Matters of the body and mind

Living up to expectations and stereotypes (often unrealistic and unachievable) can be challenging for many, particularly, I think, for women. We all conform to various degrees in how we behave, what we do and how we look. The importance we place on physical appearance varies among us and probably varies at different stages of our lives. I can remember caring more about how many hours sleep I was getting, rather than how I looked, after the birth and early days of both children! How we feel about ourselves is very important. After all, our physical appearance is how people recognise who we are; but it does not define who we are. We are all different – not just in how we look but who we are and how our life experiences have impacted on us. There can be a lot going on inside that may not be apparent in an outwardly physical way but, just as equally, the effects of chemo and psychological distress can be seen in a very physical way.

Contributions in this edition reflect that diversity. Some consider surviving breast cancer and caring about who we are on the inside to take absolute precedence in recovery after breast cancer. Some women are really proud and pleased with their new bodies and others have faced great disappointment and challenges in changed physical appearance. Every story is different, just like we are. There will be another 15,000 individual stories of breast cancer diagnosis and treatment this year. We estimate that we will deliver more than 12,000 My Journey Kits and 12,000 bras in the My Care Kit and provide free information forums to more than 2,500 women across Australia this year. We are constantly busy making submissions to government regarding new drug treatments for inclusion in the Pharmaceutical Benefits Scheme and regarding new and existing diagnostic procedures that we believe should attract a Medicare rebate.

The scope of what we do as an organisation is not possible without the support of the community. We need your help to continue our work. In this issue we’ve included a flyer for our annual donation appeal. If you are able to, please make a donation to BCNA to help us continue to provide the support and resources to the many thousands of women who are diagnosed every year. In last year’s appeal just 2 per cent of our members made a donation. If we can double the number of members donating, that would make a big difference!

Finally we are once again being supported by Shane Crawford, an AFL legend and amazingly generous person who will ride his bicycle from Melbourne to Perth to raise money for BCNA. It's an incredible challenge that will connect communities along the path of the ride, help raise awareness of the impact of breast cancer and raise much needed funds for BCNA.

Maxine Morand
Chief Executive Officer

Important message about Field of Women

I am very sorry to announce we are unable to go ahead with the Field of Women 2013 in Sydney on 10 August at ANZ Stadium.

It was a big decision to make, as I know many of you have been making plans to attend this very special event, and we sincerely apologise for any inconvenience caused.

However, the most important aspect of this event is the experience for the thousands of Australians participating and we were facing considerable logistical challenges that we felt would compromise the event.

The good news is we will work with the AFL to find another date next year and we look forward to standing with you on the Field then. Please visit our website www.bcna.org.au for more information.
We are thrilled to announce that Shane Crawford, as part of the Channel 9 Footy Show, is taking on another extraordinary challenge for BCNA. He will be riding a bike from Melbourne across the Nullarbor to Perth. While most people ride from Perth to Melbourne to have the tail winds, Shane wants to take on a bigger challenge, riding against the strong head winds. Crawf will be leaving Melbourne on Thursday 20 June and plans to arrive in Perth on Thursday 11 July 2013. Shane will give regular updates during the AFL Footy Show on Thursday nights on Channel 9 at 8.30 pm AEST and the Sunday AFL Footy Show on Sunday mornings on Channel 9 at 11.30 am.

Shane’s run in 2010 from Adelaide to Melbourne had a huge impact on the communities along the route, and for thousands of women with breast cancer, their families and friends across Australia. He holds a very special place in our hearts.

To see the route and find out ways you can cheer him on visit www.bcna.org.au/crawf.

When I ran from Adelaide to Melbourne in 2010, I met some unbelievable and inspiring breast cancer survivors. I learnt the significance and importance of Breast Cancer Network Australia for families around the country. The pain and agony I will go through riding 3,600 kilometres in 22 days and crossing the Nullarbor is nothing compared to the pain Australian women with breast cancer go through each day.

– Shane Crawford
In this article, we revisit an issue of great interest to our readers – breast reconstruction.

**Trends in breast reconstruction**

Although breast reconstruction is available free of charge through the Australian public health system, the numbers of women who have a reconstruction after breast cancer surgery are surprisingly low.

Research studies suggest only between 6 and 12 per cent of Australian women have a breast reconstruction after a mastectomy.

Perth-based breast surgeon and BCNA Board Member Professor Christobel Saunders says that while the proportion of women having a reconstruction is low, she believes that the number is slowly increasing and that more women are being offered it by their surgeons.

Professor Saunders says factors women think about when deciding on reconstruction include their age and their general health. Women who live in cities are more likely to have reconstruction than women who live in regional and rural areas, as are women who are treated in a private hospital or who have private health insurance.

A 2012 study of more than 700 BCNA members found that around 40 per cent had a breast reconstruction. Those who did not gave reasons including that they:

- did not want to have any more surgery (62%)
- did not feel the need for reconstruction (60%)
- were worried about potential complications of surgery (44%)
- did not want to go through the recovery and rehabilitation (44%).

In the same study, 10 per cent of women who had a mastectomy or double mastectomy said that breast reconstruction was never discussed or offered to them.

**Benefits of breast reconstruction**

Our body image – or how we view ourselves – is critical to how we feel about ourselves. Research shows that women who have a breast reconstruction often have a better body image and feel that the way they look after their surgery is similar to how they looked before. Having a better body image also contributes to improved quality of life.

I feel that I look just fabulous after my reconstruction; it has given me an incredible sense of wellbeing. – Alison

**Disadvantages of breast reconstruction**

Reconstruction surgery through the public hospital system is free of charge. However, waiting lists can be up to two years, or even longer, in some places.

Surgery through the private health system can come with considerable out-of-pocket costs, even for women who have private health insurance. Many women report their out-of-pocket cost at around $5,000, although some have reported paying more than $15,000.

We also sometimes hear from women who are not happy with the outcome of their reconstruction – in our 2010 survey, we found 8 per cent of women were unhappy.

**Things to think about**

At whatever stage you are in your journey, the best way to approach reconstruction is to have good quality information at hand.

If considering reconstruction through the private system, ask your surgeon and anaesthetist for a written quote. Some are willing to negotiate their fees if you ask. If you are unhappy with the quote, you can shop around.

If you have private health insurance, you can contact the fund and ask for the names of plastic or reconstructive surgeons who have ‘gap cover’ agreements with them. Surgeons who have entered into an agreement with your fund will charge your health fund directly; you should have no out-of-pocket cost.

It’s also a good idea to talk to your surgeon about different types of reconstruction and ask to see photos. It is important that whatever decision you make is made for yourself. Talk to as many people as you can, but make the decision that you think is best for you.

For more information on breast reconstruction, including tips from other women, visit www.bcna.org.au > New diagnosis > Treatment > Breast reconstruction.
Ask the Expert

Dr Kerry Sherman

Dr Kerry Sherman is a Senior Lecturer at the Centre for Emotional Health at Macquarie University, and a consultant researcher with the Westmead Breast Cancer Institute. Kerry conducts research into body image and self-compassion in women with breast cancer.

What sort of body image issues do women with breast cancer commonly encounter?

After breast cancer treatment, women experience a variety of physical changes. Sometimes this can negatively change her body image (the way she perceives her physical appearance).

We know that one in three women with breast cancer experience distress about their changed body image, even if they are well and have recovered from their breast cancer treatment.

It is very common for women to feel differently about their bodies after treatment. A mastectomy or lumpectomy leaves breasts looking and feeling different. They may be lopsided or less symmetrical, and there may be scarring.

Women who do not have a reconstruction may need to wear a prosthesis to give their breasts a balanced appearance.

In addition to changes to their breasts, women may also have to cope with skin and hair changes, as well as possible weight loss or gain after chemotherapy, radiotherapy and hormone treatment. For women on hormone therapy, hot flushes can be an unwanted side effect that can make women feel less satisfied with their bodies.

How can women improve or maintain a positive body image after breast cancer?

The most important thing is to treat yourself well, both physically and emotionally. Eating healthy food and exercising regularly helps many women feel good about their bodies.

The way that we think about our bodies – our attitudes, feelings and beliefs – has a big impact on our overall wellbeing. It is important that women be kind to themselves and not ‘beat themselves up’ for the way they look. Many women use strategies such as wearing wigs, choosing flattering clothes and wearing make-up to help them feel better about who they see in the mirror. However, we all change in appearance as we age. Learning to kindly accept these changes is an important part of coping with breast cancer.

What is self-compassion?

When we are faced with a stressful health-related event, we call on the people in our lives, such as medical professionals, to help us cope. We also have our own internal resources we can use. One of these resources is self-compassion. This is the ability to kindly accept yourself when you are suffering. This involves being kind to yourself, not being critical or judgmental of yourself, being aware of your own emotions, and understanding that suffering is a normal part of being human.

Self-compassion is linked to your emotional wellbeing.

Tell us about some of the research you are conducting around this topic.

In partnership with my colleague Astrid Przedziecki, a PhD candidate from Macquarie University, we are looking at the links between body image, self-compassion and psychological distress in women who have been diagnosed with breast cancer.

We found that women with low body image and low self-compassion are more likely to experience greater levels of distress. We also found that the cause of low body image and distress is often low self-compassion. This means that if we can improve a woman’s self-compassion, she may be more accepting of her body and experience less distress.

We are now running a study to see if we can improve women’s self-compassion using a simple writing exercise.

We ask women to imagine they have an endlessly compassionate friend with whom they feel supported and comfortable. We ask women to imagine what that friend would say to them. We then ask the women to write to themselves as that person.

We hope that this exercise will lead to the women feeling more self-accepting and self-compassionate. We hope to have the results of this study by the middle of the year. We are still recruiting for this study so if you would like to participate, you can email BCNA at policy@bcna.org.au and you will be sent an invitation.

Dr Kerry Sherman

Dr Kerry Sherman
Body matters

Dating after breast cancer

A diagnosis of breast cancer can be particularly challenging for single women who may be interested in finding a partner. It is common for women to feel nervous about dating after breast cancer. Many women feel unsure about how and when to tell someone new about their breast cancer. Dr Kerry Sherman advises that no woman should feel any obligation to disclose her breast cancer immediately in a new relationship, unless she feels comfortable doing so. It is sometimes better to wait until you know someone and feel comfortable with them as a friend before telling them about your breast cancer.

Dr Sherman recommends that women practise talking about their breast cancer experience before talking about it to a new partner. You may like to try practising to a mirror at home, or ask a trusted friend to help you. Once you decide to let a partner know about your breast cancer, be honest and ready to answer any questions he or she has about your experience. The way your new partner reacts to the news will guide the way for you. Although it is uncommon, your partner may not react well. Be prepared for this reaction and have a response ready. If your breast cancer is too much for a new partner to cope with, it may be best not to pursue the relationship. After all, you deserve better.

If you are a younger woman, at some stage you may need to talk about your fertility with a new partner. Some women may find this difficult. Dr Sherman suggests that you don’t need to rush this. Be guided by how your partner has responded to your breast cancer experience so far. You may like to drip-feed the information over a number of conversations; this will give you both time to think about how you feel about this new relationship.

Make sure you maintain good relationships with your existing circle of supportive friends and family when you start dating, and remember to be kind to yourself when meeting potential new partners.

Breast Prosthesis Reimbursement Program

The Australian Government’s External Breast Prostheses Reimbursement Program reimburses women who have had a mastectomy up to $400 towards the cost of a breast prosthesis, every two years.

Once you purchase a prosthesis, you will need to complete a claim form to receive a reimbursement. Claim forms are available on the Department of Human Services website or at your local Medicare office.

If you have private health insurance and you receive a refund which covers some but not all of the cost of the prosthesis, you can claim the difference through the reimbursement program.

For example, if you purchased a prosthesis for $350 and received a refund of $200 from your private health fund, your reimbursement through Medicare will be $150.

We know that some women have trouble finding up to $400 to pay for a prosthesis upfront, before they receive their reimbursement. BCNA has raised this issue with the government, but a solution has not yet been found.

If you are having trouble meeting the upfront cost of a prosthesis, here are some suggestions that may help:

- Use a credit card to pay for the prosthesis and buy the prosthesis early in the card’s billing cycle. Medicare pays most prostheses claims within 10 days, so you should receive the reimbursement before your credit card payment is due.
- Ask your local breast cancer support group if they can help you. Some groups offer loans to their members to help meet the cost of a prosthesis. Women pay back the loan when they receive their reimbursement.
- If you receive a Centrelink payment (e.g. an age pension) you may be eligible for an advance payment of your pension. This is a loan which is repaid via deductions from your fortnightly payments. You will still receive the prosthesis reimbursement, so you will not be out-of-pocket.

For more information about the program, phone Medicare on 13 20 11 or visit the Department of Human Services website at www.humanservices.gov.au and type ‘breast prosthesis’ into the search field.

To find a breast prosthesis supplier in your area, search BCNA’s Local Services Directory at www.bcna.org.au > Find services & support near you.
Hair loss can be one of the more distressing side effects of chemotherapy. Losing your hair may affect your confidence and the way you see yourself. Hair loss happens because chemotherapy drugs target fast growing cells in the body to kill cancer cells. Hair follicles are fast growing cells and so can be affected by chemotherapy. This can cause your hair to fall out. The hair loss is temporary and it will slowly grow back after you finish chemotherapy treatment. Some women are surprised to hear that not all chemotherapy drugs cause hair loss. Your medical oncologist will be able to tell you if the treatment they are recommending for you will cause your hair to fall out. Hair loss usually starts two to three weeks after the first chemotherapy treatment and happens over a couple of days. Some women decide to shave their head beforehand to give them a sense of control. To prevent or reduce hair loss, some oncologists offer 'cold caps' to women. Cold caps are usually a strap-on cap, which is kept in the freezer and used frozen. They work by reducing the blood flow to the scalp and so reducing the amount of chemotherapy reaching the hair follicles. You wear the cap before, during and after having chemotherapy. You have to stay at the oncology unit longer than if you have chemotherapy without a cold cap. A recent Australian trial tested cold caps on 100 women having chemotherapy and found that half did not lose their hair. If you are interested in using a cold cap, it's best to speak with your medical oncologist.

To help look after yourself during chemotherapy treatment you might like to:

- use a gentle shampoo/conditioner
- avoid using a hair dryer, or only use the cool setting
- brush your hair gently
- protect your scalp from the sun
- avoid heated rollers, curling wands or irons
- ask your hairdresser if they can use a chemical-free dye if you colour your hair
- try sleeping on a satin pillowcase if your scalp is tender.

BCNA's fact sheet on hair loss has more information and lists common chemotherapy drugs that cause hair loss. For a copy, visit www.bcna.org.au > News > Resources > Fact Sheets and Booklets or phone us on 1800 500 258 and we will send a copy to you.

Look Good … Feel Better is a free program that teaches people who have had cancer to manage some of the appearance-related side effects of their treatment. Its aim is to help improve people’s confidence and body image.

Look Good … Feel Better runs workshops where trained volunteers demonstrate different ways to take care of skin, apply make-up, and wear wigs, hats and scarves. Through these hands-on workshops women have a chance to try different cosmetics and head pieces in a relaxed and friendly environment.

The workshops are held in every Australian state and territory, at more than 180 different locations. At the end of the workshop, women are given a free kit, which includes skin care products and make-up.

To learn more about the Look Good … Feel Better program or to book for a workshop, visit www.lgfb.org.au or phone 1800 650 960.

After the workshop you really do feel better – especially when you have no eyebrows or eyelashes! The women there were at varying stages of treatment – most had already lost their hair. We each received a pack of cosmetics. They asked me to be the ‘model’, which was an extra bonus as I felt absolutely pampered! Then we had a lady show us how to wear wigs, hats and scarves. This was a lot of fun and very encouraging.

– Erica, BCNA online network member
In good shape, but a different shape

My self-worth and confidence have always been heavily dependent on my body image. I disliked my small breasts until I was diagnosed with breast cancer at 38 and then I no longer cared how small my breasts were. A mastectomy, chemo, and radiotherapy followed – I was 39, in menopause from chemo and only had one breast. I considered reconstruction but decided against it.

Having been single many years, I realised life's too short to wait for things to happen, so decided to try internet dating. I was petrified and had to consider what, how and when to tell prospective partners about my body. What amazing men there are in this world! Turns out my one-breasted status was not an issue for most. Only one man had difficulty with the idea and he was respectful, kind and honest about it. I understand that some people may find it difficult to accept (gosh, even I struggle with it sometimes!) and we can't control what we find personally attractive or what we can emotionally deal with, but the way in which this is conveyed tells us the character of a person.

Now, at 42, my confidence in my physical attractiveness is actually higher than before my cancer journey. I am also no longer single, having met a wonderful loving man, and hope to try for a family soon with the few eggs I froze before chemo.

My body is definitely not the same but then neither am I. My body and I bear the scars of a journey with cancer but we also revel in our victory. I am stronger and in the best shape of my life for having been through this journey.

Jenny, QLD

Still bearing the impact of breast cancer

At the age of 44, with a young family, I was diagnosed with breast cancer and commenced radiotherapy. Before this my body image was fine but radiation changed all that. As I am a redhead with fair skin, I burnt badly. I still have the scars. Exactly five years later, the cancer returned to the same breast and I insisted on a mastectomy. A reconstruction was not offered to me – I had no idea it was an option.

Some time later, after spending a day mulching my garden, I was shocked to notice that my right arm was particularly floppy and a lot bigger than my other arm. I was diagnosed with lymphoedema, which I must treat every day.

Ten years later, I was diagnosed with a malignant tumour in the remaining breast and had to have a mastectomy. Arimidex leaves me feeling like I've been hit by a truck. My joints ache so much and I have arthritis in my hands. I wake up in pain almost every night.

So how's my body image? Let me see …

Two long scars on my chest, radiation burn scars on my upper body, skin damage on the right hand side of my face where the radiation 'bounced off'; a painful, swollen arm which is so big I have to buy clothes a size bigger just to fit my arm in, unsightly psoriasis on my legs and back, and very painful joints.

My body image is at zero. Cancer is the pits; the body it leaves you with is the pits. No amount of positive thoughts or uplifting stories can help the hundreds of us out here who hate our bodies. I hate that I had cancer and I live in fear that one day it will raise its ugly head again.

Do I feel I am still the same person even though my body may look different? No. Cancer has changed me. I am sad.

April, WA
Embracing life again

In October 2010 I had a phone call to tell me that the results of my mammogram were not good. Breast cancer. I was 60 years old. After studying the statistics and the side effects I decided to refuse chemo after my mastectomy. I had not been ill, was not ill and didn’t want to be ill. They had taken the cancer with the breast so I wanted to be left alone to get on with my life.

As the days and months passed I became more and more depressed trying to mask my absent breast with a padded bra. I was uncomfortable and really hot in the Queensland summer. I chose not to venture out and spent most days at home in my nightdress. My doctor prescribed antidepressants but they really didn’t help. I was not small breasted so this large right breast manifested as an abnormal growth on my body. I hated it.

Two years later and the surgeon agreed to remove my right breast. As soon as I woke from the operation I was at once relieved and excited by my new look. I might not have any breasts but I feel great. I don’t have to wear a bra and do not feel at all embarrassed by my body image now. The doctors said there was no evidence of cancer in the right breast and after two years I am still cancer-free.

At 62 years old I am not interested in having reconstructive surgery, in fact I am quite enjoying my new body. I am now embracing life again, feeling younger and happier.

Maureen, QLD

Not just for younger women

I have a very demanding job and in recent years, with menopause, had become overweight. In 2011, aged 54, I was diagnosed with breast cancer. I had a mastectomy, chemo and am now on hormone therapy.

After research convinced me of the benefits of exercise, I joined a gym, planned a sustainable exercise regime and changed my diet. I steadily lost weight and built my fitness. Six months after the operation, I returned to work.

Six months later I visited my breast surgeon, explained what I understood as my high risk of contralateral breast cancer and requested a second prophylactic mastectomy. He agreed to do this. I also mentioned that one morning I had woken and forgotten for a few seconds that I had had breast cancer, until I stretched and (not) felt the missing breast.

I contemplated the ‘vanity’ of such an operation. A friend (who was diagnosed with breast cancer three months before me) said it was only for younger women. But I now have a slim and fitter body, with little excess flesh, and I would like to look ‘normal’ in my clothes. The surgeon recommended I have implants and I had tissue expanders inserted at the time of my second mastectomy.

When my skin is stretched enough (I want small breasts this time), the tissue expanders will be replaced with silicone implants.

Ruth, SA
Reconstruction not necessary

Breast cancer has affected my body image in that since my mastectomy I feel conspicuous at the beach in bathers and feel embarrassed, especially when children stare at me. It is common where I swim to be topless and there is the question about whether to cover up for children. I am not sure whether it’s to save me from stares and questioning or whether I really do feel deficient in some way. I certainly haven’t considered a reconstruction. I am 70 and really don’t want to put myself through that kind of operation.

I certainly feel the same person. It really hasn’t altered that and maybe it’s because of my age and the fact that I have had lovely experiences with beautiful breasts in my life. I have always been complimented on them and even now I feel tender and soft when I feel my one breast. I asked the surgeon at the beginning whether I should consider having both removed but he said there was no need. I am so grateful that I didn’t have the other one removed. I derive considerable comfort from touching my one breast and I think that without that as well I may indeed feel a significant difference.

My surgeon is an artist. When I had the bandages removed after surgery I was delighted to find I still had a cleavage – he was so creative the way he cut. I will always be grateful to him for this. When I wear a bra I still feel very much a woman and feel I can show off this part of my anatomy.

Sandra, NSW

Challenges for a young mum

I was diagnosed with breast cancer in 2008 as a single 35-year-old. It was a big shock, and then a huge relief when I was told I wouldn’t need chemotherapy, just a mastectomy. Luckily I was offered immediate reconstruction, and I have had a very positive experience, maintaining my shape. I wasn’t prepared, however, (as a fit, healthy, active, working woman) for how much the surgery would knock me around, and how long the recovery and reconstruction process took. I think it was two years before the implant started to feel a part of me and I stopped being constantly aware of it and the overlying numbness.

In the last two years I have faced the most confronting body shape issue so far, pregnancy! My normal breast increased in size continuously for 9 months, while the silicone implant stayed the same. As my belly grew I became increasingly self-conscious about my mismatching upper half, padding out the reconstructed side from a C to an F cup at the largest. I felt decidedly unsexy at this point despite constant reassurance from my partner. I also found myself mourning the loss of the breast all over again, not something I had expected, and probably related to all the hormones making me weepy. I was determined to breastfeed my beautiful baby boy, and after five weeks of dramas we got there in the end. I was again very self-conscious in the hospital as nothing reminds you quite as much of the past as when you are required to repeat again and again why you are only feeding off one side. Things are returning to normal now he is 10 months and only having two breastfeeds a day. I no longer have the beautiful matching pair the plastic surgeon achieved, but I am happy to be back to almost even again. Somehow every time I get a big cuddle from the baby the traumas of post mastectomy and pregnancy fade into distant memory as I feel grateful for this new life.

Stephanie, WA
Body matters

A role model for positive body image

Breast cancer is rarely something expected and I really thought it would never happen to me. How wrong I was. I was diagnosed at 39 while breast feeding my daughter. Boobs are lovely and even though I never considered that mine were anything special they were a matching pair. When I learnt that I had breast cancer I opted for a mastectomy. I wanted the cancer gone and I didn't want to think about it coming back. I had no idea how I would feel waking up with only one boob, but I figured that was something I would just have to deal with. I now wear a prosthesis and find it easy to hide the loss of my breast, so long as I wear a bra. It is only of a night when I lie naked in bed that I really feel the loss. I miss my boob and the pleasure it gave me. I miss the carefree ‘can do’ bullet-proof attitude I had with two breasts before my cancer diagnosis.

I am grateful my breasts had done their job and nourished our daughter. I treasure a photo of my daughter feeding on the breast which is now gone. My daily challenge now is to be a role model for my daughter, to be happy and show her that a healthy body is a beautiful body. I want her to grow up without body image issues and hopefully having a mum with one boob will give her a good perspective.

Tonia, NT

Going bald together!

In May 2010 at the age of 49 I was diagnosed with breast cancer. Anyone who has gone through this process knows it is not an easy time, but throughout it all my husband Mick stood tall beside me. Surgery, chemotherapy and radiation; he was there at every step. I remember how before the second session of chemo my hair started to fall out in clumps. I will never forget how numb I felt that day. I was just sitting in the ensuite, gathering my hair in my lap, when in came Mick. He asked if I wanted him to shave my head, but the proud woman inside said, ‘No thanks!’

He left, but a short while later he returned; he'd taken the dog clippers to the middle of his head and fluffed up the sides to look like Crusty the Clown. We laughed so much that day, and yes, we shaved each other’s head!

By chemo number five I was bald, bloated and feeling very down. On one of the down days I was sitting on the bed in the guest room visibly upset at how my appearance had changed. In came ‘my knight with the bald head’ and saw that I was upset. He disappeared, came back and threw himself on the bed. I look at him and think ‘There's something different about him!’ Well, he’s gone and shaved his eyebrows off! I was a howling mess by this stage. Mick looked quizzically at me and asked ‘What’s the matter?’ Through the tears I managed to get out, ‘Now you look like me!’ Bless him!

Filomena, WA
Adapting to a new look

I always saw myself as a ‘normal’ 31-year-young woman until I was diagnosed with breast cancer. Changes to my physical appearance seemed to have affected me the most of all; firstly my mastectomy then losing my lovely long hair.

I wasn’t prepared when my surgeon recommended a mastectomy; the thought of losing a breast was heartbreaking for me.

I decided to capture my body as it currently was, untouched by surgery or treatment, and organised some beautiful photos which I have hanging in my bedroom.

After my mastectomy, it was difficult to find suitable clothing for my new body shape. I was used to wearing whatever I wanted including low cut dresses. I found it difficult to find suitable high neckline clothes for my age group. I also decided to buy a wig with but the style of wig and older style clothing combined didn’t help to the degree I was hoping for; I was coping well with most of the side effects, but for me the major side effect was my physical appearance.

During my radiotherapy treatment I started to slip into depression, and then my boyfriend and I separated for a couple of reasons, although I know my appearance played a part as one of his final comments was ‘well you have physically changed you know’.

I made the decision to have reconstruction as soon as I practically could. It was an essential part of regaining the normal young me once again. My hair is still short, but that’s just a matter of time. Overall I have learnt to adapt to my new look and finally feel pleased with my appearance. I no longer compare myself to other women my age. I have been through something the majority of women my age don’t experience, which makes me special and a stronger person because of it. Plus I know when I find him, my next partner will love and accept me for who I am, as they say, scars and all!

Peta, NSW

No less a woman

Does body image matter? Yes. I have to be comfortable with me. However, I am not only defined by my body or my gender. I am also defined by what I do and how I do it.

I had a hysterectomy in 1998 aged 34 due to fibroids.

I remember the gynaecologist kindly informing my husband and myself that I would continue to have my monthly cycle, but not menstruate. He went on to say that this of course ‘did not mean I was no longer a woman’. I celebrated my new found freedom!

I had a mastectomy in 2009. My mother had died from bowel cancer in 1984 and my step mother from bone cancer in 2005 so I agreed to more aggressive surgery which resulted in not having follow-up chemo or radiotherapies. My new body is of course ‘not normal’, but does a mastectomy make me less of a woman? My husband encouraged me to accept my body. As a result of his love and support I have chosen not to have reconstruction. I am more afraid of more anaesthesia than using a prosthesis: I actually look forward to seeing the ladies at my bra fitter as they have seen it all before, which is very liberating.

Does body image matter? Yes. My body reminds me that I have had breast cancer. As I have chosen to use a prosthesis I have to consider others so that they don’t get embarrassed or upset. I have to be mindful in how I dress and in changing rooms and pools. I also have to be careful of my prosthesis when working on the farm. But still I am me and I am living my life.

Lynette, NSW
Thanking our Board members

BCNA’s Board is made up of 10 individuals who have been personally affected by breast cancer. They are leaders in their fields, and generously volunteer their expertise, inspiration and, importantly, compassion and understanding for those affected by breast cancer. Here we profile two of our Board members so you can get to know the people behind the Pink Lady. Andrew and Karen are two of our longest serving Board members and retired in May this year. Karen has been on the Board since BCNA began. Both have made an incredible personal and professional contribution to BCNA and the broader community. We thank them and know they will always be part of BCNA.

Andrew Barling
How did you get involved with BCNA?
In early 1992 I had married Judy, a childhood friend. Our plans changed when she was diagnosed with breast cancer at age 29. She developed advanced breast cancer in 1997. Judy was always a passionate social advocate and her focus became breast cancer as she lived with the disease. We attended the first National Summit in Canberra and she became involved in the earliest version of BCNA. After she died in March 2000, family and friends helped me set up the Otis Foundation to realise her vision and legacy to provide free retreats for women with breast cancer. I was invited on to the Board by BCNA’s founder where I met and fell in love with fellow Board member Mary Wooldridge. We married in late 2003 and our son Jamison is fortunate to have three sets of doting grandparents!

What inspires you to volunteer your time as a Board member?
Please refer to my answer to question one! I have also found that in working with BCNA there is opportunity to meet so many fantastic women and partners, hear so many stories and realise there is still much to be done. BCNA leads the field and is showing the way for so many other disease advocacy groups, and is supported by the most productive and efficient staff, volunteers and supporters that I have had occasion to meet. It has been a privilege to serve on the Board of BCNA.

Karen Hayes
How did you get involved with BCNA?
I was diagnosed with breast cancer in 1996, at a time when the internet was in its infancy and when no-one talked about cancer and the effect it had on their lives. I was extremely fortunate to have had access to some of the best medical professionals available. About six months after my chemotherapy and radiotherapy treatments were finished, I was approached by BCNA’s founder Lyn Swinburne to see if I would like to join her and a number of other like-minded people to start an organisation that would provide information, advocacy and support to women, and the families of women who had been diagnosed. After everything I had been through with my own treatments and learnings, I saw this as a great opportunity to help others using my experience, both from a breast cancer perspective and a business perspective. We set about building what is today a membership organisation of over 80,000 members and over 300 support groups.

What inspires you to volunteer your time as a Board member?
I’ve now been on the Board for 15 years and when I see what has been achieved in that time, the number of women and families that have been supported and the influence that BCNA has had at all levels of the community, I feel extremely proud to have been part of the BCNA journey. It is important that women are able to feel confident in the decisions that they are making at such a challenging and confusing time in their lives. They need to feel that they have the information necessary to make informed decisions and that they have a good understanding of all the options available to them. BCNA plays a key role in informing and empowering women to be able to make their own choices.

Did your breast cancer diagnosis affect the way you felt about your body?
It didn’t so much affect the way I felt about my body, as it did the way I treat it. I am more aware of the need to maintain a balance between my professional and personal life, to exercise, eat healthily and live in the moment. I have made some significant changes in this regard and am grateful that such a challenging time in my life has given me such a positive outcome.

How does the Otis Foundation help women diagnosed with breast cancer?
The Otis Foundation provides a place to escape, free of charge, at a time in the breast cancer ‘experience’ when women just want time to jump off the merry-go-round. It offers the space and time to draw breath, reflect and rejuvenate. We currently manage 15 properties in Victoria, NSW and SA, and last year hosted more than 500 women. We are planning to continue to grow and become more accessible to those who need ‘the gift’.

For more information visit www.otisfoundation.org.au.
Profiling our Member Groups

Wagga Wagga Breast Cancer Group

Marg Vonarx and Jane Crowther share how Wagga Wagga Breast Cancer Group is helping people in its community affected by breast cancer.

Wagga Wagga Breast Cancer Group (WWBCG) has been running for over 10 years. We are an incorporated organisation and work hard to raise funds for people in our region who are affected by breast cancer. Programs we have funded recently include gowns for BreastScreen, televisions and mattress protectors for Lilier Lodge, our cancer accommodation for people out of town receiving cancer treatment, and the printing of our resource booklet which our breast cancer nurses distribute to newly diagnosed women and men.

Our recent lymphoedema forum was also totally funded by us. We welcomed 168 people to the one-day forum in Wagga Wagga. Of those, 37 were local therapists and nurses keen to know more about current thinking and practice relating to diagnosis and treatment options. As one participant of the forum wrote, ‘it was well worth the 600 km drive and the 14-hour day!’

It was huge amount of hard work from all those involved that ensured the success of the event. But we will probably organise another one, because it’s surprising what a small group of committed women can achieve!

Our group meets on the third Monday of every month, and we invite guest speakers on alternate months. The group has grown considerably over the last few years and we now have more than 70 members.

Since becoming a member of the WWBCG I have been able to fulfil a promise I made to myself at the beginning of my own and my daughter’s breast cancer journey, that having received wonderful support, I would give back something to help and support others diagnosed with breast cancer. Being a member has given me the confidence to get my life back. – Karen, Wagga Wagga Breast Cancer Group member

We have several members who have not had breast cancer, who share our passion and join us in our activities. Quite honestly, we are an amazing group of women, offering support, friendship and fun to anyone who wants to join.

Linking together

Over the past 15 years a key part of BCNA’s mission has been to link together Australians personally affected by breast cancer.

We welcome new Member Groups to our network. They now total 311.

New Member Groups:
• Dream of Lilies – Inverell, NSW
• Mornington Peninsula Women’s Cancer Group – Mornington, VIC
• Breast and Gynaecology Cancer Group – St Leonards, NSW
• South C Dragons – Warrnambool, VIC
• After Hours Central Breast Cancer Support Group – West Perth, WA
• Breast Foot Forward – North Sydney, NSW
• Early Breast Cancer Information and Support Series at the Mater Hospital – North Sydney, NSW

To find Member Groups, including support groups, in your state or territory visit www.bcna.org.au > Sharing & support > Find a support group in your area.
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:

• Bicheno Golf Club, TAS
• Diane Williams, NSW
• Divas & Divos Concert – Petrina Burnett, WA
• Friends of BCNA event committee, VIC
• Goulburn Head Shave – Merinda Eden, NSW
• Hayley Walker, VIC
• Horsham Golf Club – Julie Obst, VIC
• Ingham Head Shave – Coral Rizzalli, QLD
• Lai Hing Yuen, NSW
• Mars Petcare, NSW
• Mudgee Race Meet – Sue Harding, NSW
• Order of the Eastern Star – Williamstown Chapter, VIC
• Pink GHD Straightener Promotion – Lynda Bell, VIC
• Pink Lady Cheltenham – Megan Wheeler, VIC
• Pink Lady Collingwood Art Exhibition – Gordon Sonnenberg, VIC
• Pink Lady Cora-Lynn – Diane Patten, VIC
• Pink Lady Cranbourne Dinner – Sue Knight, VIC
• Pink Lady Croydon – Sarah Colley, VIC
• Royal Motor Yacht Club, NSW
• Tamworth Country Music Festival – Nichole Parry-Leahy, NSW
• The Breast Gig in Town – Cassandra Hogan, VIC

Sporting pink for BCNA

Close to 1000 sporting clubs from across Australia turned pink over Mother’s Day weekend in honour of those in their community affected by breast cancer. Thank you to everyone involved – the clubs, committees, volunteers, spectators and our members. Your support raises much needed funds and awareness for BCNA.

Memorials

We pay tribute to the lives of:

• Gayle Janette Walker
• Mary Edleen Moloney
• Vicki Anne Ward
• Dianna Polimini

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

Celebrations

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

• Natalie Baker
• Lynette Barnes
• Pauline Watson

A very proud partnership of support

Berlei has been a proud sponsor of BCNA since 2005. In that time we have delivered more than 65,000 My Care Kits. These kits are designed to assist you in the first 10 weeks after your surgery. The bra and soft form have been designed in consultation with women diagnosed with breast cancer. We hear from many of you who’ve told us that this gift helped you leave the hospital with a little more confidence, so we wanted to celebrate our very special partnership with Berlei in this issue of The Beacon.

Our volunteers pack more than 250 My Care Kits every week, with much love and care, and the piles of Australia Post bags are a very real reminder to us of the families and women we are reaching out to every week.

There are so many people that make this partnership a great success – from the breast care nurses who order the kits and the team at Berlei who produce them, to our volunteers who pack them each week. This is a partnership we should all be proud of.

Shop at Ritchies to support BCNA

This year marks the 20th anniversary of the Community Benefit Card program with Ritchies Supermarkets, where a percentage of money spent by customers is donated to charities, hospitals, schools and clubs, at no extra cost to the customer. An outstanding $41 million has been donated since the program began, with BCNA receiving in excess of $135,000 since 2004. Ritchies Supermarkets are found throughout Queensland, New South Wales and Victoria.

If you’re interested in becoming a part of this program, visit your local Ritchies Supermarket or go to www.ritchies.com.au/community-benefit-card.
Book review

Never Stop Believing – Heartache, Hope and Some Very High Heels
by Sally Obermeder
Allen & Unwin, 2013, paperback & e-book, 334 pages
RRP: $30 (paperback)

Sally Obermeder’s portrayal of her incredible life journey was as honest and as accurate as only a cancer survivor could tell. Sally shares how she’s always been a career-orientated and very driven woman. After trying her hand at different career paths, her dogged determination paid off when she got her ‘dream job’ as an entertainment reporter on Channel 7’s Today Tonight. After struggling for years to become a mother, she found herself married to the man of her dreams, working in her chosen career and ecstatic to be 40 weeks pregnant. Sally was living her dream!

During a routine obstetrician’s appointment, she mentioned to him that she had felt a lump but ‘maybe it could wait?’ By the end of that day, her world was turned upside down and changed forever.

Sally’s emotional recounting of her appointments, surgeries, chemotherapy and radiotherapy is both heart wrenching and inspiring, with various celebrities, friends and family contributing their own thoughts. As a ‘sister survivor’ I found this book to be amazingly moving. I don’t think I had faced some of these feelings head on since my own treatments finished four years ago. I feel anyone that has walked this path will find it honest, accurate and emotionally reflective. The book is written so warmly that I really connected with everything she was going through and feeling. It was only during the ‘Fundraiser’ chapter that I felt she lost me a bit as it delved more into her celebrity lifestyle and not so much the everyday woman.

I found myself remembering, reflecting, empathising, sympathising, laughing, wishing, and just like Sally (‘big sook’) crying … a lot. To this day, I don’t think I’ve ever read or heard anyone explain the side effects of chemo the way she does. Thankfully for Sally and her family this story does have a happy ending and her name is Annabelle Grace Obermeder. Sally has been given the ‘all clear’ from her doctors and is busy recovering, writing her lifestyle blog Swiish, and being the ambassador for Bio Oil.

Samantha DiCicco,
BCNA Review & Survey Group member

Limited edition copies for BCNA members
Sally Obermeder has kindly donated to us a limited number of special edition copies of her book Never Stop Believing – Heartache, Hope and Some Very High Heels. These copies include a personal message from Sally to her ‘pink sisters’ and feature BCNA’s logo. Each book sells for $30 and for every book sold through BCNA, we receive $15.

If you would like to buy a special edition copy, please order online at www.bcna.org.au > Shop or phone 1800 500 258.

Another sweet success in 2013

Thank you to everyone who supported Bakers Delight’s Pink Bun campaign this year. Once again it was a great success and we couldn’t have done it without your support!

I was diagnosed with early breast cancer three years ago. When you face what feels like tragedy in your life, the mundane aspects of life are still present and pressing. I still had to get bread. After I was diagnosed I went to my local Bakers Delight and it was the first day of their Pink Bun campaign. I could not believe that this company was donating the entire profits of their pink buns to BCNA. I looked at these people and marvelled at how so generous they were and, in that moment, felt they were doing this for me. Because of pink buns, I sought out BCNA and, again, I couldn’t believe that they would send out to me the My Journey Kit for free. That information was a light in the darkness for me.

Thank you BCNA and thank you so much Bakers Delight.
– Sara

Bakers Delight is our Major Partner and an integral part of BCNA. Every year we are so grateful for the enthusiasm, passion and hard work its staff put into the Pink Bun campaign, but also for their support they offer us every single day.

BCNA gratefully acknowledges our partnership with Bakers Delight.
**Dates for your diary**

**Wednesday 12 June** BreaCan presents a free session ‘Now what? Finding the new normal’ 11.30 am – 1 pm, Queen Victoria Women’s Centre, Ground Floor, 210 Lonsdale Street, Melbourne. Bookings are essential. Phone 1300 781 500 or email breacan@breacan.org.au.

**20 June – 11 July** Tour de Crawf - Ride to the Other Side! AFL legend and BCNA Ambassador Shane Crawford is riding from Melbourne to Perth in his latest challenge to support BCNA. For more information on how your community can get involved or a map of his ride, visit www.bcna.org.au. Stay up to date by liking Breast Cancer Network Australia on Facebook or following @BCNAPinkLady on Twitter.

**Friday 13 September** Free BCNA Cairns community forum. For more information and to register visit www.bcna.org.au or phone 1800 500 258. Places are limited so register early to avoid disappointment.

**Community conversations around Australia**

The National Breast Cancer Foundation (NBCF) invites BCNA members and their family and friends to join their Community Conversations. NBCF would like to share with you what’s been achieved over the past 18 years, but more importantly hear your vision of the research directions of the future. What community needs and research questions do you want addressed? The conversation will cover breast cancer research, but also cancer research more broadly as, increasingly, the science is cutting across tumour types.

Community Conversations will be offered in every capital city around Australia, and a limited number of regional centres, between now and November 2013. For further information, please visit www.nbcf.org.au.

**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 BCNA at fundraising@bcna.org.au or phone us on 1800 500 258.

- **Saturday 6 & Sunday 7 July** Gold Coast Airport Marathon [www.goldcoastmarathon.com.au](http://www.goldcoastmarathon.com.au)
- **Sunday 22 September** Blackmores Sydney Running Festival. BCNA is one of the official supporter charities for this event. [www.sydneyrunningfestival.com.au](http://www.sydneyrunningfestival.com.au)

**Seeking stories – Rural areas and breast cancer**

We are seeking stories for the Summer 2013 issue of The Beacon about rural women and the challenges of dealing with breast cancer. We want to hear from readers who live away from major cities. What were your experiences, the good and the bad, of diagnosis and treatment? 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 September 2013. Please also include a high-resolution photo.

**Join our mailing list**

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