Everyday decisions and choices

As this edition of *The Beacon* goes to print much of Australia is experiencing a very hot summer. The side effects of treatments can make it even harder to be comfortable on those days. Being comfortable and looked after is a simple practical issue that takes on new meaning when going through cancer treatment and then getting on with our lives.

In this issue, you’ll hear from some of our members who have shared their reflections and advice on the everyday practical decisions and choices they make.

Understanding the issues that affect you, our members, informs what we do at BCNA. A survey of our members conducted in August last year has given us insights that will inform our strategic priorities over the next three years. The top five challenges experienced by those who responded to the survey will be familiar to many of you. They were ongoing wellbeing, emotional health, managing side effects of treatment, impact on family and friends, and financial pressure. Many of these factors overlap and intersect with each other and can magnify the overall impact of the particular challenge.

Raising awareness of the experience and challenges faced by Australians affected by a breast cancer diagnosis is one of the reasons why the Field of Women is such a powerful event. I attended the last Field of Women in 2010. At the time I was a Victorian Government Minister, invited to attend as an ambassador. Little did I know that I would be diagnosed with breast cancer myself the following year. For those of you who have never attended this event, I can promise you that standing shoulder to shoulder with thousands of other people who have been affected by breast cancer is an extremely powerful experience. So please start planning to come!

May is going to be a busy month for BCNA because along with the Field of Women, the Pink Bun campaign and Pink Sports Day events will be in full swing. If you are not able to come to Melbourne for the Field of Women there will hopefully be a Bakers Delight bakery or a footy, netball, hockey, golf or even a pony club event on in your community that you can support. It will be huge!

Maxine Morand
Chief Executive Officer
Join us on the Field of Women!

Saturday 10 May 2014, MCG, Melbourne

We are thrilled that the AFL has agreed for us to hold the Field of Women this year in Melbourne! We know many of you were disappointed, as we all were, when we had to reschedule the event last year.

The event will be held before the Melbourne v Western Bulldogs game in the evening.

We hope that you will be able to join us and stand alongside others who understand what it means to have had a diagnosis, to support a loved one along the journey, or to lose someone special to the disease.

Our aim is to have 15,000 people stand together in the shape of our Pink Lady to help us raise awareness of breast cancer and reinforce the message that people affected by breast cancer are not alone.

Everyone is encouraged to participate – partners, supporters, friends, survivors – you don’t have to have had breast cancer to take part.

Staying up to date with Field of Women news is easy! Simply visit our website www.bcna.org.au, like us on Facebook or follow us on Twitter.

Tickets are on sale now

As a BCNA member and supporter, you can purchase your ticket to the Field of Women now before they go on sale to the general public in April. We encourage you to get in early and secure your ticket to avoid disappointment, and to spread the news through your networks.

Tickets are $55 each (inc. GST) and include:
- a photo of the aerial shot to ensure you never forget!
- free admission to the footy match
- a poncho and backpack
- an opportunity to be part of this extraordinary ceremony.

All proceeds from ticket sales will go to our programs and services.

For more information and to purchase tickets, please visit www.bcna.org.au.
Insights into the wants and needs of our members

In August last year we surveyed a cross-section of our membership to find out what challenges they faced as a result of their breast cancer diagnosis, and what they think about the work that BCNA does.

Thank you to everyone who participated. Your feedback is greatly appreciated.

The results of the survey helped us develop our strategic priorities, and will continue to inform our day-to-day work.

We received completed surveys from 1,326 members – 86% who had been diagnosed with early breast cancer and 14% who are living with secondary breast cancer.

Of the people who responded, 35% were diagnosed less than two years ago and 39% two to five years ago. People from across Australia responded, with 54% from a major city, and 45% from regional, rural or remote areas. The majority (87%) were aged 45–74 years.

Responses highlighted that many of you highly value the work BCNA does, which was great news.

We also invited members to rate various challenges that had affected them since their diagnosis.

The top five challenges that members said affected them ‘a lot’ or ‘quite a bit’ were:

- ongoing wellbeing 59% (780 members)
- emotional health 56% (749 members)
- managing side effects 52% (686 members)
- impact on family and friends 45% (593 members)
- financial pressure 41% (541 members).

So many survivors suffer debilitating side effects from treatment.

Younger women (under 55 years) were more concerned about ongoing wellbeing (74%) and emotional health (68%) than those over 55 years (57% and 55%). Women diagnosed less than two years ago were more concerned about their ongoing wellbeing (70%). A higher proportion of women with secondary breast cancer were concerned about their emotional wellbeing (69%) compared to those with early breast cancer (59%).

Ongoing emotional support. Some days I feel more anxious and less confident about my future than I did when I was diagnosed three years ago. And most people think you should be over it now and should just get on with things.

Women with secondary breast cancer were also more likely to have unmet information needs than those with early breast cancer.

Issues that members said they would like more information on were physical activity and healthy eating, sexual wellbeing and information for employers when returning to work. Managing the side effects of hormone treatment was also consistently raised as an important issue.

The side effects of oestrogen-suppressing drugs like Arimidex which … [can] cause patients to agonise over whether it is really worth sticking to the five-year prescription.

We also asked members if there were any specific issues that they would like BCNA to advocate for on their behalf (641 members). The most significant advocacy issue was the financial cost of treatment (37%, 240 members), which was raised by people with private health cover and people using the public system.

The appalling cost of the whole program of treatment, surgery and reconstruction for women with private health cover.

Not everyone is privately covered and the cost is debilitating for some women.

We also asked members to comment on the information and support that BCNA provides. You can find a summary of these results on our website. Visit www.bcna.org.au > News > Latest news and media releases, or phone us and we will post a copy to you.
Managing work during treatment and recovery

Decisions about how to manage your paid work during treatment and recovery can add to the stress of breast cancer.

Dr Carrie Lethborg is the Clinical Leader, Cancer Social Work and Coordinator Psychosocial Cancer Research, at St Vincent’s Hospital, Melbourne. Carrie spoke to The Beacon about work-related issues when you’ve been diagnosed with breast cancer.

What do women need to consider when making decisions about work?

From an emotional wellbeing point of view, it is important to acknowledge the trauma involved with a breast cancer diagnosis. For most women it is an experience that shakes them up. We need to be gentle with ourselves during and after such a trauma.

If you need to keep working, be aware that you may feel more anxious, tired, forgetful and sensitive to others’ comments, and more easily overwhelmed by work, than you did previously.

Some women find that work helps them to keep a sense of control in their lives; for others it is the last thing they feel like doing. Of course, there are times when it is not possible to work because of appointments and side effects of treatment, including fatigue.

What difficulties may women face when working during treatment?

Aside from managing the physical response to treatment and trauma, there are some common social issues for women who work during treatment. These include:

• who to tell
• what to tell
• deciding if you want to talk about your cancer at work
• managing your reaction when workmates are overly concerned or, conversely, don’t seem to acknowledge your diagnosis.

In many ways, your personality at work before diagnosis will shape the way you decide to manage things. Some women have very close relationships with their workmates and get a lot of support from them during their treatment; others prefer to keep their private life separate from work. While it is important to stay true to yourself, keeping something as big as having cancer treatment a secret can take a lot of energy that may be better used for self-care.

What are some strategies that can help women?

People often don’t know what to say when they find out a workmate has cancer. Give them some direction on how you want to be treated at work. This might be by sending an email stating that this has happened, what you expect in terms of treatment and that you are open to questions and hugs, or that you value their concern but would rather not talk about it at work. You could also ask your manager to talk to your colleagues for you.

What are some strategies for women returning to work following treatment?

Talk though your fears or concerns with someone else before returning to work. Consider how you will respond to comments and questions such as ‘How are you now?’; ‘You look great!’; ‘Is the cancer all gone?’; ‘We’ve been really busy without you’. Having some planned responses can help you feel less anxious.

It is also important to pace yourself, even if you feel pressure from others to ‘get back to normal’ in terms of what you could manage before your treatment. Energy, concentration and confidence come back in time, but pushing yourself beyond your capacity will only increase anxiety and reduce self-confidence.

Where can women go for help?

Cancer social workers, psychologists and breast care nurses, as well as family, friends and other women who have been through similar experiences, are helpful to talk though your feelings about your breast cancer experience and direction for the future. The traumatic nature of such a life-changing experience is often underestimated. I would like all women to be offered the chance to debrief, recuperate and think through this impact following their treatment.

Cancer Council NSW has information on cancer and work at www.cancercouncil.com.au > Get support > Employers and workplaces > Resources for employees.

BCNA’s booklet Helping a friend or colleague with breast cancer provides advice about how friends and colleagues can provide support. You can download a copy from www.bcna.org.au > New Diagnosis > Helping a friend or colleague with breast cancer, or phone BCNA on 1800 500 258 to order a copy.
BCNA’s partnership with the Sussan Group began in 2006. Thanks to the generosity of Sussan and its customers, over $1 million has been raised to support BCNA programs and services.

Robyn Batson is the Group People & Development Manager at the Sussan Group. Robyn spoke to The Beacon about women with breast cancer in the workplace.

What is your experience working with women with breast cancer?
The Sussan business has proudly supported BCNA for the past nine years. This close partnership has helped us support our team members who have been affected by breast cancer. We have been able to connect our people with BCNA when they need support for themselves, family members or friends.

What should women tell their employer when they are diagnosed with breast cancer?
It may be difficult in the early days to know exactly what sort of flexibility and support you will need. Be upfront about this with your employer, and keep them in the loop.

Sometimes you may need to take unplanned leave. Keep in mind that your employer may also need some time to figure out how to balance your personal needs with the needs of the workplace.

Your employer may not have any experience with breast cancer, so you might be on this journey together. On the other hand, your employer may have worked with women with breast cancer in the past. Your own needs might be different from those your employer has previously encountered, so it’s important to let them know what you need from your own perspective.

You may like to discuss confidentiality with your employer. Let them know if you are uncomfortable with everyone at work knowing about your diagnosis.

What can employers do to support women?
Every situation is different, so what works for one workplace or woman may not work for another. Open communication is crucial.

At diagnosis:
• Let your employee know you are there to support her and that you value her.
• Understand that working may provide her with a welcome distraction from breast cancer.

At Sussan, we have found that work provides women with a point of focus and a sense of control and normality during a difficult time.

Working during treatment:
• Understand that her treatment may affect the way she is able to do her job. She may not have anticipated the side effects or emotional impact. She may ring you the morning she is due to work as she is unwell or running late.
• Remember that her needs and preferences may change over time.
• Don’t make assumptions about what she needs, and ensure she knows she can ask for help. Ask what you can do to support her.
• You may need to find different roles for her. Talk to her about what she would like to do and explore how the business can support this.
• Provide her with details about her entitlements, including Centrelink information.
• If she does not have personal leave entitlements, consider whether the business can continue to pay her or contribute to practical items such as meals, wigs, massages and travel to ease the financial burden.
• If a woman needs a significant amount of time away for treatment, stay in touch with her or her family and let her know there is a job for her when she is ready to return.

Returning to work:
• Understand she will probably have good and bad days. The end of treatment is not necessarily the end of her journey.
• Have regular catch-ups with her and her team to see how everything is going.

What should women do if they encounter difficulties at work?
Be open and honest with your manager about what you are and aren’t coping with. Think about the type of support you need from your workplace, and what might help. Ask for temporary changes and be realistic about what you are able to commit to within the workplace.

If you manage a woman who is having difficulties, try to approach the job in a different way. Have regular discussions with her about her workload and be willing to negotiate changes and reallocate resources if needed.

Cancer Council NSW has information for employers at www.cancercouncil.com.au > Get support > Employers and workplaces.
Pregnancy and breast cancer study

Women diagnosed with breast cancer during or immediately after a pregnancy can face particular challenges as they manage treatment and care for a new baby. To date, there has been little research into the best care for these women.

The Gestational Breast Cancer Study is investigating the number of women in Australia and New Zealand who are diagnosed with breast cancer during or shortly after pregnancy, the treatment they receive, and the outcomes for them and their babies. The researchers will use the findings to develop guidelines for health professionals to help them best treat and care for women diagnosed during or shortly after pregnancy.

The researchers are looking for women who are interested in participating in the study. You may be eligible if you have been diagnosed with breast cancer for the first time:

- during pregnancy or within six weeks of giving birth, and
- gave birth between January 2013 and February 2014.

If you are interested in finding out about your eligibility for the study, or for more information, please contact Nasrin Javid at n.javid@unsw.edu.au.

To receive regular emails about breast cancer studies like this one, join BCNA’s Review & Survey Group by visiting www.bcna.org.au > Help with research.

Insurance and superannuation – income when you can’t work

Many women tell us that being diagnosed with breast cancer causes significant financial difficulty for them and their family.

There can be high out-of-pocket costs for treatment and care, even if you are treated in the public health system. If you are in the paid workforce, you may find you are too unwell to continue your usual work and need to stop working for a period of time. This loss of regular income can place an additional financial burden on you and your family.

Insurance and superannuation can provide you with an income when you can’t work.

If you have insurance policies, such as life or income protection insurance, you may be able to make claims to cover your loss of income or other expenses. Contact your insurance company to ask about the cover you have. You may also like to check if your superannuation policies include insurance. Often people don’t realise that some superannuation funds include income protection or total and permanent disability insurance.

To find out whether your superannuation fund includes insurance, contact your fund directly.

While normally you cannot access superannuation until you have reached a certain age, in certain circumstances you may be able to access your superannuation earlier. This may include if you are experiencing severe financial hardship or on specific compassionate grounds. If you are considering applying to access your superannuation early, you should seek independent financial advice about how this may affect other areas of your finances, including benefits you may be receiving from Centrelink. For more information about accessing your superannuation early, contact your superannuation fund or the Department of Human Services on 1300 131 060 or www.humanservices.gov.au.

If you are not happy with a decision made by your superannuation fund, you can make a complaint to your fund directly through their internal complaints procedures. Complaints can also be made to the Superannuation Complaints Tribunal. For more information about the tribunal, as well as how to make a complaint and the time limits for doing so, phone 1300 884 114 or visit www.sct.gov.au.

BCNA has a fact sheet that outlines financial and practical assistance that may be available to you and your family. To download a copy, visit www.bcna.org.au > News > Resources > Fact sheets and booklets, or call 1800 500 258 and we will post a copy to you.
Practical matters

A bridge to the future

When my diagnosis came through in 2010, I felt like Alice falling down the rabbit hole. My relationship had broken up a week before and it was not my choice.

When I told my employer, he was very understanding as his mother was a breast cancer survivor. After taking my doctor’s advice, we decided I would have two weeks off after each chemotherapy treatment and then a week at work just before my next dose. Luckily I had nine weeks of sick leave up my sleeve and I needed every day of that.

Returning to work was the normality I craved after feeling ambushed by the parallel universe I was caught up in. I wore my scarf to work, heard everyone cheerily telling me I looked great even when I didn’t, and found a bridge back to my future. Working was an important step in my recovery.

I decided I could sink into self-pity and let my illness overwhelm me and indeed, this happened at times – or I could see it as a severe episode of bad luck and not let it define me. I chose the latter and the times I was at work during chemo I wrote and produced a special book on local government infrastructure, including Indigenous projects. This book was launched by the Prime Minister as an example of what can be achieved by local communities working together.

In April 2011, I decided to stretch myself further and successfully applied for a job as CEO of the Real Estate Institute of Australia. This is a job I am really enjoying. I still feel anxious when my tests are due, but most of the time I create opportunities and try to live fearlessly.

Amanda, ACT

Valuing my new life

I was diagnosed with breast cancer in November 2011 when I found a small lump by chance, which ultimately saved my life. I lived in the fast lane of corporate life, running from meeting to meeting, not eating well and working long hours. With a young daughter and a husband who travelled a lot for business I always put myself last. When I look back now I was doing all the wrong things but it is so easy to get caught up on the corporate treadmill.

The next few months were a whirlwind and in January 2011 I had a mastectomy, my doctor having advised that this was my best chance. Although it was a shock, that day I discovered what life really was about. I call it the cancer bubble; it allows you to see the real meaning of living. It wasn’t about big salaries, great jobs and nice holidays, it was about truly valuing my family and friends and being present in this one life we all have. I took six months off work to re-evaluate. It was financially tougher but somehow less money didn’t matter – we just made it work. It’s amazing what you can do without.

When I decided to quit corporate life after 25 years, funnily enough it wasn’t a hard decision. I had clarity and for the first time knew what I wanted to do, not what others expected me to do. I now work from home for an old business colleague and deal with lots of not-for-profit organisations, and in a small way I feel like I am making a difference. I still have odd days where I wish it had never happened and then I realise how much richer my life is now in every possible way. In a strange way I am thankful breast cancer gave me a golden ticket to a fantastic and new life of caring, sharing and truly appreciating my time here.

Karen, VIC

Amanda

Karen with her daughter
Being self-employed

I am self-employed; if I don’t work, I don’t earn any money. At the age of 44 I was diagnosed with a large aggressive invasive ductal carcinoma. I am a remedial massage therapist. It is very physical work but I love it as it is an extremely rewarding job. I get to see my wonderful clients leaving feeling better than they did when they arrived.

It has been nearly 18 months since my diagnosis, during which time I have had chemotherapy, a mastectomy and a reconstruction. It has all been tough but the chemo was by far the most challenging. While I was having chemo every three weeks I managed to work one of those weeks almost fully, one week I could not work at all and the other week was about half my normal workload. My clients worked in with this; they went out of their way to be as flexible as possible.

I was not able to work at all for a couple months following surgery. I am still only working half my normal workload eight months after reconstruction. If I had a less physical job that was not using my chest and shoulder muscles so much, possibly I would be back working more hours.

I still think myself lucky that I do not have to support young children and that I have a husband who is able to support me. Financially this has been incredibly difficult – the cost of not working, numerous expensive medical tests, medication and complementary medicine (without having extras medical insurance).

Donna, SA

The emotion monitor

When I was diagnosed with breast cancer the reaction of my employer was sympathetic but traditional. Unilaterally it was decided that I was no longer fit to travel despite the fact that I was a global executive in the middle of a major restructure.

I considered my options. In my industry women hold mainly front-line non-executive positions. What would they do if presented with career-limiting options? What of younger women whose futures might now be compromised? I decided to respond rather than resign.

First on the work plan was the management team. Given our challenging agenda was it fair to potentially expose a ‘weak link’? Would it better to take leave, provide extra resources and promote another? The team met to consider its position. The decision was made – I would remain but with a risk plan.

Part one of the risk plan was the designation of the ‘emotion monitor’. This could remove the captain from the brig in the event of chemo brain or stress related behaviours. The emotion monitor was also to protect the team – there could be discussion and action without fear of repercussion from the captain. Fortunately we had no need of this.

Part two of the risk plan was to provide another weekly forum to further analyse decisions. The team were keen to understand what drove me to think the way I did, to ensure that they too could apply that same rationale as we steered the organisation towards its global agenda. From these meetings grew ‘Joh’s problem solving handbook’ as we recognised what tools and techniques helped us manage the transition. We were prepared and we were successful.

For sympathetic managers who often confronted their own grief rather than my and the organisation’s needs, I provided practice. I did not need to be removed from the workforce, nor hidden, nor excluded. I simply needed to arrange my daily timetable around medical treatments.

A breast cancer diagnosis is not an organisational performance issue. It need not limit either career or remaining life options.

I am not a victim, I am a survivor, and I will treat each day with the magic that it brings.

Joh, VIC
Fitting in a wedding!

When I was diagnosed with breast cancer, like a lot of other cancer sufferers, I went through a gamut of emotions. It was absolutely imperative to me that I carried on as normal. My daughter had gone overseas the day before I discovered the lump and I swore everyone to secrecy as I did not want her coming home; she had saved and planned for so long. My partner and I had planned to get married. Everything was finalised and paid for but I suggested we postpone the wedding as I wouldn't have hair. My fabulous partner said he hadn't asked me to marry him just when I was well, he loved me no matter what, so the wedding went ahead as planned. My treatments were planned around the wedding date and we even sneaked in a honeymoon. The only time I had off work was on the two worst days of each chemotherapy cycle and a couple of hours each day of my radiation treatment. This was very important to me. I needed to pretend that everything was okay. For so long there were doctors to see, tests to have, treatments to have and then after six months it all just stopped. I felt lost. I saw a post-cancer counsellor who told me she spoke to many women who all said the same thing. It's all sorted out in my mind now. We are heading off in October to become Grey Nomads for a few years. How good is life now? It's the best!

Julia, ACT

Keeping trucking

I was 47 and working as a long distance truck driver when I discovered I had breast cancer. A mastectomy and surgery to remove lymph glands followed, along with six months of chemo. I thought I wouldn't be able to drive trucks again, but a week after completing chemo I was back driving, sporting a scarf on my head. My employer, Australia Post, has encouraged me to return to my career. It hasn't been easy. At times my body felt a lot older than my actual age, but now three years on, life is looking good. I enjoy receiving The Beacon and I attend BCNA forums when they are on up here.

Liz, QLD
What I’ve learnt along the way

Everyone is different and treatments vary. This is my advice from my experience.

• Pre-surgery, get a nice comfy bra without wires. I bought a couple of crop top type ones, just to give some gentle support. I wore them 24/7 post surgery.

• While waiting for treatment, cook meals for the freezer. It will give you something to do and will hopefully take the focus off your anxiety.

• Tell your close friends what is going on. If friends or family can drive you to appointments, cook a meal, do the washing, then let them. It helps you out and they feel like they are doing something constructive rather than feeling helpless. I am the mother of a primary school child. My news gradually got around the school but I received the most heart-warming messages of support. I still marvel at how wonderful this made me feel.

• Keep a diary. It is a good place to jot down what test you had, how you felt, etc. I think it is also a way you can express your innermost emotions without inflicting it on your nearest and dearest.

• Keep a good financial record. I recorded all expenses on a spreadsheet. I couldn’t rely on my memory to remember which account was sent to Medicare or which one was paid in full. Perhaps it gave me a bit of control when sometimes I had none.

• When you can, do something nice – a massage, a coffee with a friend, etc.

• Meditate. Your mind can run amok with worst case scenarios. It is easier said than done to put your concerns aside but I think meditation helps.

• I had six weeks of radiotherapy. For the most part, I dropped my son off at school, had my radiotherapy and continued on my way to work. I did get tired towards the end and tried to rest after work. I found the end of radiotherapy to be very emotional. While you were having treatment, ‘something’ was being done. Then it stops and there is ‘nothing’ happening. Apparently it is very normal but it did take me a couple of weeks to get over that sense of loss.

• Ask lots of questions of your medical team and don’t be afraid to voice any concerns.

Lesley, VIC

A new kind of normal

I was diagnosed with breast cancer in 2011 just two months short of my 50th birthday. Everything happened very quickly and in no time I had my first of three surgeries – the last one being a full mastectomy. I work in a school and chose to take the first term of 2012 off to concentrate on my health and to have chemotherapy. I had my last round of chemo and returned to full-time work two weeks later.

Returning to work was, in a sense, a return to normal but I wasn’t prepared for the tiredness and fatigue that came with working full time. I was trying to return to my old self but the treatment had taken its toll. I wasn’t Wonder Woman after all!

I had heard about ‘chemo brain’ and spoken to plenty of people who suffered it. Now I have experienced it and 18 months down the track it still comes around when I get fatigued. My husband and children have learnt to adapt to their now forgetful wife and mother and are wonderfully supportive and patient. Work colleagues have also been fantastic.

My biggest frustration both at home and work is that I sometimes forget the most basic things, or say a wrong word (fridge instead of washing machine) … chemo brain! With the benefit of hindsight I should have taken another term off work to give myself more rest and recovery time. I have finally learned to accept the new me and am now making sure I get plenty of exercise (physically and mentally) as well as rest.

Anita, NSW

Anita
Fighting for income protection

In 2012 I was advised that I had a cancerous tumour in my right breast. As I had had a lumpectomy with chemo and radiation on my left breast 15 years previously, I was devastated, but life is a process and I found that dealing with cancer the second time round was just another process I had to go through. However, it wasn’t and isn’t so easy.

Fifteen years ago, I took leave without pay for eight months and was able to survive due to a private income protection policy. This time round, as I hadn’t increased this private insurance at all, the sum was too small to cover the repayment of our mortgage let alone other expenses. However, I found out that my superannuation had an income protection policy that would pay 75% of my monthly salary. My husband and I were much relieved but there was a battle ahead.

There are so many forms that have to be continually completed by yourself and your GP. I would like to know why insurers try to make us feel guilty about needing this payment. Why is it that a simple medical certificate from your GP is not enough to satisfy them that you are ill? Every month I have to answer many questions and annoy my very busy GP with an extensive questionnaire about my health, otherwise they refuse to pay me. This process should be made easier for those of us who are unwell and struggling to cope.

My position at work was held for me for as long as they could afford to do so but after a year off it became untenable and I was terminated after 26 years of service. This could not be helped by either me or the company. However, no payout was made and now my husband and I are facing the fact that I am 54 years of age, struggling with side effects and worried that when I am deemed fit again by my income protection company, we will not have that income coming in anymore.

I would love to see something done about making income protection easier to collect. We are talking about people struggling here with sickness. They do not need the extra stress.

Stella, QLD

Creating something special with love

I am 87 years of age and was diagnosed with breast cancer in March 2013. I know that death will come to me in good time but I have personally made the decision to put cancer in a place outside my mind where it cannot interfere with my individual natural death processes.

Although pain, fear of the unknown and perhaps even death itself are always waiting in the background threatening to overtake my moments, every day I choose to be positive and cherish the moments I have left to me, to soak in the sunshine, to laugh with my friends, to feel the love of my family, to create new and special memories to leave behind.

I have always been a keen craftswoman so after my mastectomy operation my daughter inspired me to knit cushion covers for her new home. My fingers were constantly in action creating with all the bright and cheerful colours in my knitting basket. This project was wonderful therapy and the result is 20 cushions scattered around among family members who tell me they will think of me when they cuddle their cushion.

The joy of using my skills to create something special for others was truly life giving and was welcomed at this special time in my life where I needed strength and encouragement to move beyond the trauma related to breast cancer.

Thelma, SA
Introducing 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.

Gabrielle Trainor

How did you get involved with BCNA?
Like so many people, I had a number of very dear friends who have died of breast cancer and lots of others who are survivors. I had served on the Board of the Breast Cancer Institute and had become aware of the many needs and challenges in supporting breast cancer. Terry Bracks called me one day asking if I would be interested in getting involved with BCNA and I jumped at the chance. After having worked a bit at the research end, it was very inspiring to get involved with the women and men who were affected by breast cancer.

What inspires you to contribute?
Lyn Swinburne’s work in identifying the need and setting up BCNA, and the warmth and inclusiveness she engendered, was something I wanted to be a part of. The culture has been picked up by Maxine Morand and is part of our DNA. It has been an incredibly fulfilling experience. And the continuing contribution of the extraordinary Raelene Boyle is a joy to behold! She is amazing – everyone involved with BCNA loves her. She is one of the people who is the heart and soul of the organisation. Our Board and the whole team, together with our wonderful partners and supporters, are so committed to our members. The energy and passion is palpable. But most of all, it’s the members themselves. Their courage and resilience and their sense of belonging and giving to each other makes BCNA what it is.

Debbie Smith

How did you get involved with BCNA?
My first contact with BCNA was through my breast cancer diagnosis in 2003 when I received a My Journey Kit. Five years later, I was introduced to Lyn Swinburne through Michael Happell, a fellow BCNA Board member. Lyn’s passion and enthusiasm inspired me to volunteer to use my finance skills to help the organisation in the first instance. As I learned more about BCNA, I have been privileged to now be able to be part of the Board.

What inspires you to volunteer your time as a Board member?
A second breast cancer diagnosis last year, and interacting with lots of other women, especially through Young Pink Sisters, has opened my eyes to the many different challenges that women face. I hope that I can contribute to reducing these challenges and ensure women feel empowered and supported throughout their breast cancer journey. My own experience was better than what it may have been 20 or even 10 years ago. We need to continue to strive for improvements to the system and women’s experience overall.

What changes still need to happen for people affected by breast cancer?
As an organisation, we are at an interesting juncture. The number of women battling the disease is increasing, government funding is uncertain and there is a lot being asked of the community in providing financial support to organisations like ours. Aside from treating the disease, there are many other aspects to a woman’s experience that need to be addressed. Helping women to come to terms with their changed physicality, fertility, changing nature of relationships and dealing with the uncertainty around recurrence are all aspects.

What changes do you think still need to happen for people affected by breast cancer?
The health care needs of people in rural and remote areas is a major issue as services are rationalised and centralised. For women with breast cancer in the bush, treatment options can be extremely limited without long distance travel. This compounds the stress and logistical problems of having breast cancer in the first place. The need to travel and be away from home for treatment compounds the pressure on the whole family. More and better decentralised services and availability of tele-health solutions will need continual investment by governments to ease these burdens.
Profiling our Member Groups

Ocean Grove/Barwon Heads Breast Cancer Support Group

Julie Rodger from the Ocean Grove/Barwon Heads Breast Cancer Support Group shares some of the ways the group provides practical support to its members and how this incredible community support came about.

The Ocean Grove/Barwon Heads Breast Cancer Support Group has been meeting since March 2012. We have 25 members, many of whom are currently undergoing treatment. Over the past two years we have focused on the ways we can provide practical support and we’ve been overwhelmed by the generosity of our local community.

We began by organising a fashion parade to raise money to fund this support. Group members spoke to community businesses that they already knew and were amazed by their willingness to support the group. We had the venue, finger food and wine donated for the evening. We were also thrilled to be able to run a raffle with the community donating all the prizes, including car detailing, accommodation packages and dinner on a beautiful yacht. It felt like the whole community was behind us.

The fashion parade was a huge success with more than 40 local businesses getting involved – some donated products and services, others offered discounts to group members. Our fundraiser has set us up to provide practical support to women undergoing treatment, including meals and Jim’s Mowing vouchers. Our local Bakers Delight store continues to provide support by donating bread to families in need.

We feel very lucky to have amazing support from our community. We always follow up by having a group member visit the supporting business or individual to thank them and give them a certificate of appreciation to display in their store.

At Christmas the community donated toys and gift vouchers for kids. A highlight for many group members was when a local pilot recruited some fellow pilots to donate their time and aircraft for joy flights for the group before our Christmas party. Six planes and a helicopter took the group on a 20-minute joy flight – even flying over group members’ houses! It was such a memorable experience for everyone, including the pilots, who said they can’t wait to take the group again next Christmas!

This year we hope to work with the community to start a wig and scarf library. We believe that this practical support can make a huge difference to our members.

The Ocean Grove support group ready for their joy flight.

Connecting people

A key part of BCNA’s mission is to connect Australians personally affected by breast cancer. We welcome new Member Groups to our network. They now total 310.

New Member Groups:
• The Melbournites – Melbourne, Vic
• Living Wellness Meditation Group – Petersham, NSW
• Bunyip and District Cancer Support Group – Bunyip, Vic
• Lymphoedema Support Group of NSW (Tamworth) – Tamworth, NSW
• Oxenford Cancer Support Group – Oxenford, Qld

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

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

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

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

- Blairgowrie Yacht Club – Veronica De Poi, VIC
- Buzz Hair Studio – Jillian Carmody, VIC
- Catherine Earl, VIC
- CMV Group, SA
- Connie Dobbin, VIC
- Donath Cricket Club – Chervon Maher, VIC
- Encounter Lutheran College – Jenna Putland, SA
- Felini Health & Fitness – Kelli-Anne Holtham-Felini, VIC
- Glendell Mine – Bronwyn Dowd, NSW
- H's Place Hair Studio – Hayleigh McIntyre, VIC
- Hampton Park Bowls Club – Gwen Clough, VIC
- Helen Durell, WA
- Holy Spirit College – Lisa Gullick, NSW
- HSV Owners Club – Lisa Chambers, VIC
- Immanuel Lutheran Primary School – The Schmidt family, SA
- Indirect Tax Department, ATO – Janet Micallef, VIC
- Josephine Staltaro, VIC
- Karen Cappellazzo, QLD
- Keysborough Bowls Club – Gloria Munro, VIC
- Kylie Calderwood & Joy Tebbens, VIC
- Leanne Sher and friends, VIC
- Loreto College – Penny Minchin, SA
- Louise Turner, NSW
- Maling Rd Canterbury – Helen De Ross, VIC
- Mentone Girls Grammar – Philippa Lohmeyer-Collins, VIC
- Mooroolbark Lawn Bowls Club – Beryl Turner, VIC
- Motorcycle Riders Association of the ACT – Trish Holdsworth, ACT
- Mount Gambier Ladies Race Committee, SA
- Mount Hawthorn Primary School – Vicki Roberts, WA
- Mountain District Ladies Tennis Association – Rosamunde Rodgers, VIC
- MSIT Loganlea Campus PWS students – Christine Woods, QLD
- Mt Martha Primary School – Des O’Connor, VIC
- Our Lady of the Rosary Primary School – The Roberts family, NSW
- Pingelly Golf Club – Bev Giles, WA
- Powercor Network Services, VIC
- Rita Papagiannis, VIC
- Roses & Hearts Pink Charity Ball – Sonya Murray – VIC
- Rotary Club of Rockhampton South, QLD
- Sandringham Baseball Club – Greg Street, VIC
- Scarborough/Wombarra Bowling Club – Yvonne Eismann, NSW
- Shannon Cross and friends, VIC
- Sofia Costanzo, VIC
- Southern Golf Club, Brad Robb – VIC
- St Monica’s College, VIC
- St Patrick’s College – Tom Lahey, QLD
- The Sporties Health and Fitness Centre – Joanne Hoolahan, VIC
- Woodlands Golf Club – Louise Cooper, VIC

Memorials
We pay tribute to the lives of:

- Anne Dodd
- Betty Black
- David Rutter
- Elsie Rich
- Heather Marchment
- John Nelson
- Julie Mackie
- Lynette Finlayson
- Margaret Illman
- Patricia Brain

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:

- Carolyn Hammond
- Clara Mendoza

New BCNA resources now available

Most Australians diagnosed with breast cancer are women. However, around 125 men are diagnosed with breast cancer in Australia each year.

BCNA’s new booklet for men with breast cancer, *Men get breast cancer too*, includes information on breast cancer treatment and care, and practical tips to help men cope with common challenges they face.

BCNA has also developed a fact sheet, *Bone health and breast cancer*, which explains the impact that breast cancer treatments can have on bone health, and provides some tips to help you improve your bone health during or after your treatment.

Both resources were developed with input from people diagnosed with breast cancer and health professionals.

All of BCNA’s fact sheets and booklets can be downloaded at www.bcna.org.au > News > Resources > Fact sheets and booklets, or you can phone us on 1800 500 258 to ask for a printed version to be posted to you.
Our annual Pink Sports Day will again take place over the Mother’s Day weekend (10 and 11 May). The event has grown every year and in 2014 we are hoping that more than 1,000 clubs will show their support for BCNA. It is free for clubs to participate and we provide them with a great ‘pink starter pack’, including Pink Lady tattoos, balloons and posters, to help them pink up on the day. Clubs from every sport and every state and territory have been involved so far. We have seen pink umpires, pink hairdos, new pink lady uniforms, fabulous raffles, donations from gate takings and so much more!

Registrations open in March. We would love you to help us tell your family, friends, work colleagues and your community and encourage them to get involved in Pink Sports Day. It is a great way to unite a team for a great cause and is guaranteed to be fun and very rewarding!

For more information visit www.bcna.org.au > Events > Key fundraising events > Pink Sports Day or email pinksportsday@bcna.org.au.

Planning for the annual Pink Bun campaign is underway and will run this year from 24 April to 14 May.

Over three weeks every Bakers Delight bakery around Australia will be decorated in pink and will sell pink buns and paper Pink Lady silhouettes.

During the campaign 100% of the sale of Pink Buns and Pink Lady silhouettes is donated to BCNA.

Each year the Pink Bun campaign helps to raise:
- funds to help BCNA continue our work ensuring women and their families receive the very best support, information, treatment and care
- awareness of the support in local communities for women and their families affected by breast cancer.

We encourage all of our members to be a part of the campaign. You can help support it by:
- being a regular Bakers Delight customer during the campaign. The following link will help you find your local Bakers Delight store – www.bakersdelight.com.au/BakeryLocator
- visiting your local bakery and thanking them for supporting BCNA
- buying a pink bun or two, or if you don’t have a sweet tooth, you can put a donation in the Pink Bun tin on the counter
- urge your family and friends to purchase pink buns too
- write a message of support on a Pink Lady silhouette in the bakery
- like your local bakery on Facebook.

This is a wonderful opportunity for you to be involved with your local community and Bakers Delight bakery and, of course, help us to raise funds and let people know how BCNA supports Australians affected by breast cancer.

This year marks 14 years of our special relationship with our Major Partner Bakers Delight. We continue to be overwhelmed by their enthusiasm in making a real difference locally and nationally to people affected by breast cancer.

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

**Friday 21 March** Free BCNA Mt Isa Information Forum, ‘Living well beyond breast cancer’. For more information and to register phone 1800 500 258. Places are limited so register early to avoid disappointment.

**24 April – 14 May** Pink Bun campaign. Visit your local Bakers Delight store to show your support. For more information visit www.bcna.org.au or email pinkbun@bcna.org.au.

**Saturday 10 and Sunday 11 May** Pink Sports Day. Local sports clubs will turn pink on the Mother’s Day weekend to support BCNA. Clubs participating will be playing with a specially designed pink footy or netball. For more information and to find out if there is a game in your local area, visit www.pinksportday.org.au.

**Saturday 10 May** BCNA’s Field of Women in Melbourne! Join us on the field at the MCG. Tickets: $55 per person (inc. GST). Visit www.bcna.org.au to buy tickets now.

**Sunday 11 May** Mother’s Day Classic, held in capital cities and various regional centres, raises money for the National Breast Cancer Foundation. For more information or to register visit www.mothersdayclassic.com.au.

**Steps for Support: BCNA’s Great Wall Challenge**
Can you imagine trekking along the awe-inspiring Great Wall of China? How about discovering the contrasts of ancient and modern Beijing? Would you like to make a difference in the lives of women affected by breast cancer?

By joining Steps for Support: BCNA’s Great Wall Challenge, you’ll have the trekking adventure of a lifetime and raise funds for BCNA.

**Fast facts**
- Dates: 11–22 October 2014
- Registration fee: $770 (non-refundable)
- Fundraising target: $3,500 (excludes travel)
- Travel cost: $4,370, including taxes (can be fundraised)
- Trip duration: 12 days
- Challenge duration: 5 days
- Challenge grade: 3/5
- Accommodation: Hotels and basic accommodation
- Minimum age: 16

For more information or to register your interest please visit www.inspiredadventures.com.au/bcna/greatwallchallenge

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**Seeking stories – What’s on your mind?**

We are seeking stories for the Spring 2014 issue of The Beacon about whatever you’d like to share with others about your breast cancer experience. Let us know what’s on your mind at the moment. It could be a challenge you’re facing, a funny experience you’ve had, a lesson you’ve learnt or your hope for the future. 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 June 2014. Please also include a high-resolution photo.