Reconstruction: no right or wrong way

This issue of The Beacon revisits a topic we have considered before – breast reconstruction – as it continues to be of interest to our readers. New surgical developments evolve, newly diagnosed women are considering their options and some women are revisiting this even though they are years down the track from their breast cancer diagnosis.

There is no right or wrong way for women to approach reconstruction. However, we hope their decisions are based on good-quality information, a discussion of the full range of options and, most importantly, each woman’s preferences.

Unfortunately, it seems the decisions women make are sometimes limited by a lack of availability of services in the public hospital system and where they live.

BCNA is passionate about reconstruction being considered part of a woman’s treatment, if that is what she chooses, rather than as a cosmetic ‘extra’.

The information offered in this issue of The Beacon is consistent with BCNA’s philosophy around empowerment of women. We offer you, the reader, the latest clinical information, a range of responses and experiences from women who have ‘been there and done that’ (or not), and encouragement to do what is best for you, while pointing you in the direction of further resources that might help.

I would like to particularly thank all those women who sent in their articles. We were overwhelmed by the volume of the responses and interest.

For some of our readers, this year will have been a challenging one and they will be pleased to wave 2010 goodbye and to turn their sights towards a new, healthier year ahead.

It has been another busy year for BCNA, one in which we can feel proud of our achievements. Significantly, we have just registered our 50,000th BCNA member!

I always think about the size of our membership with mixed feelings – sadness that there are so many of us, but satisfaction in knowing that we can reach so many women and men, and that we are linked together.

While it’s a club none of us would have volunteered for, hopefully BCNA offers strength, a sense of resilience and connectedness, and some inspiration to all of us on our breast cancer journeys. At the very least, women should know they are not alone!

I would like to thank our dedicated and energetic Board members, staff, volunteers and supporters for the extra commitment and energy they have given to BCNA and our work this year.

Finally, I wish all our readers happiness and love, and a year ahead full of special moments.

Lyn Swinburne
Chief Executive Officer

The Pink Lady was seen in communities all around Australia, in October. Liz Martin and her daughter at their Mini-Field at Mildura on the Murray River.

We wish all our readers a happy, safe and healthy festive season and new year.
Priorities from the Minister

Following the federal election in August, The Beacon asked Health Minister Nicola Roxon to outline the Government’s priorities for breast cancer for the next three years. Here is the Minister’s response.

The Gillard Government is strongly committed to the prevention, treatment and quality care of women with breast cancer.

Breast cancer is the second most common form of cancer in females behind lung cancer, with more than 12,000 Australian women diagnosed each year.

Australia has made significant improvements in diagnosing and treating breast cancer. Since 2009, we have committed $2 billion in infrastructure, medicines, screening and research to build a world-class cancer care system in Australia.

The Gillard Government will continue to support women with breast cancer, their families and carers through initiatives including providing funding to Breast Cancer Network Australia, digital mammography equipment for BreastScreen Australia, reimbursements for external breast prostheses, funding for the McGrath Foundation specialist breast care nurses, $168 million over four years to subsidise the breast cancer treatment drug Herceptin, and a survey to help better understand the progression and treatment of breast cancer.

The focus on rural and regional areas will continue with ongoing funds for supporting rural women diagnosed with breast cancer. This complements the Government’s $560 million investment in new or upgraded cancer centres in regional and rural communities across Australia.

The establishment of Cancer Australia as a single national cancer control agency will draw on best practice. The agency will maintain a substantial commitment to breast cancer as it delivers the Government’s broader cancer programs, research priorities and improved health outcomes for all Australians with cancer.

I would like to take this opportunity to wish readers of The Beacon and everyone at BCNA a Merry Christmas and all the best for 2011.

BCNA’s Herceptin survey

In July this year BCNA, with the support of Cancer Australia, surveyed women with HER2-positive early breast cancer about their experiences with the drug Herceptin.

The survey was designed to inform us about women’s heart health during their Herceptin treatment and whether they received regular heart monitoring. Heart problems can be a side effect of Herceptin for a small number of women.

Our results found that nearly all women who responded (99%) received heart monitoring. Seventeen women (6%) said they developed a heart condition which required stopping their Herceptin treatment. However, at least eight of them were able to resume Herceptin after receiving treatment for their heart condition.

Of particular concern was the finding that 40% had to pay for their heart monitoring tests, with some women paying up to $300 per test.

BCNA was thrilled to be invited to present the findings of this survey at a major oncology conference in Melbourne in November. This demonstrates the impact BCNA members can have on influencing the breast cancer agenda.

To read a full report of the survey results, visit www.bcna.org.au > News > Resources > Research reports.
Types of reconstruction

Breast reconstruction surgery recreates the shape of a breast following mastectomy or, less frequently, breast conserving surgery. It can be performed using implants, your own tissue, or a combination of both. Most types of reconstruction will involve more than one surgical procedure. You can also have a nipple reconstruction or tattoo to create the look of a nipple.

Implants

Silicone or saline implants can be inserted under the chest muscle onto the chest wall. Usually, a tissue expander will be inserted first to stretch the skin and muscle to accommodate the implant. The expander is filled over a period of weeks or months by injecting it with saline about once a week. Once the expander has reached the desired size, you will require another operation to remove the expander and replace it with an implant.

The main advantage of implants is that the operation is relatively simple and recovery time is usually short. The main disadvantages are that it can be difficult for the surgeon to match the shape of the existing breast, the new breast may not feel natural and it won’t lose or gain weight as your body loses or gains weight. Potential risks of the surgery include infection in the breast and donor sites. There is also a small risk with a free flap that the breast tissue may die (due to a lack of blood supply) and another operation may be required to remove it.

Tissue flaps

Tissue flaps use your own skin, fat and muscle to form the shape of a breast. There are two main types of tissue flap procedures – ‘attached flaps’ and ‘free flaps’.

Attached flaps use skin, fat and muscle from your back (latissimus dorsi) or abdomen (TRAM flap). A portion of fat and muscle is tunnelled under the skin from the back or abdomen to the chest to form the new breast. The flap remains attached to its original blood supply. A saline implant may be inserted behind it to increase the size of the breast.

Attached flaps may not suit you if you don’t have enough tissue on your back or stomach to form a breast.

Free flaps are similar to attached flaps, but the skin, fat and muscle is detached and removed from the abdomen (free TRAM flap) or buttock (gluteal flap) and then reattached to the chest using microsurgery to attach it to the chest wall’s blood supply. You may also hear of ‘perforator flaps’. These involve removing skin and fat, without muscle, from the abdomen (DIEP or SIEA flap) or buttock (GAP flap) and attaching the blood vessels that feed the tissue to the chest blood supply using complex microsurgery.

Skin and fat tissue from your healthy breast can also be used to create a new breast. This is called breast sharing reconstruction.

The main advantage of a tissue flap reconstruction is that it produces a more natural breast shape, which will change as your body changes. The main disadvantages are that surgery and recovery times are longer than for implant surgery, and you will have scarring to the donor site as well as the breast. Latissimus dorsi procedures can sometimes result in loss of arm strength, and you may have scarring to the donor site as well as the breast. Latissimus dorsi procedures can sometimes result in loss of arm strength, and you may have scarring to the donor site as well as the breast. Latissimus dorsi procedures can sometimes result in loss of arm strength, and you may have scarring to the donor site as well as the breast. Latissimus dorsi procedures can sometimes result in loss of arm strength, and you may have scarring to the donor site as well as the breast. Latissimus dorsi procedures can sometimes result in loss of arm strength, and you may have scarring to the donor site as well as the breast.

Nipple reconstruction

After breast reconstruction, you may like to have a new nipple created or tattooed. Nipples can be made using tissue on the new breast or a skin graft from another part of the body, such as the inner thigh or labia. Once the nipple is created, the area around it can be tattooed to match the colour of the other breast’s areola. Some women choose just to have a nipple tattoo, without any nipple reconstruction. Because the new breast has little or no sensation, tattooing is usually painless.

A list of resources for women considering breast reconstruction is available at www.bcna.org.au > News > The Beacon magazine.
Issue of concern

Women’s experience of breast reconstruction

Breast reconstruction should be considered part of the treatment program for breast cancer patients, not an optional extra for those who can afford it.
– BCNA survey participant

Over the past few years, many women have spoken to us about challenges they face with breast reconstruction – long waiting lists in public hospitals and high out-of-pocket costs in the private system, even with private health insurance. Some have also spoken of their dissatisfaction with the outcome of their reconstruction surgery.

With support from Cancer Australia, BCNA recently conducted a member survey to learn about their personal experiences with breast reconstruction. We were overwhelmed with the response – 462 women completed the survey. Some (70%) have had reconstruction surgery; others (30%) have considered it but not proceeded for various reasons.

I didn’t go ahead as the waiting lists were too long and I was told it would cost more than $14,000 privately.

Out-of-pocket costs

Eighty per cent of women who completed our survey had their surgery through the private health system. Nearly half of them (40%) had an out-of-pocket cost of more than $5,000, with some paying more than $15,000.

The worst thing about my surgery? The expense!

The high out-of-pocket cost of private surgery means this is not a realistic option for some women – 28% of survey respondents who have not had a reconstruction said they could not afford it.

We are unsure why out-of-pocket costs are so high for some women. It may be that Medicare rebates do not accurately reflect the cost of this type of surgery, especially for more complex procedures which can take seven or eight hours of operating time. It may also be that private health insurance (PHI) companies are not entering into ‘gap cover’ agreements with a sufficient number of plastic surgeons and anaesthetists, leaving women to pay the gap between the Medicare and PHI refunds and the specialists’ fees.

Waiting times in public hospitals

A number of women have contacted us complaining of waiting times of up to 10 years for a reconstruction.

Of 18 women on a waiting list at the time of our survey, 13 had been waiting less than 12 months and none had been waiting more than two years. There is, then, a considerable discrepancy between what women have told us (waiting times of up to 10 years) and what our survey found (waiting times of two years or less).

As only 20% of our survey respondents had their surgery in the public system, we think our survey may have failed to reach women who could not afford to pay for a reconstruction and did not want to go on a waiting list. Our findings may not be truly representative of what is happening in the wider community. BCNA will carry out further work to determine whether or not this is the case.

Satisfaction with surgery outcomes

Nearly 75% of women who had a reconstruction were happy with the outcome, rating their satisfaction level at 8 or more. 8% were unhappy, rating their satisfaction at less than 5.

Women said some of the best things about their surgery were feeling and looking normal again, no longer having to wear a prosthesis, and increased self-esteem and confidence.

It has given me my life back, restoring most of my self-esteem and confidence as a woman.

The worst things included pain, long recovery times from surgery, and scarring.

To read a report about the survey’s findings, visit www.bcn.org.au > News > Resources > Research reports.

BCNA will continue its work to improve breast reconstruction services for women and will report back to you in 2011 via our website and The Beacon.
Not all plain sailing

I was diagnosed with breast cancer when I was 32. I wanted to have the reconstruction at the same time as the mastectomy but my surgeon said it was better to wait.

For the next 12 months I walked around with one E-cup breast and the biggest prosthesis I could get! I read anything I could get my hands on about reconstruction, consulted two plastic surgeons and decided on the TRAM Flap reconstruction method. I felt totally prepared. What I didn’t expect was that something may go wrong.

Initially it went well and looked great; a flat tummy and a perfectly shaped breast. However, after being released from hospital, despite a fever, part of the wound on the breast was black and I knew something wasn’t right.

The surgeon said part of the flap had died and was infected and I went straight back to theatre for surgical debridement. I was left with a gaping hole, had to have a skin graft, and dress the wound three times a day for the two months and take antibiotics.

I have a defect in the reconstructed breast (which my surgeon says can be repaired), and still need to have the left breast reduced. I know I will be happy with the end result compared with the concave scar left from the mastectomy.

Full recovery was about eight weeks and it was definitely painful for the first three, but you soon forget that!

Kirsty, QLD

Waiting game

I was 30 when I found a lump in my left breast. The youngest of my four children was four months old, and as I was breastfeeding him I assumed that had something to do with it.

My husband and I went off to see the doctor and, to my surprise, I was told I had cancer.

I had a left breast mastectomy, and going through the public hospital system, was told I would be put on a waiting list to have a reconstruction.

There was no doubt in my mind, even at that time, that I wanted to rebuild my breast to something that I was comfortable with.

I went a long while with only one breast, and although I lived with it I never felt very confident about myself. During that time it was found I had the BRAC2 gene mutation, and I was told the chances of the cancer occurring in my remaining breast were high, so I decided to have my right breast removed and reconstructed.

I was on the waiting list for 2½ years. I had a TRAM Flap procedure and used my stretched stomach (having four children helped me with that!) to make my new breasts.

It has been six months since my reconstruction and I am so happy with the result. Although it was sore for a while, the results are wonderful and it is fantastic to have a flat stomach again!

Using my own tissue has made my breasts feel just like my old ones, only with a few added scars. I am a week away from the final stage of having my nipples done, and then tattooed, and hopefully this will be the last time I need to be in hospital for a very long time!

Kylie, QLD

Making the most of it!

In September 2005 I was diagnosed with early breast cancer and underwent a partial mastectomy, chemotherapy, radiotherapy and hormone therapy.

Two years later I had a full right mastectomy when a routine mammogram showed the cancer had returned. I was left with an ugly scar because my previously irradiated skin did not heal well. I decided to have a breast reconstruction because I found the 600g prosthesis awkward and heavy and it constantly reminded me of my cancer.

My surgeon performed a free TRAM flap reconstruction of my right breast, and a left breast reduction and nipple tattoo.

I chose a free TRAM flap operation because it would give me the most natural result as well as a ‘tummy tuck’ that would reduce the apron of flesh left after a caesarean section some 32 years ago.

I told the surgeon I didn’t care what size breast he made, as after having F cup breasts I would be happy to have a reduction of the other breast.

I found the pain after surgery was tolerable and I only needed paracetamol on the first day.

The most uncomfortable thing was having to be in a room heated to 28°C for 24 hours to help the circulation to my new breast.

I am delighted with the results and would recommend it to anyone wondering if it is worthwhile. I now swim with my granddaughter without worrying about my prosthesis floating away!

Andrea, SA

Kirsty and her partner.
Ask the Expert

Dr Kerry Sherman

Dr Kerry Sherman is a researcher and senior lecturer in health psychology at Macquarie University, Sydney. Her research focuses on the emotional wellbeing of women with breast cancer and developing information and resources to help them. She is currently developing a decision aid to help women who are considering breast reconstruction following a breast cancer diagnosis.

How important is body image to a woman’s self-esteem and emotional wellbeing?

For most Australian women there is a strong emphasis on physical appearance. Research shows that our perception of ourselves – our body image – is critical to how we feel about ourselves. It tends to be more important to us than our other attributes or skills.

What can be the psychological benefits of breast reconstruction?

Some of the benefits include enhanced body image and increased quality of life. Research shows that women who have a reconstruction often feel better about themselves because they feel they have an appearance that is not so different to how they looked before breast cancer.

Does timing make a difference – immediate v delayed?

Our research does not suggest that the timing of reconstruction surgery makes any difference to women’s emotional wellbeing.

The more important issue is the timing of making a decision about reconstruction. For an immediate reconstruction, a woman may have only one or two weeks from diagnosis to breast cancer surgery – that is a short time in which to make a big decision. If women are not well informed at the outset, they may not make the decision that is best for them and may be less likely to be happy with the outcome.

What advice do you have for women trying to make a decision?

My advice is to be well informed about the full range of options available to you. Do not rely on a 20-minute consultation with the surgeon for all your information and do not make your decision too quickly. Consider all the options and the possible side effects or complications that could arise from each of them. Are you prepared to live with these? It is really important to understand what the outcome of any surgery might be, so talk to the surgeon about different types of reconstructions and ask to see photos. It is also important that whatever decision you make is made for yourself – do not make it for anyone else. You have to live with that decision. Talk to as many people as you can, but make the decision that you think is best for you.

Some women are physically unable to have a reconstruction. What can these women do to help their emotional wellbeing?

Speaking as a psychologist, I would strongly advise any woman who is not feeling good about herself, or who is feeling distressed, to seek some professional help. A psychologist can help you develop skills to manage your feelings and change the way you feel about yourself, including accepting the changes to your body.

Do women who decide not to have a reconstruction always adjust well?

The way any woman with breast cancer adjusts to her treatment will depend on a number of aspects, including whether she is satisfied with the decision she made about reconstruction and her ability to accept her new body in the way it looks and feels. Any woman having trouble accepting the changes to her body may like to seek support from a counsellor or psychologist.

Comfortable in my skin

A breast cancer diagnosis in 2006 meant a mastectomy. I discussed a reconstruction with my wonderful breast care nurse and my female surgeon, but decided against it as I was 60, had been separated for many years and had no special man in my life at the time. Importantly, I was comfortable in my skin and did not need to do it for myself.

Four years on I do not regret my decision. In the early days I twice forgot my prosthesis when going to work – the first time I stuffed my bra with tissues and the second time I went back to retrieve it.

I am content with myself and have had relationships with caring and considerate men (my choice not to continue the first and the second is still going well). The lack of a lump of fatty tissue does not seem to be a problem at all. They accept me, as I accept me.

I have been given the flexibility to have a reconstruction should I decide I want one, but so far I have no intention of going down that road.

Wendy, WA
Second time round

I was first diagnosed with breast cancer in 1995 while pregnant; therefore reconstruction at the time of the mastectomy was not an option. Instead I had a reconstruction five years later. As it was classed as elective surgery, I had to go on a public system waiting list for a TRAM flap reconstruction with donor tissue and skin from my abdomen. The experience was horrible, I felt like Frankenstein’s monster, the outcome was not much better and the aftercare was terrible – as was the finished product. My second breast cancer was this year, but this time I had a skin-saving mastectomy and reconstruction at the same time. The doctors were marvellous, more compassionate and seemed to care more than last time (a different hospital this time). The final result has been fantastic – there are plans in the future for further fine tuning, i.e. nipples and areolas tattooed on. The only negative thing about this reconstruction was that the donor site was my bottom – I couldn’t sit up for a month, although I was able to recline, and walking was pretty difficult. Now three months later, there is no pain except for an occasional dull ache in the new breast. I am walking fine and am in a much better frame of mind due to the aftercare the doctors have given. It took a second time round to get the result and compassion I had hoped for the first time, but I am still here to tell the tale and that is the most important thing. 

Debbie, VIC

Taking time to make my decision

I was told that I had cancer a week before my 46th birthday. I went on to have bilateral mastectomies (exercising my choice to have both removed at the same time) and chemotherapy. At that time I did not want to have a reconstruction; in fact, it was something that I said I would never do. I just wanted to get fit and healthy again, get my life back to what it was, and, as I was only just an A cup, I didn’t feel that I had too much to lose. Also, I am a theatre nurse and I did not want to undergo, what was to me, major surgery just for a figure. For the next year I didn’t wear prostheses. I bought clothes that hid my flatness. I was just happy to be well. I then decided to get fitted for a pair of prostheses. Suddenly I looked great, but unfortunately I found them hot and uncomfortable to wear. Two years after my mastectomies, I decided to have a reconstruction; a bilateral latissimus dorsi with tissue expanders. I have now completed all the surgery and had the permanent implants inserted. I feel that I look just fabulous, and it has given me an incredible sense of wellbeing. They are beautiful breasts! Both surgeries for this procedure were uneventful. The only negative aspect I can think of is having to wear a crop top for a few weeks. Having the tissue expanders in for about three months gave me an opportunity to ‘test drive’ the size. At first I felt too busty, but this gave me time to adjust to having a figure. As a result, I feel totally comfortable with the choice of permanent implants. I have a figure that I feel is perfect for me; it’s a great novelty having breasts!

Alison, WA

Turning around

I had a TRAM Flap bilateral reconstruction done in November 2008. It has meant a great deal to me. I became depressed when trying to cope with using a prosthetic breast, and these feelings were almost too much to bear. So I began doing some research on the internet starting with the Aussie Breast Cancer Forum and then other more formal medical internet sites. Armed with this information, I went to my half-yearly appointment with my breast surgeon and told him that I was looking into TRAM flap reconstructive surgery. He immediately recommended a surgeon in Sydney. This surgery, although difficult, painful and expensive, was the best thing that I could have done for myself. My self-esteem has improved dramatically; I have my cleavage back! I’ve recently had the nipples done and now, instead of having the areolas tattooed on, I’m thinking about getting roses tattooed over my breasts (to give the aged care nurses a laugh when I’m 90)!

Annie, ACT
The waiting game …
reconstruction in the public system

I was put on the waiting list for reconstruction but was told it was likely to be a five-year wait, even though I am only 23.
– BCNA survey participant

The prospect of long public hospital waiting lists for reconstruction surgery is distressing for some women who undergo breast cancer surgery, especially those who cannot afford to pay for surgery.

In recent years, the federal and some state/territory governments have allocated additional funding to help reduce waiting lists. Some public hospitals have also introduced their own initiatives.

The Beacon recently contacted three public hospitals to ask what they do. We know there are others around the country that offer similar services.

In Melbourne, the Western Hospital has a specialist reconstructive surgeon, Mr Damien Grinsell, who attends outpatient clinics fortnightly for consultation for delayed reconstruction. Other times are available for women requiring advice on immediate reconstruction. Consultation with a Breast Care Nurse is also available, where women can view photos, tissue expanders and breast implants, and discuss any concerns.

Nipple reconstructions and tattooing are also offered, with no charge to women.

Hunter New England Health in northern NSW was able to launch a breast reconstruction service earlier this year after a plastic surgeon moved into the area and agreed to carry out publicly funded reconstructions one day per month. This gives women an option to have their reconstruction at a local public hospital rather than travelling to Sydney. Depending on the hospital, waiting times are currently around 12 months.

In Adelaide, the Flinders Medical Centre (FMC) has run a comprehensive breast reconstruction service since 2007. FMC employs a full-time plastic surgeon, Dr Nicola Dean.

The appointment of a full-time breast reconstruction surgeon has had a remarkable impact. In her first full year there, Dr Dean performed 72 breast reconstructions. Previously, the hospital provided 10-15 reconstructions each year.

It has also helped to keep waiting times down. The current waiting time for a delayed reconstruction at FMC is 3-6 months.

‘Most reconstructions are a three-stage process – reconstruction surgery, surgery to make any adjustments, and then nipple reconstruction and/or tattooing.’ Dr Dean told The Beacon recently. ‘My aim is to have this process completed within 12 to 18 months.’

Dr Dean also runs a nipple tattoo clinic once a month.

‘I am a firm believer in trying to offer a comprehensive service,’ she said. ‘I like to make sure I see women through the whole process of reconstruction.’

The services provided by Western Hospital, Hunter New England Health and Flinders Medical Centre give an indication of what can be achieved in the public health system when there is a willingness to improve reconstruction services for women affected by breast cancer.

Certainly, the appointment of a full-time plastic surgeon dedicated to breast reconstruction appears to make a big difference to surgery rates and waiting times. Dr Dean acknowledges that hospitals need to provide a supportive environment, including regular access to operating theatres, in order for a good reconstruction service to be run.

BCNA hopes more hospitals will take on the challenge to improve breast reconstruction services for women, and that more plastic surgeons will follow the lead of Dr Dean and others into the public hospital system.
Time heals all wounds

I live in Geraldton in the middle of Western Australia, approximately 430 km from Perth. I was diagnosed with breast cancer in my right breast in December 2008 and following two lumpectomies decided to forgo radiation treatment and instead have a mastectomy.

Part of that decision was arrived at because radiation treatment is only available in Perth and I would have had to leave my young children and husband for six weeks to access it.

I was lucky enough to be in a financial situation to consider a breast reconstruction with a plastic surgeon in a private hospital. I didn’t realise how lucky I really was, until I met someone who had to wait two years in the public system – that’s just cruel. I never considered not having a reconstruction. At 42 I felt that I was still on the young side and deserved to have breasts.

The mastectomy was a success and I woke up with much smaller breasts (the left breast had been reduced). After a lifetime of being big busted I was absolutely delighted!

The first part of my reconstruction was the insertion of an expander. Over the next eight weeks I travelled to Perth weekly to have the expander inflated. The money tree had dried up by then so I was grateful for the financial support of the Patient Assisted Travel Scheme (PATS). In fact my whole treatment would not have been possible without PATS. Having to travel to Perth so regularly became a little bit of an ordeal but I got through it by reminding myself that the worst was actually over and the cancer had been removed.

Three months after having the expander inserted, I was back into hospital to have the expander out and the implant inserted. I actually found this operation to be harder than the mastectomy and took longer than I expected to recover.

Unfortunately I got quite a severe infection following this procedure and needed to go back to hospital. The infection cleared up but the nipple needed to be redone. Nothing is simple with me!

All this time I was travelling up and down from Geraldton like a yoyo and having time off from work! Thank goodness for a sympathetic boss!

One of the hardest things about the reconstruction was the drains after the surgeries. After all my surgeries I went home from hospital still attached to drain bottles. I frequently ended up with painful infections.

Despite everything I am really pleased with the final product. It is sad that I can’t feel touch in those areas anymore and they can also be quite uncomfortable at nights. However, the alternatives just didn’t appeal to me and, as I said before, time heals all wounds. My advice to anyone considering a reconstruction is to make sure you are comfortable with your plastic surgeon as you are going to be seeing a lot of him or her!

Suzannah, WA
A long journey

My breast cancer journey began in August 2005. After diagnosis I had a left breast mastectomy, followed by chemotherapy and radiotherapy.

Along with this, I was given a lot of information about breast reconstruction. I liked the idea; it helped going through all the treatment knowing that one day I would have a reconstruction. I read all I could, spoke to women who had had the different sorts of treatment, and waited until I was mentally ready for the operation. Sometimes I did consider not having it at all, but by the end of 2008 I was ready.

I discussed the reconstruction I would have with my surgeon – a tissue flap from the back followed by a reduction of my right breast.

On the day of the operation I was nervous but excited. However, when I woke from the operation, I was told reconstruction was not possible. I do not know who was more devastated, me or the surgeon.

I had been warned of possible internal scarring from the radiotherapy; I did not have any scarring, but the radiation had badly damaged the main artery needed to supply blood to the reconstructed breast.

The surgeon tried her best to see if another artery could be used, but it wasn't possible. She did insert a tissue expander, but after months of injecting saline solution to expand the skin, this option also had to be abandoned as the radiotherapy had damaged the skin's elasticity.

Along the journey, I met a family of big-breasted women. My grandmother lost one breast at 54 and the second at 84 and she hated not having her breasts. After her first mastectomy her body looked like she had been mutilated. Those were the days of the radical surgery – but she survived. Her first prosthesis was a bag of birdseed she made herself, and she was always worried that if she perspired excessively she would begin to sprout! She also hated the lopsided feeling as we are a family of big-breasted women.

From that day on she advised me to take care of my breasts, so after a lumpectomy in 1993, a partial mastectomy in November 2007 and a bilateral mastectomy in April 2008 I was already thinking that a reconstruction at the same time as the surgical removal of my breasts was the answer for me.

Medical advice was given freely, most of it with caution as it was to be a massive operation. My husband felt I should not take such a drastic step but was with me all the way, with love and support, once he realised that this was the path I had chosen.

I researched information, read all the pros and cons but still decided to go ahead.

Unfortunately I did have lots of problems; a massive haemorrhage after a 1½ hour op, back to surgery for another 4½ hours to reconstruct the vein that had not held – put down to the six weeks radiation that I had 16 years before as this can leave the tissue and skin very fragile. The amazing medical team removed a vein from my foot and skillfully replaced the damaged vein and put me back together again. There was concern that I could lose that breast, but the skill of the surgeons did not let that happen.

I was in hospital for 23 days, much longer than was initially thought necessary, and it was a long and painful recovery. What helped me through this was a loving family, amazing care and the nursing staff telling me what wonderful cleavage I had.

At a later date the surgeon wanted to give me nipples but I did not go back. I hear it is a relatively simple operation and they look great but as I am no longer at an age where I would consider entering wet T-shirt competitions, I can live happily without them.

It was tough, but I came home feeling and looking as I did when I entered that hospital, and I can honestly say that it was the best decision that I have ever made.

With love and support

Jacqui, SA

Six months after that first operation, I went back to hospital to have the expander removed and my right breast reduced. It has been a long recovery, physically and mentally. The physical side of it I could deal with, but the mental anguish has been difficult, and something that will take time to accept.

While going through breast cancer, there is a wealth of information and support from the community, family and friends, which is wonderful, but there is no support or information for those of us when a reconstruction is not possible. I have felt so alone in dealing with it.

I have just passed my five-year milestone, so there is much to celebrate, but I do wonder if there are more women out there like me for whom reconstruction was not possible.

Jacqui, SA

With love and support

Jacqui and her husband Kevin celebrate their 20th wedding anniversary at Uluru.

Lynn, VIC
The Young Women’s Breast Cancer Support Group is an informal social group that has been running in the Geelong area since November 2007 for women under 50 diagnosed with breast cancer. Like many groups it was started by one woman’s need to connect with others who could understand what she was going through. That woman was Tammy McDonald and here is her story.

At the age of 32, while pregnant with my third child, I was diagnosed with breast cancer. Although my friends and family were amazingly supportive, I felt the need to connect with others. I contacted the local support group and attended one of their meetings. I sat in the meeting room with my premature baby in my arms and a scarf on my bald head. I was easily the youngest by 20 or 30 years. The group had a guest speaker who spoke about osteoporosis prevention. It was obvious to me that, even though we shared an illness, our need for support and information was different.

I knew I had to find a group specifically for younger women – but none existed in the Geelong area. Melbourne offered what I needed, but the task of travelling to Melbourne at night while having chemo and radiation was much too hard.

As it turned out I wasn’t the only one living in the Geelong area who wished to connect with other young women. In the beginning there were only a few of us but the group has grown over the past three years. We have all benefited from each other’s knowledge, experience, friendship and, most of all, support.

One of our members recently underwent a prophylactic bilateral mastectomy and implant reconstruction and was asked by her employer if she was prepared to talk to a friend who was trying to decide what type of reconstruction to have. During our next group meeting, when the woman’s dilemma was brought up, we realised that as a group we had a ‘smorgasbord of boob jobs’ and that our experiences could help.

A ‘Show and Tell’ session was decided upon as a light-hearted and humorous way to help her. Our usual hotel location clearly wasn’t suitable for such an occasion, so we arranged to meet at one of our homes. The night started quite formally with introductions and chit chat while everyone arrived. The awkwardness soon disappeared as a member took it upon herself to stand up and say ‘this is what we’re here for’ and lifted up her top. A chain reaction followed and within minutes we all had our tops up, showing our reconstructions. Lots of laughter and relaxed conversation followed. By the end of the night, armed with the experiences of our group, the woman had changed her mind about the type of reconstruction she felt was right for her.

By connecting with others who had been through this process, this woman felt able to make an informed decision. That is what our group is about.
2010 was a bumper year for Mini-Fields around Australia. The magic started in October and more than 300 Pink Lady displays coloured the landscape across every state and territory to celebrate Australia’s Breast Cancer Month.

Once again the Mini-Fields were a wonderful way for communities to come together to pay tribute to women and families who have been affected by breast cancer.

The events were as diverse as the communities they represented. The variety was wonderful – from the month-long display at the Floriade Festival in Canberra to the 20 silhouettes in a private garden during a special morning tea. There were gatherings in gardens and morning teas in workplaces, displays at roundabouts in country towns and municipal libraries, champagne corks were popping, beetroot sandwiches and pink cupcakes were set out on pink tablecloths. From a gathering at a picture theatre to drifts of silhouettes across local gardens – the diversity was inspiring and each paid tribute to women with breast cancer.

An important element of the Mini-Field event is the acknowledgement of support that is available locally – many of our Member Groups took the opportunity to let locals know how their groups support women.

‘The local hospital was an ideal location for our Mini-Field – we will be doing it there again next year.’ – Judith

‘We had a wonderful day and the best part of it was that we now have three new ladies in our support group.’ – Zoe

Thank you to all the 2010 coordinators and their supporters who spurred their communities into action to spread the word with great enthusiasm – without your work the magic would not have happened. Providing opportunities for communities to come together with a shared focus leads to laughter, quiet contemplation, meeting new friends and most importantly further opportunities to provide support for women and their families. It is a vital way that we can reach out and help community members affected by breast cancer. A Mini-Field in a local community results in dynamic and personal connections that can transform women’s lives. The commitment of organisers is a precious resource.

‘Thank you for asking me to share such a beautiful day.’ – Mary
‘The women really enjoyed the day and got a lot out of it.’
– Debbie

Thank you to the **Community Liaisons** who added to the impact of **Mini-Fields** by sharing their personal breast cancer stories and making inspirational addresses.

The **Mini-Field** events are enhanced by the support of our valuable partners.

We acknowledge especially the wonderful support of our partners **Bakers Delight** and all the bakeries around Australia who baked delicious morning and afternoon teas, and **Australia Post**, the sponsor of **Mini-Field of Women** events.
Thank you

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

- Andrew Price, NSW
- Barbara Epstein – Pink Ladies Christmas Golf Day, Thirteenth Beach, VIC
- Barbara Richards, VIC
- Bella Blight, VIC
- Beverley Milligan, QLD
- Blackmores Sydney Running Festival participants & donors, NSW
- Calder Park Raceway, VIC
- Corrine Patch, QLD
- David Munroe – West Wallsend High School, NSW
- Deb & Pearl’s Pink Party, VIC
- Dianne Kennedy, VIC
- Dixie-Lee Collits, SA
- Ellen Hepworth – Think Pink Maida Vale Primary School, WA
- Essendon Ladies’ Hockey Club, VIC
- Estate of Paul Burgess, VIC
- Floriade, Kerrie Griffin, ACT
- G-Force Recruitment, VIC
- Gail Wing-Tang, VIC
- Gail Gear – Morisset Ladies’ Golf Club Ladies’ Day, NSW
- Green Acres Golf Club, VIC
- Jade Ryan, QLD
- Janet Hoyer, NSW
- Janelle Trebbin, QLD
- Jane Howard, VIC
- Jarrad Holmes, WA
- Jason Henderson, NSW
- Jenny Horn, QLD
- Johanna McCall, VIC
- Judy Dallas, TAS
- Julie Pegg, QLD
- Kerry Palmer, VIC
- Laurieton Haven Craft, NSW
- Linda Collins, VIC
- Lisa Seward, VIC
- Lisa Turner, VIC
- Lynn Brewster, VIC
- Madeline Paske, TAS
- Margaret Browne, NSW
- Margaret McKenzie, QLD
- Mary Crickett – A Voice for Pink, Fundraising Dinner & Opera, VIC
- Michell Stewart, NSW
- National Council of Jewish Women of Australia
- Nikki Henderson – Tickled Pink Breast Cancer Charity Ball, VIC
- Patricia Houston – Lawson Mixed Bowling Day, NSW
- Patties Foods Ltd
- Ross Cardinal, TAS
- St Columba’s Essendon, VIC
- Stazy Give & Getaway
- Susan Group
- Tesselaa’s Tulip Festival, VIC
- Tony Hamilton, VIC

Memorials
We pay tribute to the lives of:

- Anne Templar
- Annetta Zanon
- Brian Ponting
- Darcy Brady
- Fay Trickey
- Jean Chamberlain
- Jean-Marie Vivian D’Avoine
- Julie Ann Lyon-Theodotou
- Linda Nadort
- Marie Polla-Mounter
- Mavis Taylor
- Patricia Kregor
- Roland Jecis
- Sue Deans
- Vera Kostovski

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

- Aloysius Moses
- Lyn Hunter
- Melissa Strudwick
- Michelle Marriott
- Rob Daniel
- Simone Miles
- Vivien Kainer

Shane Crawford stops to thank The Hills Breast Cancer Support Group on his journey from Adelaide to Melbourne. We thank all the communities and corporate supporters from around Australia.

Young women’s conference

The 2nd National Conference for Young Women affected by Breast Cancer was held on the Gold Coast in early September. Around 150 young women attended from across the country to meet and share their experiences with other women and to hear from guest speakers about strategies to manage issues affecting them.

Topics included the latest treatments for young women, sexual wellbeing, exercise, lymphoedema, managing the side effects of treatment, getting involved in the breast cancer community and dealing with financial issues.

Other sessions included a Look Good Feel Better workshop, ‘pink’ pilates and a conference dinner where participants were able to get together, have some fun and dance the night away.

BCNA was very pleased to support this conference.


Ovarian Cancer Australia has launched a new-look website at www.ovariancancer.net.au. For further information, phone 1300 660 334.
Reviews

Reading by Moonlight by Brenda Walker, Penguin 2010, RRP $29.95

The idea of a book that talked about how reading had helped the author (a professor of English literature in Western Australia) to get through her breast cancer experiences from diagnosis to survivorship, was intriguing (particularly as during the same process I had lost all ability to read for pleasure).

While reading this book, I reached the 12-month mark after my post-bilateral mastectomy, associated chemotherapy and abrupt transition from pre-menopausal to complete oestrogen deprivation and was recovering from multiple other surgeries and investigations as a result of the diagnosis of a rare multiple cancer gene. I discovered in reading this book what is no doubt obvious to many – how a book affects you is the result of your previous experiences, where you are currently at mentally and physically, and what hopes and expectations you carry.

Depression surrounding re-staging and recalling my own experiences as I read this made it both compelling but occasionally distressing – provoking memories of fear, hurt and the inevitable passing unkindnesses experienced.

I found it frustrating that initially some profound issues were only lightly touched on – guilt, shame, fear for children, crippling anxiety mixed with emotional paralysis. However, greater detail of her experiences is covered later in the book. The bulk of the narrative is taken up with descriptions of plot and characters from the books that Ms Walker felt reflected these experiences or helped her deal with them, interspersed with reflections from her previous life experiences growing up, working and travelling.

The direct connection between her experiences and the literary works is not always obvious and the works chosen are not necessarily easily accessible to the reader as a result of their style and complexity. Some may find stories such as Samuel Beckett’s Malone Dies or the tales of Edgar Allan Poe hard going.

Ms Walker’s writing style is engaging and a pleasure to read and as each section unfolds it is easy to relate to her emotional and physical journey: the relief to be alive but the feeling of having been unjustly punished, the ongoing shock of having willingly submitted oneself to physical and chemical mutilation, the abruptly menopausal sleep-deprived body and the surprising words of comfort from the unexpected.

Ms Walker has chosen somewhat dark authors who write about ‘the fluctuations of emotional survival’ and whose characters range from the horrific to the pitiable, to help her explore and make sense of the darker emotional path of cancer survival. In this way she reminds herself and the reader of the truth of her experiences and the reality of survival.

Bits of this are great and other bits are hard going for reasons, but if you are at all a reader this is worth tackling.

Reviewed by Amanda Woodward

Breast Cancer: Taking Control

Breast Cancer: Taking Control is a resource to assist patients and caregivers in making informed choices and find a path to recovery.

The author, Professor John Boyages, MD, PhD, is an oncologist and founding director of the Westmead Breast Cancer Institute in Sydney.

This book is the culmination of research, peer and patient reviews. It also includes case studies and 20 key ‘control points’ that are important decisions you need to make on your path to survival. Each section is colour coded for easy reference: red (at diagnosis); orange (before treatment starts); and green (after surgery).

BCNA member Sue Timbs said ‘I found the book to be excellent. It is easy to read, well thought through in its approach and structure and very easy to understand. The tone is very good. John’s ability to explain different parts of the journey is outstanding.’

Until 31 December (while stocks last), BCNA members will pay $34.99 and receive free postage and handling worth $13.20 and an additional $5.00 discount off the recommended retail price.

To order, go to www.breastcancertakingcontrol.com/BCNA.

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

23 January 2011: One-day seminar, Meditation, Meaning and the Mind, presented by Petrea King, Quest for Life. Augustine Centre, 2 Minona St, Hawthorn, Melbourne. For further information or to register go to www.questforlife.com.au


28 April – 18 May 2011: Bakers Delight and BCNA Pink Bun Campaign. Visit your local bakery to show your support.

10-12 November 2011: 16th Reach to Recovery International Breast Cancer Conference, Taipei, Taiwan. For further information go to www.reachtorecoveryinternational.org

Pink Lady around the world

Right: Daniel Deason with the Pink Lady at Mt Kilimanjaro.

Below: Australian Youth Ambassador Bridey Kerwick was inspired to hold a Mini-Field of Women in Kenya. She hopes the event will help start the conversation about breast cancer in Kenya.

The printing of The Beacon is kindly supported by Vega Press

Seeking Stories

We are seeking stories for the Winter 2011 issue of The Beacon on the topic of emotional wellbeing.

Did you struggle with anxiety, depression or feelings of low self-esteem? Who or what helped you in your recovery? How have you come to terms with the ‘new you’? Perhaps breast cancer prompted you to reassess your life, try new things or fulfil a lifelong dream. What advice do you have for women still adjusting to their diagnosis?

Please email articles of 200-300 words (about half a page) to beacon@bcna.org.au by the end of March 2011. We ask you to also include a high-resolution digital photo, or post your photo to us and we will scan and return it to you.

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