Representing all women with breast cancer

Early detection and improved treatments for breast cancer have significantly improved survival rates. Australia has the highest five-year survival rate in the world, which is a great achievement. However, that 89 per cent five-year survival statistic does not tell us how many women are living with secondary breast cancer (also known as advanced or metastatic breast cancer). Secondary breast cancer is incurable, but women can live for many years with the disease. We know that thousands of Australian women, and their families, face unique challenges that come with a diagnosis of secondary breast cancer, and we want to ensure that their needs are included in our advocacy efforts and programs.

October is Breast Cancer Awareness Month and 13 October is recognised around the world as Secondary Breast Cancer Awareness Day. This year, BCNA will recognise the day in a number of ways throughout October to ensure women with secondary breast cancer are better understood, represented and supported. Keep an eye on our website and social media channels for more information.

We recently surveyed some of our members who are living with secondary breast cancer. The results will be used to ensure that our advocacy work and programs remain focused on the issues that matter to women, such as financial concerns, fair access to treatment, and support for families. We thank all our members who took the time to complete this survey.

Cancer, including breast cancer, is a disease of global impact. In December, the Union for International Cancer Control (UICC) will host the World Cancer Congress in Melbourne. The UICC is based in Geneva and works to reduce the significant and growing global cancer burden. BCNA has been invited to present a masterclass on consumer advocacy. Our class will assist in building the capacity of delegates from cancer control and consumer organisations, particularly those from developing nations. Participants have registered from many developing nations in Africa and Asia and we are looking forward to welcoming them to Australia and sharing our knowledge.

Once again, this edition of The Beacon is filled with stories that we hope you will connect with in some way. I love the honesty and insight that every contributor has shared. You can connect with more stories, opinions and insights through our online network and website.

I hope many of you will be able to join in some of the local activities planned for Breast Cancer Awareness Month. Please visit our website www.bcna.org.au for Pink Lady events or Mini-Fields of Women that may be taking place in your community. Thank you to everyone running events and raising funds to support other Australians affected by breast cancer.

Spring is in the air so let’s go out and enjoy it!

Maxine Morand
Chief Executive Officer
About two-thirds of all breast cancers are hormone receptor positive, which means they need the hormones oestrogen and/or progesterone to grow. Most women with hormone positive breast cancer will be recommended hormone therapy treatment. These are tablets taken every day for at least five years after other breast cancer treatment (that is, surgery, chemotherapy, radiotherapy) is completed.

Hormone therapies work by stopping oestrogen from ‘feeding’ the breast cancer cells, so they are sometimes called ‘anti-hormone’ therapies.

The two main types of hormone therapies used to treat breast cancer are:
- Tamoxifen
- Aromatase inhibitors (Arimidex, Femara and Aromasin, and generic brands of these).

Aromatase inhibitors are only prescribed for women who are post-menopausal, while tamoxifen is suitable for women before or after menopause.

Benefits

*Hormone therapy gives me peace of mind that I am doing everything possible to live a long fulfilling life.* – Sarah

Taking a drug every day for five years or more can be daunting, especially if you are having unpleasant side effects. It may be helpful to know that these drugs are very good at reducing the risk of breast cancers from coming back. Clinical trials have shown that hormone therapies reduce the risk of breast cancer returning in the same breast, and of developing a new breast cancer in the other breast. Hormone therapies also reduce the risk of developing secondary breast cancer.

Trials have also found that the beneficial effects of hormone therapy last well beyond the years you actually take them.

**Five years vs 10 years**

Decisions about how long to take hormone therapy treatment are discussed and debated by clinicians, researchers and women receiving treatment.

The current standard treatment is to take it for five years. However, recent results from large clinical trials have found that 10 years of treatment with tamoxifen is better for some women than five years.

Research has shown that five years of tamoxifen substantially reduces the risk of breast cancer recurring for up to 15 years after diagnosis. The new studies have shown that 10 years of treatment is even more effective, with fewer women developing a recurrence of their breast cancer, and fewer women dying from breast cancer.

If you are currently taking tamoxifen or an aromatase inhibitor, you might like to speak with your medical oncologist about whether taking it for up to another five years is appropriate for you.

**Managing side effects**

Many women experience menopausal-like symptoms when taking a hormone therapy. For some women, side effects can be distressing, while for others, they can be mild.

Side effects can include hot flushes, night sweats, heart palpitations, anxiety, sleep problems, fatigue and vaginal dryness. The aromatase inhibitors can cause joint stiffness and pain.

There are things you can do to help manage these side effects. BCNA’s booklet *Hormone therapy and breast cancer* includes a number of suggestions for managing side effects, and the *Breast cancer and sexual wellbeing* booklet includes helpful tips on managing the impact of treatments on sexual wellbeing.

If you are finding side effects difficult to manage, talk to your doctor, as there are often solutions. Your doctor may also be able to switch you to one of the other hormone therapy drugs.

Some hormone therapy treatments can cause bone loss, which can result in bone fractures and osteoporosis. Your doctor may recommend you have a bone mineral density scan, called a DXA or DEXA scan, before starting your treatment. You may also have your calcium and Vitamin D levels checked.
Ask the Expert: chemo brain

Associate Professor Nicholas Wilcken

Associate Professor Nicholas Wilcken is a medical oncologist at Westmead and Nepean Hospitals, and Associate Professor of Medicine, University of Sydney. He is currently Director of Medical Oncology at the Westmead Cancer Care Centre. BCNA recently spoke to Nicholas about ‘chemo brain’.

What is chemo brain?

After chemotherapy, some women may experience difficulties with thinking and memory. Women and health professionals often refer to this as ‘chemo brain’. Although doctors and researchers are still unsure about exactly what causes chemo brain, there is no doubt that the condition exists and can be managed.

Some of the difficulties reported by women with ‘chemo brain’ include:
• forgetting things you’d normally remember without any difficulty
• having trouble focusing on a task or taking longer to finish
• not being able to multi-task the way you could before breast cancer treatment
• finding it difficult to find words; for example, not completing sentences or forgetting names.

Despite its name, chemo brain may not always be directly related to chemotherapy. In many cases, other medical conditions can cause or contribute to these changes in brain function. Some research suggests that hormone therapies (tamoxifen and aromatase inhibitors) and menopause can cause similar difficulties with thinking and memory in some women. Other factors, such as age, stress, sleeping difficulties, fatigue, depression and anxiety can also cause similar symptoms.

What can women do about chemo brain?

If you are currently having chemotherapy and are concerned about your thinking and memory, consider talking to your treatment and care team. Your breast care nurse or doctor can help figure out what the underlying cause may be and help you manage the symptoms throughout the rest of your treatment.

Some women continue to experience chemo brain after their treatment is completed. Some strategies that may help you manage the condition include:
• Make a habit of writing things down. This may help you keep track of appointments, important dates, phone numbers and addresses.
• Do something new to challenge your brain: crossword puzzles, ‘brain training’ apps, or even a new class may help. Some women find yoga, meditation or Pilates helpful.
• Establish routines. If you tend to lose things, set up a special place for important items such as house keys and make a habit of leaving them in this place each time you are finished with them.
• Try to figure out whether anything in particular may be affecting your thinking or memory. When you notice a problem with your thinking or memory, jot this down in a diary along with what you are doing. Over time, you may see a pattern. This will help you to plan your days and avoid doing important things when your memory may be worse.
• Visit BCNA’s Online Network at www.bcna.org.au. Women with similar symptoms may be able to share their suggestions for coping with chemo brain.

Most importantly, be kind to yourself. Breast cancer treatment is a physical, emotional and mental challenge. Allow yourself time to recover and encourage your friends and family to help you.

When do women recover from chemo brain?

The length of time to complete recovery from chemo brain will be different for each woman. Some women will experience symptoms for a few months after treatment, and a very small minority of women may report symptoms many years later.

Researchers are looking at a number of ways chemo brain can be treated. For example, researchers in Sydney are looking at whether a specialised computer-based ‘brain training’ program can help women manage the symptoms of chemo brain.

Where to go for more help

If you feel you may have chemo brain or are worried about your ability to think and remember things since breast cancer treatment, talk to your doctor or a health professional you trust.

More information
• BCNA website www.bcna.org.au > Living with breast cancer > Physical wellbeing > Chemo brain
Is my daughter at risk?

The majority of women who develop breast cancer have little or no family history of the disease. However, it is natural to be concerned about the other women in your family, even if you are the only one in your family to have breast cancer. Many women worry about their daughters’ risk of developing breast cancer.

Generally, the more first degree relatives with breast cancer that a woman has, the more likely she is to develop breast cancer herself. A first degree relative is a mother, daughter or sister.

If you are your daughter’s only first degree relative with breast cancer, her risk of developing breast cancer is low. For example:

- If your daughter is 20 years old, her risk of developing breast cancer in the next ten years is 0.1 per cent, compared with 0.04 per cent if she had no first degree relatives with breast cancer.
- If your daughter is 40 years old, her risk of developing breast cancer in the next ten years is 2.5 per cent, compared with 1.4 per cent if she had no first degree relatives with breast cancer.
- If your daughter is 50 years old, her risk of developing breast cancer in the next ten years is 3.2 per cent, compared with 1.9 per cent if she had no first degree relatives with breast cancer.

Your daughter’s risk may be influenced by other factors. There are a number of tools available to help her assess her risk. Cancer Australia has an interactive online calculator that takes into account both sides of the family. By answering the questions, your daughter can find whether she is at the average population risk, at a moderately increased risk or at potentially high risk of developing breast cancer.

You can find the calculator at the Cancer Australia website: www.canceraustralia.gov.au.

BCNA’s Family history fact sheet is for women with a strong family history of breast cancer. You can download or order a copy by visiting www.bcna.org.au > News > Resources > Fact sheets and booklets.

New clinical guidelines for treating women with a BRCA mutation

Between 5 and 10 per cent of breast cancers occur because of gene faults (or mutations) that are passed down through families. Mutations can be passed down through either the mother’s side or the father’s side of the family.

Not all women who carry a gene mutation will develop breast cancer. However, women with certain gene mutations are at increased risk. Two genetic mutations known to increase women’s risk of breast cancer are the ‘breast cancer 1’ (BRCA1) and ‘breast cancer 2’ (BRCA2) mutations.

In May, Cancer Australia released new clinical guidelines with recommendations for doctors about how best to treat early breast cancer in women with an identified BRCA1 or BRCA2 gene mutation or who are at high risk of carrying a gene mutation.

Cancer Australia is the government agency that develops clinical guidelines for health professionals, giving information and recommendations about best practices in cancer treatment and care.

The guidelines include recommendations for treatments such as surgery and systemic therapy (e.g. chemotherapy) and risk-reducing options for women at high risk of developing breast cancer. When developing the guidelines, a Cancer Australia working group reviewed a wide range of research and evidence about how best to manage and treat women with early breast cancer with a BRCA mutation, or who are at high risk of a gene mutation. Two BCNA Consumer Representatives, Bronwyn Wells and Lorraine Woods, were part of this working group, helping to ensure that the views of women affected by breast cancer were represented and taken into account.

The guidelines are available on Cancer Australia’s website at www.canceraustralia.gov.au > Publications & Resources > Clinical Practice Guidelines.
Helping couples cope with cancer

Women and their partners can face challenges in their relationship after a diagnosis of breast cancer. The resources available to help couples cope together are limited.

_Health professionals tell you to relax and to communicate with your partner but they don’t tell you how. Strategies to explain that would be very beneficial._ – Coping Together study participant

The Coping Together research project, run by the University of New South Wales, is studying which of two information packs is most useful in helping couples cope together after a cancer diagnosis.

To date, the researchers have found the benefits of using the information packs include:

- helping to prepare for challenges that lie ahead
- helping couples to cope independently
- helping couples to feel more ‘normal’
- connecting couples to helpful people and services
- complementing support received from health professionals
- providing couples with hope.

_The study provided an opportunity for my partner and me to communicate about things of interest to both of us. We sat down in a comfortable setting and went through the books together._ – Coping Together study participant

The researchers are looking for couples who are interested in participating in this project. You may be eligible if you:

- have not had a previous cancer diagnosis, and
- have a partner.

If you participate, you will be sent one of two information packs to read and use. You will then be asked how useful the information was to you and your partner by completing three surveys over a six-month period. For more information, or to participate, please email coping.together@unsw.edu.au or phone 1800 104 597.

Pink Lady merchandise

Every purchase you make from our merchandise range helps BCNA support Australians affected by breast cancer.

_Purchase merchandise online today_

- **Pink Lady Pin** $5
  - Show your support for BCNA by proudly wearing our original Pink Lady pin. A great gift idea for family and friends.

- **Key Ring** $5
  - Never lose your keys again with our Pink Lady key ring! The perfect way to show your support and a great gift idea.

- **Cap** $10
  - This comfortable sun smart cap is ideal for sporting events and fun runs.

- **Notebook** $14.95
  - Stylish A5 notebook with elastic closure, comes with a stylus and ball pen. Great for note taking, shopping lists and personal reminders.

Please visit [www.bcna.org.au](http://www.bcna.org.au) and click on **SHOP** to view the full range of BCNA merchandise or phone us on 03 9695 9944.
Training women to represent women

At the end of May, BCNA ran a three-day Advocacy and Science Training program to train women to work as Consumer Representatives. We trained 12 women, including nine from rural and regional areas and two living with secondary breast cancer. Eight current Consumer Representatives undertook a refresher. We also welcomed two women from the New Zealand Breast Cancer Aotearoa Coalition at the training.

BCNA now has 81 trained Consumer Representatives across Australia. Our Consumer Representatives work with researchers, clinicians, health professionals and policy makers on a variety of international, national, state and local projects and advisory committees. They ensure that the voices, needs and experiences of Australian women are taken into account in decisions made about breast cancer treatment and care.

The women who attended the training participated in a variety of sessions:
- hearing about the latest in breast cancer treatments
- familial breast cancer and genetics
- issues affecting women with secondary breast cancer
- clinical trials
- survivorship and psychosocial issues
- communication and advocacy.

The sessions were presented by health professionals, Dr Gayle Jones and Susan Hanson from Cancer Australia and staff from BCNA. Several current BCNA Consumer Representatives who attended the training shared their experiences of various projects, including:
- sitting on the Cancer Australia working group developing clinical guidelines for the management of central nervous system metastases in women with secondary breast cancer
- providing consumer input into the Kathleen Cunningham Foundation Consortium for Research into Familial Breast Cancer (kConFab), which collects data and bio specimens from families with a strong history of breast and breast/ovarian cancer and makes this data available for the use in research.

All the women who attended the training are committed to volunteering their time to help ensure women affected by breast cancer receive the best treatment and support possible. BCNA thanks all our Consumer Representatives for their hard work and commitment.

You can find out more about BCNA’s Consumer Representative program by visiting www.bcna.org.au > About BCNA > Advocacy > Consumer Representatives.

Dealing with my unwelcome tenant

Sharon Driessen (pictured with her husband and son) is a BCNA Community Liaison and gave this speech at the Field of Women 2014.

To watch it online, visit www.bcna.org.au > Events > Field of Women 2014.

My name is Sharon and I am 47 years young.
Sometimes I have found it extremely difficult to express my situation, especially to family and friends who have already seen me deal with my unwelcome tenant – breast cancer – back in 2004.
We thought it had been beaten, but it returned in 2012 and I now am living with advanced breast cancer. Squatters, who are even more unwelcome.
I stand here for myself, my family and for everyone who hears those four little words, ‘You have breast cancer’.
But, most of all, I stand for those who then hear the words, ‘We cannot cure you’. I have put my thoughts into a poem that I would like to share with you all.

Cancer – You Will Not Defeat Me

I am surrounded by many,
supported by some,
and yet stand alone before it …
A path for me and me alone.
How it hurts as I walk down this path,
seeing others hurt as they watch me travelling
Not all can see it, but it is there
Lurking and hiding in the shadows.
Just waiting for its chance to continue to grow
And to take over
My battle against it is relentless
and it rages all the time.
Not loud, not angry, but a calm and determined battle it is indeed.
Anger will not be wasted on it as that will only make it stronger.
I am at one with it and in some ways
am weaker because of it
Yet, I am stronger now than ever before,
because I have changed and continue to change
I have grown and am still growing
I have learned and keep on learning
I will not give up
I do not know how to
It will never get my heart
It will never get my soul
My every waking moment has something to do with it
But it is just a word, just a name and it does not define me
I am living with it and It Will Not Defeat Me
Life in the slow lane gets better and better

My breast cancer story began with a diagnosis in May 2013. With two children in their twenties, a busy husband, running my own migration consultancy, many social events, my to-do list was endless. I was always trying to cram too much into my days. I felt strong enough to cope with what lay ahead, but I knew that my life would need to change.

My brief friendship with mindfulness and meditation the year before prepared me well for the challenges ahead. I began to find enhanced enjoyment even in the routine tasks of everyday life. I developed more patience with things that did not please or go so well.

On chemo days, walks with my family became a special ritual. And on the days that even the small previously ‘taken for granted’ aspects of my life like eating a meal were overwhelmingly hard, taking more care and time made the food taste better and the sun shine more brightly.

Linda

I have made the conscious decision that simplicity and an approach grounded in the present are what help me most in post-treatment life too. I am happier and far more in tune with my senses and inner voice. Gone too are the feelings of misplaced obligation. If I need to have a siesta I do, without guilt. If I need peace and quiet, I switch off my mobile phone without guilt.

Having cancer has put me in the slow lane, and right now, I want to stay there – one sees, appreciates and enjoys so much more.

Linda, NSW

Reflections on how far I’ve come

Last month my oncologist told me not to come back – after eight years of visits to specialists I was being transferred back to my GP. My oncologist said, ‘Don’t take this the wrong way, but I hope I never see you again!’

Fragments of memories from those early days of surgery and treatment … Autumn sun in the garden in Canberra surrounded my golden leaves; overwhelming nausea in the hours after chemo; my darling partner, children and granddaughter sitting close by watchful, dark holes of despair, chanting Buddhist monks in the museum, three-monthly checks, monthly facials, terrible constipation, a new kitten called Lilly representing softness and life, panic attacks about life and death.

At last I climbed out of the medical rhythm and retrieved a normal life. Oh, how precious is normality. My hair grew back, my body resumed some order again, and my emotions started to settle a little. Still anxious and hypervigilant, I stepped out into the world of ordinary things.

Then I was offered the remarkable gift of a grandson with golden hair – hair like my daughter and her partner. ‘Come and live near us’, they said. ‘And enjoy your grandson.’ And so I did. We moved from the familiar dryness of Canberra to the lush green dairy pastures of the Northern Rivers.

And a second child was born: another little boy whose hair glows with gold. So, my life is sustained by this environment of gold and green and love.

Anne, NSW
Getting used to the new normal as a single young woman

When I was diagnosed with breast cancer at the age of 27 I could not believe it. Although our family does have a history of breast cancer, I didn’t expect it. Fortunately I had a supportive team of doctors and a great breast care nurse who helped me immensely throughout my journey. One of the defining moments was after I had my mastectomy (unilateral). I was still in hospital and having a shower with help from one of the nurses in my ward and she asked me if I wanted to look at my chest. After a few moments I said ‘Okay’. I had thought I would burst into tears, and I did, but mostly I felt very comforted with the fact that by being so proactive I had literally saved my own life.

It’s now nearly three years since I was diagnosed and life has slowly returned to somewhat normal. One thing that has really helped me is meeting so many amazing breast cancer sisters, some who have won the fight and others who are still fighting. This makes me feel less alone. Even though I’m not married or even dating right now I still feel that being young and single with this disease does have its good moments but I would love to have someone to share the rest of my days with.

Until then I will look forward to starting the reconstruction process and keeping on promoting breast cancer awareness for young women like me.

Melissa, SA

Grieving for a time without worries

I stood with my breast squeezed against the cold compression plates of the mammogram machine. I held my breath, eagerly anticipating the moment that I would be free. It was just another standard test in my collection of preventative health checks. The possibility of cancer never occurred to me.

As I faced the machine for a second time in six weeks I vaguely remember questioning the safety of my exposure to the radiation. Preoccupied with getting to my next appointment on time, I still did not seriously consider the possibility of cancer. It wasn’t until I was sympathetically advised that more tests were required that my complacency vanished. I was alone in the crowded waiting room. I struggled to breathe as the diagnosis of breast cancer drowned me in a thunderous ocean of fear.

I was confronted with making decisions about my survival. I chose breast surgery and radiotherapy, and as a result of these treatments I have now lost the natural shape of my breasts, the full movement of my left arm and the luxury of living a pain-free life. But this is not the source of my grief. I grieve for the time when I didn’t worry about my health, when I could go for screening tests and check-ups and not fear the results. I grieve for the time before treatments greedily devoured my energy and I became dizzy on the medical merry-go-round. I grieve for the time when I innocently believed that cancer wouldn’t happen to me.

Wendy, NSW
Getting older is good

Tomorrow, I turn 60 years old and I’m loving life. I’m ready to plan a late birthday party to celebrate; a party that will be bigger and better than before. It tells the universe I am here to stay for another year. I can secretly say what a great milestone I have reached. I have many more precious moments to enjoy. Life is for living, and loving. I look my graceful age, fit, feminine and feel sexy as ever.

I think the idea of lying about your age is sad. It is such a demeaning thought for all women. I feel my best years are ahead. I am wiser, smarter, and more caring. I feel more beautiful somehow. I know I look older but I can see a light shining through from the inside.

Ever since I was 25 years old, I would feel down about getting older. I would scream inwardly, ‘Oh no, not another birthday’. Well you know, my body finally got the message, and gave me breast cancer. My obedient cells listened intently to what I was saying to myself. Breast cancer, it knocked me down. It came to test me, it came to awaken me, and it came to realign me. It came to help me thrive, through the important years ahead – important, because I treasure them more than ever.

Faye, VIC

A new lease on life

In 2012 at the age of 68 I was diagnosed with an aggressive cancer in my right breast. I opted for a double mastectomy, and doctors discovered that the cancer had not yet travelled to my lymph nodes. The surgery, although successful, left me with tight, painful scar tissue across my entire chest. I did all of the exercises given to me by the hospital team daily, but this did not relieve the pain.

Over time I started to become rather depressed, feeling there was no hope and that I would be stuck with this pain for the rest of my life.

My breast nurse suggested I try physiotherapy. I started treatment and within a short amount of time I started to feel the difference. The pain has gone and the scar tissue has softened. My physiotherapist, Jennifer, has given me back my life and my happiness. I tell her she has healing hands and I will be forever grateful to her.

Raylee, QLD

Thanking my lucky stars

I was totally shocked when I received my diagnosis. I couldn’t talk about it for the first two weeks without bursting into tears. I had just turned 50 and had never been fitter in my life. As I sat in the hospital waiting room, I was surrounded by cancer patients. I was sure I didn’t belong there – but it turned out I did.

Things moved very quickly once I was diagnosed. In the early hours of the morning following my first treatment I woke with a jolt. I was gasping for air. Something was not right. I managed to get through the night but spent the next four days struggling for breath. My first mistake was not going straight to the doctors for help. To this day we do not know why I had the attack. I had to quit chemotherapy but continued with Herceptin and radiation. Later I had my mammogram and ultrasound and all was clear.

We all have a different experience with breast cancer. I had a few unexpected turns including four days back in hospital with an infection. Losing my breath was a shock. I take a pill every day, my nails are shot, my short-term memory has been affected, my fitness gone but I am so grateful to be alive. I will always appreciate the efforts of those who treated me, my family, my friends and I thank my lucky stars every day that I live in Australia.

Sharon, VIC
Gaining a new perspective on life

In May 2011, aged 57, I was diagnosed with Her-2 positive breast cancer. I had a right breast mastectomy and 24 lymph nodes removed in June. Chemotherapy and Herceptin followed but 10 days later I developed neutropenia. I finished chemotherapy in November but stayed on Herceptin for another 12 months. Unfortunately on the day I was to finish I had a heart attack.

Overwhelming depression followed requiring four weeks off work. With the help of a social worker from the cancer clinic I was given tools to work with. I have overcome depression but experience anxiety; when this happens I tell people.

In April 2013 I had my left breast removed with expanders put in. Six months later I celebrated my 60th birthday with a surprise party. Shortly thereafter, again to be proactive, I had ovaries and tubes removed with a prosthesis put in my chest.

Although I live on my own, have no children, and only two siblings interstate, I was never alone. I manage a menswear store in Casino, a small country town. I have had amazing support from friends, family, work colleagues, customers and the general community. I was fortunate to be able to drive to my clinic for treatment, a one-hour round trip every three weeks, on my own. By doing this, I kept as much normality and independence as possible. Other than a few hiccups I worked full-time.

I turn my negatives into positives enjoying every day. My appreciation of life has improved tenfold.

Helen, NSW

Inscribed the scars

As a breast cancer survivor of two years I have observed that all avenues of treatment ignore one of the aspects of being human that has meant the most to me: the story I generate that makes sense of my journey.

My latest excursion into meaningful imagery has been to have Celtic dragons tattooed across the scars from my bilateral mastectomy. At 66 I decided that a reconstruction was unnecessary. While the scars were neat, they shouted the absence of my 18CC breasts! I wanted to reclaim this space.

My surgeon gave me the all clear to work over the scars and introduced me to a website featuring mastectomy tattoos, where I found that hundreds of women worldwide had chosen to celebrate their physical change with artwork. Tattoo artist Paul McCracken helped design the image. The drawing of the images took about five hours, then another five for colouration. The radiated side was super sensitive. Yes, it was a painful process. The results however were trouble free from the beginning and moisturising is the only ongoing commitment.

My tattooist told me the legend of the Celtic warrior, who, when he saved the life of a fellow soldier, earned the right to tattoo the crest of that warrior’s house on his body; a lasting badge of courage.

It is difficult to fully explain what the tattoos mean to me. When I catch a glimpse of my nakedness in the mirror I no longer see the scars, I do not feel maimed or ugly. Instead I have reclaimed this space on my body. I have replaced absence with presence. They are my survivor’s badge of courage. My husband tells me he finds them sexy (that’s a bonus!). A friend reminded me recently when I was going into a difficult meeting: ‘You shouldn’t be worried, you’re taking two dragons with you!’

Judy, QLD
What's on your mind?

Hope with humour

I was diagnosed with breast cancer in February 2014; at 36 this was not in my plan. To say that the news floored me would be an understatement. I am currently going through my chemotherapy treatment and it would have to be the most challenging experience I have ever faced.

I understand the treatment is killing the cancer, but it’s hard to remember that when your bones ache, your mouth is sore, you have no concentration and you are tired all the time. I struggle some days to vacuum or do the washing – things I could once do in five minutes with one hand tied behind my back before! It’s funny how the little things get you – I tried to open a yoghurt container the other day but couldn’t because my nails hurt.

My medical team have been really great, but it’s my husband that I need to say thank you to. He has had to go through this with me every step of the way; all the appointments, my tears and frustrations. Without his support and understanding, I wouldn’t get through each day without being a complete mess. This illness is not just about us, it’s about our loved ones too.

Yes, we have to be strong to get through treatment, but perhaps it is those around us who have to be that much stronger to watch us go through this. Once I finish chemo, watch out world, I’ll be vacuuming like a mad woman in no time!

Donna, VIC

My illness is not just about me

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I am currently going through my chemotherapy treatment and it would have to be the most challenging experience I have ever faced.

I understand the treatment is killing the cancer, but it’s hard to remember that when your bones ache, your mouth is sore, you have no concentration and you are tired all the time. I struggle in anything but sleep! The ‘roids’ subsequently caused rampant thrush, so to avoid tooth brushing with Candida or mastectomy ointments,

I assigned my oral treatments to the left of the basin and everything else to the right! Prostheses: Much as I appreciated this free post-op support, I was ill prepared for the challenge of anchoring the perky shaped form to my flat draining board ribcage, and aligning it to its droopy neighbour on my left! While reaching up in supermarkets, it invariably snuggled into my right armpit, resulting in much trolley diving for readjustment purposes!

I have been encouraged to share these humorous highlights by my wonderful family and friends, whose love and support these past four months has been invaluable. Life presents many challenges, but I do believe a good sense of humour works wonders when the chips are down.

Jessica, NSW

Jessica with her husband and son

Hope with humour

Even after 12 weeks of chemotherapy following a mastectomy last year, I still question why me? However, after undergoing treatment with both male and female cancer patients of varying ages, I realise it’s non-discriminatory and I am fortunate my own diagnosis was early.

Moulting started after two-and-a-half weeks, so I posed with my husband and son for a rear view family portrait of our three bald heads together! I’m a master at tying headscarfs, but enjoy alternating between my red and silver wigs, depending on my mood! ‘Chemo brain’ is the most understated symptom!

After stopping the steroids, I physically morphed into a stunned sloth, lacking interest

in anything but sleep! The ‘roids’ subsequently caused rampant thrush, so to avoid tooth brushing with Candida or mastectomy ointments,

I assigned my oral treatments to the left of the basin and everything else to the right! Prostheses: Much as I appreciated this free post-op support, I was ill prepared for the challenge of anchoring the perky shaped form to my flat draining board ribcage, and aligning it to its droopy neighbour on my left! While reaching up in supermarkets, it invariably snuggled into my right armpit, resulting in much trolley diving for readjustment purposes!

I have been encouraged to share these humorous highlights by my wonderful family and friends, whose love and support these past four months has been invaluable. Life presents many challenges, but I do believe a good sense of humour works wonders when the chips are down.

Jessica, NSW

Jessica with her husband and son
Even the most positive person in the world gets cancer: Love, laugh, live with cancer

by Mezwyn D’Junus
H&H Publishing 2013
paperback, 123 pages

This is an informative book written in simple language covering topics people with cancer encounter. It is easy to read and the illustrations help to lighten the seriousness of the themes.

The letter in the front of the book is a good introduction and covers cancer and its implications in clear language. The book covers the main emotions experienced by people diagnosed with cancer – shock, denial, anger, bargaining and acceptance. It is many years since I was diagnosed with cancer but can still relate to many of the feelings expressed in the book such as thinking of death, what life will have in store for me and will I see my children grow up, etc.

I think this book will appeal to a large range of people, newly diagnosed and following treatment. It has a section on young people and relationships after cancer. It touches on the topic of depression with encouragement to seek help if this occurs. When I first read the book I felt that some of it was perhaps ‘a bit over the top’, but on second reading realised that it may be an age thing and it would certainly appeal to most people. As I mentioned, the illustrations provide a lighter note and some may bring a smile at times.

I liked the final section of the book which provided encouragement and emphasised the positive aspects of surviving cancer, living life to the full and recognising the important aspects of your life.

This book could appeal to many people facing the cancer journey; it is easy to read with a strong message of hope.

Isabel Hose, BCNA Volunteer

From the feet up
(a memoir)

by Tanya Saad
Harlequin Mira Publishing
2014; paperback, 420 pages

In this wonderfully written book, Tanya takes the reader on a journey from her childhood through to very deep family decisions. The eldest of three Lebanese sisters growing up in Taree, NSW, Tanya leads a healthy lifestyle with swimming and competitive cycling.

At age 30 she learnt of the BRAC1 gene in the family, and the need for to be tested for the gene. The BRAC1 gene is inherited and if tested positive for carrying the gene, the risk of developing breast cancer and/or ovarian cancer is greater. Younger women found with the gene can have counselling, screening and the opportunity to have preventative surgery in the form of hysterectomy and mastectomy.

Tanya and one sister tested positive for the BRAC1 gene and were faced with decisions they never thought would arise. She leads the reader through this journey of counselling and risk management options.

Tanya tells her story truthfully and openly and includes helpful references at the back of her book.

I would recommend this book to women who may have a family history of breast cancer and/or ovarian cancer and are considering undertaking testing for the gene. I would have found this book most helpful to read many years ago. I have a strong family history of breast cancer, and at age 57 was diagnosed with breast cancer myself. Even for those without a family history, this true story of young women having to make such deep family and health decisions is very enlightening.

Robyn Butson, Review & Survey Group member
Profiling our online groups

Louise Turner, facilitator of BCNA’s online Breast Reconstruction group shares why she established it and some of the ways it supports women around Australia.

I was referred to BCNA when I was first diagnosed. My husband put me on to the BCNA website where I found the online network.

I read every post … I couldn’t believe I found such an amazing place where women like me were chatting about everything to do with breast cancer. I was hooked.

I joined, wrote up my profile story and went from there.

In hindsight it was a great way to remember how I was feeling at the time and very cathartic to be able to write about my experiences.

I became a regular reader and blogger on the main forum during my initial surgeries and treatment. When it came to my reconstruction stage, I wanted to see photos and talk to women about their experiences.

I contacted a few women I knew who had had a reconstruction and some emailed me pictures. This helped me enormously. I kept a photo story of myself during reconstruction but didn’t know really how I could reach other women to share it. After a few false starts it was suggested I start an online group that would be private to protect the privacy of members sharing their photos.

My motivation was to bridge a gap that I experienced while planning breast reconstruction. I could not find a place to connect with Australian women going through the same thing and to share the difficulties we had and to rejoice in the milestones as our procedures progressed.

I find the interaction between members in this group to be inspiring. They share their wisdom and experiences, ask questions and find resources to share. Nothing is too personal to share and the support for each other is enormous.

Members can choose to be very private and observe only, or they can get involved and create their own blogs. We are welcoming on average 30 to 40 new members a month.

The ongoing challenge is time. The facilitation of this group is a daily activity and I have enlisted a few like-minded members to help. Facilitating this group is an enormous privilege. It is like being the keeper of incredibly personal information, stories and images. I would encourage more members to join our admin team.

It’s important to keep up a personal relationship with members, remembering their milestones, and keep a balance between friendly interest and too much online presence. We try to organise information, so it can be retrieved easily, are I’m always searching for ways to promote the group. I use media, breast cancer support Facebook groups, face-to-face support groups, and anyone who will listen. The best promotion is if the members themselves tell others.

To anyone thinking of starting an online group it can be very rewarding. It takes commitment and requires a real sense of purpose. It helps me enormously with my own sense of wellbeing, and along the way, I have developed new skills and friendships.

For more information about BCNA’s online network or to join the Breast Reconstruction group, visit www.bcna.org.au > Network.

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 304.

New Member Groups:
- Pink Sisters – Tassie – Hobart, TAS
- Perth/WA Women’s Group – Perth, WA
- Berwick Ladies Cancer Support Group – Berwick, VIC
- Journey Friends in Pink – Runaway Bay, QLD

To find a group in your state or territory visit www.bcna.org.au > Sharing & support > Find a support group in your area.

If you can’t find a face-to-face support group in your area, consider joining our online network and connecting with one of our online support groups. We have more than 130 topic-based groups, including:
- Breast reconstruction
- Depression and anxiety
- Inflammatory breast cancer
- Hormonal therapy
- Loss of libido
- Living with secondary/advanced breast cancer
- Men diagnosed with breast cancer
- Partner support
- Supporting a parent
- Triple negative breast cancer
- Young women

For more information, visit www.bcna.org.au > Network, or phone 1800 500 258.
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:

- Ballarat & District Trotting Club, Steve Salter, VIC
- Brenton Daniels, Rian & Angela Nelson, SA
- Gloucester High School, Ryan Yates, NSW
- Greenbushes Ratepayers and Residents Association Ltd, Patrick Scallan & Didith Atkin WA
- Karen Green and Committee, VIC
- Kerri Welsh, VIC
- Kylie Wallace & Leah Caelli, NSW
- Lynn & Carly Brewster, VIC
- Maria Della Rocca & Committee Members
- Matt Daniels – MD Road Warrior, VIC
- Northside Community Church, Lysbeth Downs, WA
- Pat Canteri, VIC
- Port Wakefield Bowling Club, Lydia Berry, SA
- Uraidla Districts Football Club, Megan Down, SA
- Wesley College, Matthew & Michaela, VIC
- Williamstown Tennis Club, VIC
- Yarra Valley Grammar School, VIC

Memorials

We pay tribute to the lives of:

- Barbara Gange
- Beth Crowden
- Frances Gill
- Garry Williams
- Jennifer Hughes
- Lesley Barkla
- Mary Crickett
- Mary Swanson
- Moira Goodchild
- Rita Fletcher

We are grateful for the donations we received in their memory.

Supporting BCNA through the workplace

Workplace Giving brings employers and staff together to support a cause close to their hearts. It is an easy and convenient way to donate to a charity via pre-tax payroll deductions.

One of our Workplace Giving partners, Collins Foods Limited, is proud to have more than half of their team members participating in Workplace Giving. They have donated more than $2.4 million to five charity partners.

BCNA’s CEO Maxine Morand presented Collins Foods Limited CEO Kevin Perkins with a plaque in recognition of the funds they have raised for BCNA through their Workplace Giving Program.

We rely on the generosity of our supporters and sponsors to provide free information and support. By supporting BCNA through a Workplace Giving program you will help us continue to provide free programs, resources and support to those affected by breast cancer.

If you are interested in finding out more about Workplace Giving, contact BCNA on 1800 500 258 or email beacon@bcna.org.au.

Hold an event in your community

All year round, BCNA members host events to pay tribute to those affected by breast cancer. If you’d like to be involved, BCNA is here to help! To register a Mini-Field of Women tribute event or a Pink Lady fundraising event, visit www.bcna.org.au > Events. We’ll send you a free pack to help you pink up your event.

Celebrations

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

- Mike Mooney

Maxine Morand, BCNA CEO, with Kevin Perkins, CEO Collins Foods Limited.
Berlei and BCNA deliver 100,000 My Care Kits

Together with our Supporting Sponsor, Berlei, we are proud to announce that the 100,000th BCNA member has received a free My Care Kit.

Since 2005, with Berlei’s support, BCNA is now sending more than 13,000 My Care Kits out each year – around 250 per week.

The My Care Kit contains a specially designed Berlei bra and soft forms that can be worn in the weeks immediately following surgery for breast cancer. It also has information and support material to assist women in the recovery process.

BCNA CEO, Maxine Morand describes Berlei’s contribution to the My Care Kit program as invaluable.

‘Having a special comfortable bra to wear after surgery makes such a difference for women at a very stressful time. The delivery of the 100,000th My Care Kit is a huge achievement and we are so grateful to Berlei for their contribution,’ said Maxine.

Great supporters of the Pink Lady in October

Showcase Jewellers is proud to have produced another stunning piece of jewellery to raise funds for BCNA. This bracelet retails at $14.95 with the proceeds of $5.00 coming to BCNA.

To find your local Showcase Jeweller or to buy online visit www.showcasejewellers.com.au.

Liv is pleased to have developed a special limited edition BCNA Pink Lady bike for summer. Only 100 bikes are available at $1,499.00 with 10% being donated back to BCNA for each bike. To find out more visit www.mygiant.com.au.

Over a 10-year partnership, Ritchies through its Community Benefit Card program has donated more than $142,000 to BCNA. We encourage our members in Victoria, New South Wales and Queensland to sign up for a card at their local store. Visit www.ritchies.com.au for store locations.

The My Care Kit is available for free to women in Australia in the 12 weeks after breast cancer surgery, and is distributed through health professionals (mainly breast care nurses) enrolled in the My Care Kit program.

Berlei post-surgery bras are available to purchase for $59.95 from Berlei stockists or online: www.berlei.com.au > Bras > Post surgery.

Berlei supports BCNA in October

This October, Berlei will once again donate $5 from the sale of every pink Berlei bra to BCNA. Each year the Berlei team develop a range of pink bras that provide customers with an opportunity to raise funds for BCNA. To find your local retailer supporting the campaign visit: www.berlei.com.au.

Special Berlei offer for BCNA members

Berlei is currently offering BCNA members 25% off all full priced items purchased online before 31 October 2014, including the post-surgery bra. Visit www.berlei.com.au and enter the promo code BCNA25M at the checkout.

Terms & conditions: 25% off applies to RRP of full priced items. Not in addition to other discount or multi buy offers. Not available on gift cards. Offer expires 11:59 pm 31/10/14. While stocks last.

BCNA gratefully acknowledges our partnership with Bakers Delight.
Help for women with secondary breast cancer

What is secondary breast cancer?
The majority of women with early breast cancer recover. However, despite improved treatments, some women will develop secondary breast cancer (sometimes also called advanced or metastatic breast cancer).

Secondary breast cancer occurs when cancer cells spread from the original cancer in the breast to other parts of the body through the blood or lymphatic systems. The most common sites affected are the bones, liver, lungs and brain, although it can affect other places. It may also affect more than one part of the body at a time.

Every woman’s experience of secondary breast cancer is different. Symptoms depend on the spread of the cancer and the part of the body affected. Some women will have many symptoms while others will have very few or none at all.

As yet, secondary breast cancer cannot be cured. However, there are many treatments available so it can be controlled – sometimes for many years.

BCNA resources for women living with secondary breast cancer

Hope & Hurdles is BCNA’s free information pack for women with secondary breast cancer. It contains an information guide about the disease, treatments, and managing side effects. It also includes the Messages of hope and inspiration booklet, a CD of guided meditations, information for partners, family and friends, and a subscription to The Inside Story, our free magazine especially for women with secondary breast cancer.

Optional items can also be ordered, such as booklets about each of the four main metastases sites (bone, liver, lungs and brain), Cancer Australia’s Guide for women with secondary breast cancer, and other BCNA fact sheets and booklets.

I love the pack and the night it arrived stayed up much later than I should have reading it. It helped me with my fears and gave me a sense of calm. My daughters have been comforted from reading the material in the pack.

If you or someone you know has been diagnosed with secondary breast cancer and has not received Hope & Hurdles, or if you would like to subscribe to our free Inside Story magazine, please phone BCNA on 1800 500 258. Hope & Hurdles can also be ordered directly from BCNA’s website, www.bcna.org.au.

Secondary Breast Cancer Awareness Day will be recognised in Australia on 13 October. This day will highlight the needs and challenges of women living with secondary breast cancer. For more information visit www.bcna.org.au.

Seeking stories – Sharing the journey

We are seeking stories for the Autumn 2015 issue of The Beacon about the impact of your diagnosis on the people around you.

We often hear from women who are concerned about how their diagnosis has affected their partner, family and others around them. We invite you or those close to you to share your stories. The stories should be about half a page long (200–300 words) and can be posted to BCNA, 293 Camberwell Rd, Camberwell 3124 or emailed to beacon@bcna.org.au by the end of December 2014. Please also include a high-resolution photo.