming editions of The Beacon.

Focus on style

Proud Major Partner Focus on Furniture continues to support BCNA through its beautiful Pink Lady cushion range.

The gorgeous cushions are available in stores now for $30, with 100 per cent of the profits donated to BCNA.

There are 30 Focus on Furniture stores in the ACT, New South Wales, Queensland, South Australia and Victoria.

To find your nearest store, visit focusonfurniture.com.au.
Breast cancer information forums

Tuesday 13 June – Melbourne
Breast reconstruction – your questions answered
Hear from Professor Bruce Mann, Breast Surgeon, and Dr Simon Overstall, Plastic Surgeon.
Bayview Eden – 6 Queens Rd, Melbourne VIC
5.15 pm – 8.00 pm

Tuesday 4 July – Port Lincoln
Breast cancer treatment, care and looking after yourself
Port Lincoln Hotel – 1 Lincoln Hwy, Port Lincoln SA
9.30 am – 2.40 pm

Friday 11 August – Adelaide Pink Lady luncheon, National Wine Centre of Australia

Tuesday 22 August – Sydney Pink Lady luncheon, Sofitel Sydney Wentworth

Wednesday 30 August – Brisbane Pink Lady luncheon, Sofitel Brisbane Central

Wednesday 11 October – Melbourne Pink Lady luncheon, Crown Melbourne

Friday 13 October – Metastatic Breast Cancer Awareness Day

TBA – Canberra Pink Lady luncheon, National Gallery of Australia

Challenges for you, your family and friends
BCNA is supported by fundraising participants in various fun runs. These events are a great opportunity to keep fit and healthy, achieve your personal best, challenge yourself or your friends, and raise money for BCNA.

For more information, visit the websites listed below, email fundraising@bcna.org.au or phone 1800 500 258.

Fun runs
17 September – Blackmores Sydney Running Festival, Sydney sydneyrunningfestival.com.au
3 December – Carman’s Women’s Fun Run, Melbourne carmanswomensfunrun.com.au

Cycling events
28 October – Ride Daylesford. This inaugural event starts in Daylesford and travels through the beautiful countryside of Hepburn, Macedon Ranges and Mount Alexander shires. Participants can choose to ride 33 km, 63 km or 146 km. ridedaylesford.com.au

BCNA returns to Spain
Following the success of last year’s El Camino trek, we are delighted to announce that we will return to Spain in May 2018.

Last year 27 participants together raised more than $175,000 embarking on the adventure of a lifetime along the Camino de Santiago in Spain.

Registrations for our 2018 trek will open soon. Keep an eye on our website and Facebook page for details.

Seeking stories – giving back
In the lead-up to our 20th anniversary, we are seeking stories for the Summer 2017 issue of The Beacon about giving back.
Has your experience with breast cancer inspired you to help others? Have you made changes in your community to try and improve the system? Have you found support in unexpected places?
Stories should be about half a page long (200–300 words) and can be posted to BCNA, 293 Camberwell Rd, Camberwell VIC 3124 or emailed to beacon@bcna.org.au by the end of August 2017. Please also include a high-resolution photo.

BCNA Partners

Join our mailing list
Would you like to be on the mailing list for The Beacon or The Inside Story (a supplement for people with metastatic breast cancer)? To subscribe, telephone 1800 500 258, email beacon@bcna.org.au or visit bcna.org.au.

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