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Focus on:
Financial impact



The dollars and sense of breast cancer

At BCNA we have always made a commitment to providing our services and programs without any cost. That's mostly because we know how costly it can be to have breast cancer. We couldn't bear to think one woman might miss out being connected to us simply because she couldn't afford to pay.

In this issue of *The Beacon*, we hear from women about the financial hardships they experienced, both from direct and indirect expenses. Reading the articles sent in by our readers made me feel sad that women have to face these extra hurdles which come at a time that's already very challenging.

Several articles offer creative and clever ways to minimise the cost and to reduce this stress. We all know that some people are in a better position to pay than others. However, for those women and families who have been paying private health insurance for years, it does seem so unfair that many of them are still out of pocket, and sometimes for very large sums. It's challenging enough dealing with breast cancer without worrying about how you're going to pay!

Several years ago, I was attending the annual US Breast

Cancer Lobby Day on Capital Hill in Washington DC. Key advocates met with their Congressmen to raise issues and improve the state of play for US women with breast cancer. I was shocked to learn that one key issue they were trying to sort out was on behalf of women who did not have health insurance and could not afford to be treated for their breast cancer! Their breast cancers were being detected by mammograms, but the medical costs for treatment were certainly beyond anything we could imagine.

In travelling overseas, there have been many times when I've been reminded that, although certainly not perfect, our health system compares well with others. There are, however, definitely hints which would be helpful for women to know. One of those is to find out, up front, what costs you are likely to be charged; another is to know what community-based assistance might be available. It's also important to know that you can claim for benefits in all sorts of ways.

I love the concept of having a partner or close friend keep tabs on the bills and the refunds for you – these can easily get out of hand and, if you're anything like



Events such as Raelene Boyle's 60th birthday party help BCNA raise funds to continue to provide free information and support to those affected by breast cancer. See inside for more details about the party

me, this is a big, boring chore. What a really practical way someone can help. Hopefully, this *Beacon* will provide all sorts of useful information to help minimise both the costs and some of the anxiety involved.

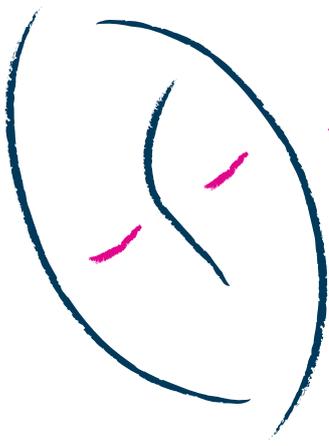
We will soon be heading into the month of October – Breast Cancer Awareness month around the world. For those of you who are newly diagnosed, this can be a time of annoyance and worry, especially seeing so much pink everywhere can be a reminder of something you'd much rather forget.

However, I know that many of our BCNA members – now more than 60,000 across all parts of

Australia – will be attending pink functions, running community-based programs, holding *Mini-Fields of Women* and celebrating with your support group, your family and with one another. I wish you all the best in your October endeavours.

*Lyn Swinburne AM
Chief Executive Officer*





Issue of concern

The financial cost of breast cancer

The financial stress was unbelievable. Not being able to work, medical expenses, living expenses. This is a really tough one that I think isn't talked about enough. – Nicole

For many women, the shock of being diagnosed with breast cancer is worsened when they realise the financial implications this may have on them and their families.

Regardless of whether treatment is through the public or private health system, most women will be affected financially in some way.

You may have to pay for tests that are not covered by Medicare, such as MRI scans and bone mineral density tests, or you may lose income if you have to reduce your work hours, or stop work altogether.

There is also a raft of 'incidental' costs you may not expect: wound dressings, post-surgery bras, lymphoedema garments, transport to and from appointments, and child care.

We had good private cover, but there are still a lot of costs attached to having cancer. Complementary therapies, tests, medications, wigs, turbans, creams, etc. These relatively smaller costs all add up surprisingly quickly. – Robin

For women in the private system, the costs can still be significant. Even with private health insurance, women may have out-of-pocket costs for surgery, chemotherapy and radiotherapy.

I had private health insurance but at a low level. The cost of (my treatment) was enormous. I must have gone through about \$10,000. – Delia

This out-of-pocket cost, or 'gap', comes about because doctors in the private health system are free to set their own fees. These fees can be well above the rebates you will receive from Medicare and your private health insurance (PHI) fund – leaving you to pay the difference.

The Medicare rebate you receive is set by the Australian Government through the Medicare Benefits Schedule (MBS). The Government lists the price for individual medical procedures on the MBS. The Medicare rebate covers a proportion of this price and, for women with private health insurance, one would expect that their PHI funds cover the balance. PHI funds can also enter into agreements with individual doctors to pay them more than the MBS price for their services. If you are treated by a doctor who has signed an agreement with your PHI fund, there should be no out-of-pocket cost paid by you.

Tips from women

Use a spreadsheet, such as the one contained in the *My Journey Kit* Personal Record, to keep track of out-of-pocket expenses so you can claim a tax rebate at the end of the financial year.

If you are having trouble paying your utilities bills – gas, water, electricity – contact your utility company as many offer assistance to customers in financial hardship. This can include extending due dates, developing a payment plan, and sometimes even providing a discount.

Some women tell us they have no out-of-pocket costs for tests such as X-rays, ultrasounds, MRIs and blood tests if they have them done as an in-patient. Talk to your doctor to ask if this might apply in your situation.

I gave my husband the job of looking after my bills and keeping track of the out-of-pocket costs. It meant I didn't have that added stress, and it gave him a practical way to help.

– Joan

Often women who have been paying for private health insurance for a long time do not realise it might not cover all their costs. It is important to ask your doctor about his/her fees before starting treatment or any follow-up procedures and if they have a gap agreement with your PHI fund.

For women in the paid workforce, having to work reduced hours or give up work altogether can also result in considerable financial stress.

My biggest expense was loss of income. I couldn't work during my treatment, but I still had to pay rent, food and all the normal stuff. – Merylee

Losing part or all of your income can leave you struggling to pay everyday household expenses, such as the mortgage or rent, utilities bills and even food.

This issue of *The Beacon* looks at some of the ways you can manage or reduce your medical expenses, and places where you may be able to find financial assistance. There is more information on our website at www.bcna.org.au > News > The Beacon magazine > Beacon 56 resource sheets.

Ask the Expert

Cass Boyle

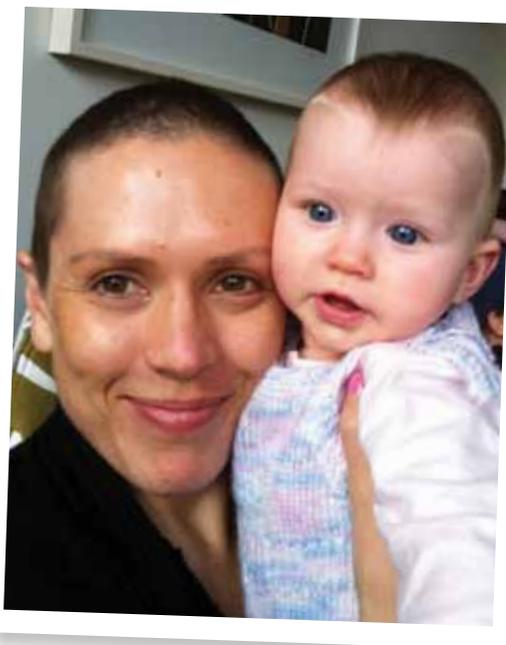
Cass Boyle is Financial Advisor and Operations Manager with Madison Financial Group. She was diagnosed with breast cancer in November 2010. *The Beacon* asked Cass for her advice for dealing with financial issues after a diagnosis.

What general advice do you have for women?

As we all know, the ability to comprehend what's happening to us when we are diagnosed with breast cancer can be daunting. This can directly impact on our ability to tackle other issues in life, like dealing with finances. Ideally, speak with a financial adviser who can guide you through your options. Alternatively, perhaps you could ask a family member to take over this responsibility for you. Importantly, **keep all your receipts** associated with your treatment.

Can women claim medical expenses as a tax deduction?

If your net annual medical expenses exceed the ATO threshold (\$2,000 in 2010/11), you can claim an offset of 20% in your tax return. To work out your net medical expenses, you calculate the total medical expenses for you, your spouse and dependants (if any), then subtract any refunds you received from Medicare, your private health insurer and any other providers. You can apply for a Medicare benefit tax



Cass Boyle with her daughter Sydney

statement through the Medicare website or your local Medicare office. This will list your claims for the last year where a Medicare rebate was paid. Not all medical procedures can be used when calculating your net expenses (e.g. cosmetic services where a Medicare benefit was not paid) so refer to the Medicare website, your accountant or the ATO website when completing your calculations. Breast reconstruction **is** covered by Medicare and these costs **can** be included when calculating your expenses.

What about early access to superannuation?

Superannuation funds have strict rules regarding accessing superannuation. Generally, you must be at least 55 years old.

However, in some circumstances, you may be able to apply for early access to your super to cover costs associated with medical treatment, medical transport and mortgage assistance (among others).

Are there insurance policies women can claim on?

There are a number of insurance types you may be able to claim. These may be policies taken out by you, or may be part of your employer superannuation. They include:

Salary Continuance – this pays you an amount each month for a specified period of time (usually two years).

Income Protection – generally pays around 75% of your salary for the period you are either

unable to work at all, or unable to perform the tasks associated with your employment.

Trauma – this insurance provides a lump sum in the event that you suffer a specific medical condition covered by the policy. Importantly, trauma cover is paid out on *diagnosis* which can be extremely valuable in helping to cover living expenses, medical costs, and reducing or managing debt.

If you think you can claim on an insurance policy, contact the insurance provider as soon as possible to ask about the claiming process.

If you have not taken out insurance yourself, you can contact your superannuation fund and request a copy of your superannuation statement. This should list any insurances linked to your account.

What advice do you have for women struggling with mortgage payments?

If you are having trouble meeting your mortgage payments, it's imperative that you contact your mortgage provider. They may offer holiday periods on repayments or temporarily reduced rates.

Do you have any other advice for women?

Rules around superannuation, insurance and mortgages can be very confusing. If you can, speak to a financial planner who can guide you through the process and clearly explain your options.

Help from Centrelink

Centrelink has a number of payments and services which may help to ease the financial burden that can result from a diagnosis of breast cancer.

You can visit a Centrelink office or call Centrelink on **13 27 17** to talk about your financial situation. If you are feeling too unwell to have this discussion, you may like to ask your partner or a family member to seek advice on your behalf.

Centrelink can advise about payments for which you may be eligible, and how to lodge a claim. It's best to do this as soon as you can, as waiting periods can apply.

Some women tell us that dealing with Centrelink can be frustrating at times. Don't be afraid to ask questions until you understand what is being said to you about your entitlements.

Some of the payments that may apply to women with breast cancer are outlined below.

Sickness Allowance

If you are employed and are unable to work, you may be eligible for a fortnightly Sickness Allowance. You will need to meet certain age and income requirements. If you have a partner, their income and assets will also be taken into account, along with your outstanding sick leave. Your doctor will need to send Centrelink a medical certificate confirming that you are not able to work.

Disability Support Pension

If you are assessed as being unable to work for 15 hours or more per week, or to be

re-skilled for work for at least the next two years because of your breast cancer, you may be eligible for a fortnightly Disability Support Pension. Your income and assets and those of your partner will be taken into account.

Health Care Cards

A Health Care Card is available to people receiving certain payments from Centrelink. It can entitle you to cheaper medicines, bulk-billing and more refunds for medical expenses. It may also entitle you to concessions for utilities bills, ambulance costs, public transport, and dental and eye care.

If you are not receiving a Centrelink payment but are on a low income, you can apply

to Centrelink for a Low Income Health Care Card. This provides you with the same benefits as the Health Care Card.

Other services

Centrelink's Financial Information Service (FIS) officers and social workers can also support you in difficult times. You can call 13 63 57 for FIS information and 13 17 94 to speak to a social worker. These services are free.

You can find out more about all Centrelink services at www.centrelink.gov.au.

More information about Centrelink payments is also available at www.bcna.org.au > Living with breast cancer > Practical issues – finances.

Finding financial support

There are a number of programs designed to assist with medical costs. Some are national, while others are run by state, territory and local governments.

National programs include the Medicare and Pharmaceutical Benefits Scheme (PBS) safety nets, the External Breast Prosthesis Reimbursement Scheme, a dental health scheme for people with chronic medical conditions, and mental health care plans which offer a subsidy for up to ten sessions with a mental health professional. You may also be eligible for a GP chronic disease

management plan that provides Medicare rebates for up to five consultations per year with allied health professionals such as physiotherapists.

State and territory governments run Patient Assisted Travel Schemes for rural and regional people who have to travel for treatment. While we know these are often inadequate, they are worth investigating.

All states and territories, except Queensland and South Australia, also offer lymphoedema subsidy programs to help with the purchase of compression garments.

If you have access to a breast care nurse or social worker, she/he may be able to advise you on services available in your local area. Some local councils provide home help services, and may also be able to help with childcare.

Your state/territory Cancer Council (phone 13 11 20) may also have a list of services available in your area. All Cancer Councils except the ACT can provide a one-off payment to help you meet your expenses, although this is means tested. Some Cancer Councils also offer interest-free loans.

If you are having trouble managing your finances, you may like to seek financial counselling. There are free services available, including Centrelink's Financial Information Service and Salvation Army's 'Moneycare'.

More information about the schemes mentioned here, and some others, is available at www.bcna.org.au > News > The Beacon magazine > The Beacon archive > Issue 56 resource sheets, or call us on 1800 500 258 and we can post a copy to you.

Government 'safety nets'

The Australian Government has established 'safety nets' to help reduce costs for people with high medical expenses.

Medicare Safety Net

The Medicare Safety Net helps families and individuals who have high out-of-pocket costs for out-of-hospital services that attract a Medicare rebate. These include X-rays, pathology tests, GP and specialist consultations, and radiotherapy. Once you meet the Medicare Safety Net threshold, you may be eligible for additional Medicare benefits for the rest of the calendar year.

Individuals do not have to register for the Safety Net; however, it is important to keep your contact details up-to-date with Medicare.

Couples and families do need to register. This ensures that the medical costs of all family members contribute towards your family's Safety Net. To register, call Medicare on 13 20 01 or visit your local Medicare office.

For more information about the Medicare Safety Net, visit www.medicareaustralia.gov.au > For individuals and families > Medicare.

PBS Safety Net

The PBS Safety Net helps you with the cost of medicines. Once you or your family reach the Safety Net threshold, you can apply for a PBS Safety Net card. Your PBS-subsidised medicines will then be less expensive or free for the rest of the calendar year.

You don't need to register for the PBS Safety Net, but you do need to keep a record of all your PBS medicines on a Prescription Record Form, which you can get from your pharmacy. Each time you have a PBS medicine supplied, give the form to the pharmacist so it can be recorded. Your pharmacist might be able to keep a computer record for you, but if they can't or if you visit different pharmacies, it's best to keep your own records.

If you have a family, ask your pharmacist about combining the

amounts for each family member so you can work out your Safety Net total.

When you get close to the PBS threshold, ask your pharmacist how to get a PBS Safety Net card. The threshold for the current year is \$1,317.20 for individuals

and families, or \$336.00 for Concession Card holders.

For more information about the PBS Safety Net, visit www.medicareaustralia.gov.au > For individuals and families > Pharmaceutical Benefits Scheme.



Couples and families need to register for the Medicare Safety Net

NBOCC merges with Cancer Australia

On 1 July this year, the National Breast and Ovarian Cancer Centre (NBOCC) and Cancer Australia merged to form one new organisation called Cancer Australia.

Dr Helen Zorbas, Chief Executive Officer of NBOCC, has been appointed CEO of the new Sydney-based Cancer Australia. Since its establishment in 1995, NBOCC has led the

way in the development and implementation of clinical practice guidelines and their accompanying consumer resources on breast cancer. Its aim was the establishment of a gold standard of care for those affected by breast cancer. BCNA has previously expressed concern that the amalgamation may reduce the focus on breast cancer.

We are pleased to see that Cancer Australia has a three-year plan for breast cancer work. While breast cancer is only one of its many responsibilities, we hope that Cancer Australia will be able to continue the work started by NBOCC, and achieve outcomes to ensure that the best possible treatment and care of women with breast cancer remains a priority.

Although NBOCC no longer exists as an entity, its website is still available for the time being, although it now has the Cancer Australia banner.

BCNA will continue to collaborate with, and monitor the work of, Cancer Australia. We will keep our members informed about any further developments in its breast cancer work.

Public vs Private

At some of our recent forums, women have asked us whether they are better off having their treatment in the public or private health system. There are advantages and disadvantages with both. *The Beacon* looks at the main differences.

Public

One of the main advantages of the public health system is that there are no out-of-pocket costs. Surgery, chemotherapy and radiotherapy in a public hospital are free.

You are more likely to see a breast care nurse, social worker and physiotherapist in a public hospital – many private hospitals do not offer these services. You are also more likely to have a multi-disciplinary team coordinating your care, and to have access to clinical trials.

There are, of course, also disadvantages. While the treatment and drugs you receive are equivalent to those in the private system, you are unlikely to be able to choose your specialists, including your surgeon. You will be seen by whoever picks up your file on the day. While this person may try to follow you through your treatment, that is not always possible. Even where it does happen, your specialist may not always be available and you may see more junior hospital doctors instead. In some cases, breast cancer surgery may be performed by a trainee, under the supervision of a consultant. Some women will see many different medical staff during

their treatment and follow-up, and so may not feel a sense of continuity in their care.

There are often waiting times for treatment in a public hospital. While breast cancer surgery is usually classified as urgent and so waiting times are not long, there can be longer waiting times for breast reconstruction surgery – up to two years. There can also be long waits between the first and second stages of the reconstruction process.

You may also be put on a waiting list for radiotherapy. In some areas there is no public radiotherapy service at all and so women have to travel to another suburb or town, or pay to use a private service.

Private

Women who have their treatment in the private system say the main benefit is being able to choose their specialists and their hospital. This increases your sense of continuity of care and the confidence that you are seeing someone who knows you and your treatments.

This support may be available 24/7, which many women find reassuring.

Timelines for treatment are generally shorter in the private system. While this does not normally enhance survival, the shorter waiting times for test results and treatments make the cancer journey easier psychologically.

A definite disadvantage is that there may be considerable out-of-pocket costs, even after any Medicare and private health insurance rebates. This is because doctors set their own fees – see the Issue of concern on page 2 for more about this. Talking about costs with your specialists before your treatment begins is important. We suggest asking for written quotes so there are no misunderstandings. Some specialists are prepared to negotiate their fees and may be able to request bulk-billing for your pathology and other tests. Being treated privately may also mean you are less likely to see a breast care nurse or have access to a multi-disciplinary team or clinical trials.

Changing systems

We know that sometimes women switch between health systems for different parts of their treatment. You can ask to be referred to a specialist who works in the public sector or who will bulk-bill you, even if you have had your previous treatment in the private system.

I had my surgery and chemo in the private system, but went public for radiotherapy. – Linda

If you are still considering your treatment options, our advice is to take some time to consider carefully. Ask your doctor or breast care nurse about the pros and cons of treatment in each health system in your local area. The differences can vary significantly from area to area. Keep in mind that you can change systems for different parts of your treatment if you wish, although maintaining continuity of care is important. Whichever way you go, we suggest asking about the out-of-pocket costs in advance and discussing these with your doctor if you have any concerns.

Making a complaint about your care

If you are unhappy with the treatment or standard of care you receive from a hospital or doctor, you can raise your concerns with the hospital or individual involved. We acknowledge, however, that this can be difficult at such a

challenging time. If you are not happy with the response you receive and wish to pursue the matter, you can make a formal complaint. All states and territories have independent complaints resolution bodies which deal with complaints about health services and

individual health practitioners. You can find contact details for each state/territory service at www.bcna.org.au > News > The Beacon magazine > Beacon 56 resource sheets or phone us on 1800 500 258 and we will send a copy to you.

Radiotherapy now in Cairns

There was great news for North Queensland women in June this year when a radiation oncology centre was opened at Cairns Base Hospital. Previously, radiotherapy was not available in Cairns and women from the area had to leave home for up to six weeks to have their treatment elsewhere.

Funding for the centre was provided by both the Queensland and Australian governments following lobbying by a committed group of Cairns residents, including Liz Plummer, who was diagnosed with breast cancer in 2004 and had to travel to Townsville for her radiotherapy treatment.



Liz Plummer

Liz's husband, Max Plummer, told *The Beacon* that Liz was determined that Cairns should have a radiotherapy service.

'Through her own experience of having to leave home for radiotherapy, Liz knew how destabilising it is for women and their families,' Max said.

A local action group called COUCH (Committee for Oncology Unit at Cairns Hospital) was formed and it drove the campaign for a radiotherapy service in Cairns, with Liz as its focus.

'There was a huge community response to the campaign,' Max said. 'Liz was delighted when, in January 2009, the Queensland Premier announced that a radiation oncology unit would be built at Cairns Base Hospital. Liz was very proud of what she achieved for her community.' Sadly, Liz passed away in 2009, but she has left a wonderful legacy for the people of Cairns and surrounding regions, the Liz Plummer Cancer Care Centre. Liz's story shows how the voices of women and their supporters can make a difference to the lives of so many others.



Women wanted for clinical trial

Many women tell us they worry about their breast cancer returning.

An international clinical trial, *LATER*, is investigating whether the drug letrozole (Femara) can help prevent breast cancer recurring after women have completed at least four years of hormone treatment, e.g. tamoxifen.

The researchers are looking for women who may be interested

in participating in the trial. You may be eligible if you:

- have been diagnosed with breast cancer
- were treated with hormonal therapy (e.g. tamoxifen, Arimidex, Femara, Aromasin) for at least four years
- finished hormonal therapy at least one year ago
- are post-menopausal
- have no currently existing cancer.

The trial is available in Victoria, NSW, South Australia, Western Australia and Tasmania, in capital cities and some regional and rural areas.

To register your interest in the trial or find out more, call the Australian New Zealand Breast Cancer Trials Group on 1800 039 634 (freecall) or visit their website at www.anzbctg.org

Free programs support exercise

I found two wonderful support programs available free of charge.

The first was 'Encore' run by the YWCA. I cannot recommend it enough. It's an eight-week course of gentle exercise specifically for breast cancer patients and includes fun in the pool.

It offers comfort and care in a little support group with a trained assistant, which is so helpful as a first step. Encore is available at various venues.

The other program I found is Life Now, a 12-week individually tailored program through Cancer Council WA for cancer patients (and their carers). You work at your own pace in a little group under the care of an exercise physiologist. Life Now starts with an assessment and even this can be covered by Medicare by using an Enhanced Primary Care (EPC) Referral form from the Department of Health and Ageing. When your GP completes this form it covers a further four allied health care services such as a visit to a chiropractor, physiotherapist or podiatrist.

Patricia, WA



Robbing Peter to pay Paul

After each chemotherapy treatment, I left hospital with a bill of about \$200 for medication. I had a double mastectomy and reconstruction in November 2010 and the cost was extreme (even with top hospital cover). The out-of-pocket charges included:

- mastectomy – \$143
- plastic (reconstruction) surgery – \$8,000
- anaesthetist – \$1,500
- hospital – \$465

I knew about these charges before entering hospital and had to pay 'up front'. There have also been ongoing medication costs. As we have a chronically ill son

too, the costs are crippling.

To pay for these, I had to use money received through my superannuation under the total disability clause; so now I have no superannuation. No financial assistance was offered through any government agencies. If it wasn't for my husband's workmates generously instigating a fundraiser for us – which helped a little – we'd have had no assistance whatsoever and would have had to cope on our own.

Since my diagnosis, we are more than \$15,000 out of pocket. I can't work anymore, so we live off my husband's salary and we constantly 'rob Peter to pay Paul'.



Tracey with her husband Andrew and son Leigh

The financial strain compounds the stress of dealing with cancer hugely, but with the help and

support of family and friends I'm still fighting the fight.

Tracey, VIC

Finding a way

At the time of my diagnosis, I was 33 years old, a wife and a mother of two sons. The last thing I could focus on was my job, let alone having to call my manager to tell her I'd need time off to get through numerous surgeries, chemotherapy and radiotherapy.

Luckily, I was a public patient, so the costs were minimal. I had no idea, however, that I was supposed to pay for the radiotherapy because there is no public facility where I live. It was brought to my attention at my first appointment. I was up for seven weeks of radiotherapy to be followed by a bill of around \$4,000.

You don't have time to question



Maria

whether or not you have the money. Somehow you just have to find it. There was no way I would compromise my health for that money. We were lucky enough to have savings. My only regret was that I'd rather have used our savings for something a little more pleasant!

My time off work was in stages. During chemotherapy, I would take up to one-and-a-half weeks off work. I'd go back when I felt well enough to do so. There was many a time when I was sent home because I was sick and exhausted.

My work colleagues were incredible. They wore bandanas when I lost my hair, so I blended in with everyone else.

It made a huge difference to know I had support from my work group. I could imagine nothing worse than feeling like you have put your employment at risk due to your cancer diagnosis.

Where there's a will, there's certainly a way!

Maria, VIC

Stay connected with BCNA's Online Network

Our Online Network continues to grow with more than 4,000 members and more than 75 interest groups. If you're a member and you haven't logged on lately, why not drop in and see what's been happening. Our members are always coming up with fresh topics. If you haven't joined yet, you might find it's a great way to connect with others who understand what you are going through. Register at www.bcna.org.au > Network. If you need some help please email bcnaonline@bcna.org.au or phone us on 1800 500 258 (freecall).

Learning to accept

My husband is long-term disabled and we are part-pensioners, so there is not a lot of spare cash at our house.

At diagnosis I was working part-time (aged 63) for a friend who was two years ahead of me on the breast cancer journey and who was a wonderful source of support. I was able to take six months off to deal with the diagnosis and treatment, and my position was kept open for me.

My surgery and chemotherapy were covered by my private health insurance. I had radiotherapy at a public hospital.

The best support by far came from breast cancer nurses, who provided advice and reassurance as well as lots of printed information and the invaluable crescent-shaped cushions, worn like a shoulder bag, to protect the breast and underarm area in the weeks following surgery.

I couldn't possibly put a dollar value on my nurse's contribution.

My church family supported us with home-cooked meals brought to the door, and a complete roster of people to drive me to and from

radiotherapy sessions over six weeks.

The emotional support they provided was invaluable, as well as the practical help. I don't know what it would have cost in taxis, given I was not up to driving at that time.

Three years on from the end of my treatment, it is costing about \$100 every two months for medication to control neuropathic pain triggered by the chemo.

Overall I would say that the financial impact was huge, but nothing compared with the



Carol

learning experience of coping, recognising and learning to accept the help that was offered.

Carol, NSW

The generosity of others

I have worked full-time for most of my life following the death of my husband when my children were very young. One of the first worries that came to mind when I was diagnosed with breast cancer in January 2010 was how I would manage financially with the expense of having to undergo a mastectomy and then chemotherapy.

The burden of a mortgage and bills was almost more stressful than the cancer diagnosis. I did not know what the future held, but I certainly did not want to be bogged down in financial anxiety.

Contrary to expectations, it was my work colleagues and friends who helped me most.

When I first became aware of my diagnosis, I talked to my manager and explained that I would still like to work as much

as I could manage. Not only did I need the money but I thought the distraction of work would also help me take my mind off things. I cannot say enough about how wonderfully my workplace treated me through this time. I owe my good health now in part to the assistance received from work friends. Quite often people would chat to me or comment about the various hats I wore to cover my bald head – just the general camaraderie was healing.

They secretly took up a collection for some credit card vouchers to pay for groceries and petrol as well as the services of a cleaner for six months, as I could not use my arm for mopping or vacuuming (I'd also had an axillary clearance).

Not everyone may be as fortunate as I was in being able

to work through my treatment, but I am sincerely appreciative of being given the chance.

Sheryl, SA



Sheryl with her son Luke and grandson Liam

Help from the CWA

In late January 2010, at the age of 60, I was diagnosed with breast cancer. As Canberra Hospital was unable to provide the treatment I needed in the required timeframe, I had to select a clinic in Sydney to which I could be referred.

In financial terms, my interstate transfer proved very costly. The ACT's Interstate Patient Travel Assistance Scheme (IPTAS) subsidy was at that time \$35 per night and, because I opted to drive myself, one tank of petrol per trip (I came home at the weekends). The hospital social worker offered me supermarket vouchers (kindly provided by a local cancer support group). At this time of high stress I broke down completely at being offered charitable assistance for the first time in my life and rejected the offer.

As it turned out, my financial salvation came from an unlikely quarter. The previous October I had joined the Country Women's Association (CWA). With my radiation therapy commencing in late April, I was eligible, as a member of six months' standing, to access member rates at the CWA's Residential Club in Potts Point. For a modest cost, I was able to have a three-course meal every night in their dining room, in most congenial company.

To my relief, I discovered that although the cost of the weekly radiation therapy was very high, I was reimbursed a high proportion very quickly by Medicare. The clinic facilitated this by sending the paid account details electronically to Medicare for me.

I made a careful summary of my out-of-pocket expenses and my

accountant included these in last year's tax return.

I feel aggrieved that, on top of the big disruption to my life brought about by having to spend more than six weeks interstate because my local hospital was unable to assist in time, the ACT Government subsidy was so poor. Interestingly, the CWA of NSW/ACT's recent conference in Nowra passed a motion calling for an increase in the low NSW Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) subsidy. In addition to offering scholarships and its other good work, the CWA is also a lobby group on issues affecting country people. My own feeling is that the subsidy should reflect the entitlements of public servants required to work for set periods away from home.



Carol

Carol, ACT

Going private

Six years after my older sister was told she had breast cancer, I too was diagnosed.

My husband and I had cancelled our private health cover several years earlier because of financial difficulties, so I wasn't in a health fund. Our finances had since returned to normal, but we hadn't rejoined.

I was diagnosed just before Christmas; and everything in the public system was taking a lot longer than normal. I was distressed and felt that I didn't want to wait, so I decided to self-fund the whole process.

This included a private doctor, private hospital and private radiotherapy. (Fortunately, I did not have to have chemotherapy). I would have opted for the public radiotherapy but it is not available on the Sunshine Coast where I live and fortunately a private radiotherapy practice had opened nearby. I was stunned to find that private radiotherapy can cost up to \$1,400 per week but in fact, it ended up only costing \$3,606 and I was out of pocket \$1,300, after my Medicare rebate.

I totally recommend going down

this path if free radiotherapy isn't available as I would have had to travel to Brisbane each day, which would have been horrendous.

In total, my breast cancer bill was \$13,000 and my out-of-pocket expenses cost me \$6,000. I didn't consider this too much for someone to save my life and to have it all dealt with quickly. As a matter of fact, my sister saved my life, as if I had waited another 12 months for my check, the aggressiveness of my cancer may have been incurable. So thank you Nancy.



Helen, right, with her sister Nancy

Helen, QLD

Using the tax offset

I'm forever being told I'm one of the lucky ones. When I read about others' journeys, there are a whole lot worse off than me. As well as having the most treatable breast cancer I also had my private health insurance, lots of sick leave entitlement, close proximity to excellent specialists and hospitals and most of all my supportive husband, family, friends and employers.

After I had my lumpectomy in September, I then chose to have a bilateral mastectomy with implants. That meant three operations in all, nine weeks sick leave and an out-of-pocket expense of approximately \$5,000. My reckoning is that I

now have more peace of mind and am in the enviable position of having a 98% chance of being cancer-free in four years, according to my doctor.

By chance I read a newspaper article about a tax offset for medical expenses after the first \$2,000. Lucky me again as all my expenses occurred in the one financial year. I am in the process of filling in my tax return and found no mention of this in the tax pack. It was, however, buried in the tax supplement where I think they don't want too many to find it. I was able to log on to Medicare and print out

my whole year's claim history, which, while rather daunting and depressing, helped me to calculate my total medical expenses, less refunds.

Compared with those who had similar operations to me, my out-of-pocket expenses aren't too bad. Having private health cover certainly gave me more options and more control and I don't know what I would have done without it.

Judy, QLD

Simple savings ideas

My tips are around being super organised.

I had six operations, six trips for chemotherapy and multiple procedures for which I had to travel from rural Queensland to Brisbane. The Patient Assisted Travel Scheme was a small help, however, you find you are largely out of pocket for accommodation and travel. My tip is to suggest you save all your dockets for tax purposes.

If you have the ability to stay with family and friends, that can help defray costs. Accept offers of food, clothes or other support – you deserve it.

Some of my operations and ongoing issues meant I was in



Kylie

Brisbane for over a week at a time, so that meant we needed accommodation and food for

my husband. I found that if we prepared some meals and froze them and took cereal, coffee, long-life milk and bread, etc, it meant we did not have to buy food from the motels or hospital cafeteria.

When I felt well, I cooked up meals, slices and biscuits to take with us.

I kept an Esky packed with basics for emergency trips, including our own crockery and cutlery, dishwashing liquid, soap powder, etc. Nothing like your own cup!

Make the most of it and write your experiences down.

Kylie, QLD

Keeping track of costs

To help manage financially I found the costs tracking pages in the *My Journey Kit* useful. I kept good records of all out-of-pocket expenses on these pages, including 'gap' payments to surgeons, specialists, chemotherapy drugs, hospital admissions, other pharmaceuticals, lymphoedema therapy and compression garments, physiotherapists, counsellor, etc.

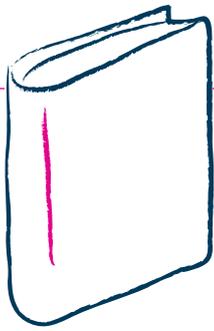
It took a bit of discipline to make myself keep these up to date but many times I was so glad I did. It made following up payments really easy, and I could do a quick total to see how much the whole breast cancer experience had cost me – so far totalling nearly \$9,000. Rather depressing, but it helps to explain why my husband and I have often felt poorer than usual in the past couple of years!

The other tip is, don't forget to claim your medical expenses on your tax if applicable, and register for the Medicare and PBS Safety Net schemes.

Denise, NSW



Denise



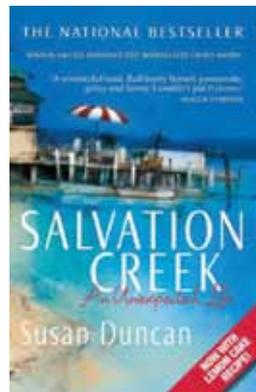
Reviews

Salvation Creek: An Unexpected Life

by Susan Duncan
Bantam, 2006 (paperback),
404 pages, RRP \$24.95

In her book, *Salvation Creek*, former journalist Susan Duncan shares a tumultuous time in her life: a time of loss and grief, a time when she faces a life-threatening illness, and a time when a complete change in lifestyle eventually leads to new love and happiness.

The story begins when Susan is in her mid-40s, living and working at a fast pace in Sydney. Her world begins to fall apart with the deaths from cancer of her husband and her beloved



brother within a few weeks of each other. Rather than face her grief and deal with it, Susan buries herself further in work, partying and alcohol. Eventually, she decides to leave work and

move to Melbourne, hoping that a change of scene will keep her depression at bay. It doesn't, in spite of support from good friends and her step-daughter.

In desperation, she accepts an invitation from other friends to stay with them at Pittwater on the NSW coast. Susan falls in love with the beauty and tranquillity of the area and, after renting for a while, buys a small water-access only house on Lovett Bay. An entertaining description follows of the problems and joys of living in such a location.

She begins a new job with a magazine in Sydney, but not long after her move, she is diagnosed with breast cancer. I think most women who have

had breast cancer will relate to her candid expose of her feelings and experiences, and all those people who have not been so afflicted will gain a greater understanding of what it is like.

I found this an excellent book in many ways. The storyline is interspersed with vivid descriptions of the beautiful landscape. The recipes Susan provides are an added bonus. It is written with warmth and humour, and offers hope and understanding for those in the depths of despair. I recommend it as an inspiring and insightful book that is also entertaining and informative.

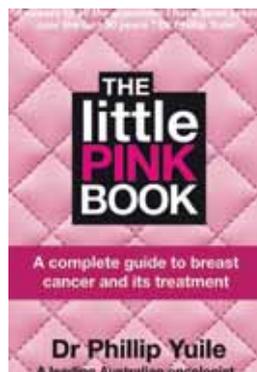
Chris Horsman
BCNA Review &
Survey Group Member

The Little Pink Book

by Professor Phillip Yuile
Finch Publishing, 2011
(paperback), 296 pages,
RRP \$29.95

The Little Pink Book reinforced for me that breast cancer is a disease with many variations and successful treatments, but no complete cure at this time. It is important, therefore, to continue all follow-up tests with your cancer treatment doctors.

The book is a comprehensive and professional guide to everything that is known about breast cancer. It is suitable for anyone who wants to learn all aspects of the disease – from the early history of diagnosis and treatment to current treatments



and developments, and much more. The book is easy to read for a general overview. Any of the 16 chapters can be turned to for ready reference. Each chapter has a summary of the major points at the end. An extensive glossary and index are also included.

If I had had this book at the

time of my early diagnosis, I would probably have just turned to particular chapters relevant to my case; otherwise I would have found it too overwhelming. Others, patients, family or friends, who want to know everything may read it all through and refer back to specific topics.

I would highly recommend the book: as it says on the cover, it is 'a complete guide to breast cancer and its treatment'.

Heather Hamilton
BCNA Review &
Survey Group Member

Professor Phillip Yuile is a Sydney-based radiation oncologist with 35 years' experience in managing breast cancer and supporting breast cancer patients.

*Once we believe
in ourselves,
we can risk
curiosity, wonder,
spontaneous
delight, or any
experience
that reveals the
human spirit.*

– e e cummings



Profiling our Member Groups

Whyalla Pink Spirits

The regional town of Whyalla is 380 km north-west of Adelaide, with a population of about 22,000. Our group, the Whyalla Pink Spirits, was re-formed in February 2011 following the BCNA Forum in Whyalla and the appointment of a McGrath Sellers Breast Care Nurse.

The group is for survivors of breast cancer and their friends, family and carers. We have a very active weekly group meeting at the Sundowner hotel-motel on alternate Fridays. It supports us by providing us with subsidised afternoon tea and opens especially for us as it is usually closed during our meeting times. These meetings deal with the more formal aspects of running a group, organising events and hosting guest speakers. They also provide time for networking.

Every second Friday we meet at Spotlight, which has allowed us to use its studio free of charge, and we use these days for crafting. This provides a therapeutic outlet. As hands and minds are busy, depression is kept at bay. During these meetings we share our cancer journeys, fears, anxieties and concerns, and form friendships. The items we make will be sold at a stall at our upcoming Big Pink Breakfast in October. We are currently decorating bras with the theme 'Outrageous' to display at our *Mini-Field of Women* to be held on 1 September.

The costs associated with a breast cancer diagnosis when living in a regional town can be overwhelming. We have a local hospital with two general surgeons. A limited amount of chemotherapy is available in partnership with the Royal Adelaide Hospital. Even so, many women continue to have to travel to and from Adelaide for surgery, chemotherapy and radiotherapy, a round trip of 760 km. This trip is exhausting and, believe me, it is no fun when you are feeling extremely nauseous and tired after chemo. On top of this there are the costs involved in taking time off work, finding accommodation, air and taxi fares if you do not have a support person, finding child minders and all the many other details that need to be attended to. If radiotherapy is required, then up to six weeks needs to be spent away from home. The

financial burden can become very heavy.

We try to help out where we can. While the Medicare rebate is extremely generous there is currently the issue that women have to buy a prosthesis before getting the rebate. This can be up to \$400! Whyalla Pink Spirits has implemented a program with our local lingerie shop, Top of Town Lingerie, where we pay the upfront costs. We have recipients sign a contract agreeing to reimburse the group once they receive the Medicare rebate. We also provide money for taxi fares as Patient Assistance Transport Services (PATS) does not cover them. While we may be a new group, we have lots of ideas and hope to be going strong for a long time to come!

*Elizabeth Anttila
Secretary of Whyalla Pink Spirits*



Amoena's Donna Thorton, Anne Byles and Elizabeth Anttila discussing the funding scheme for a prosthesis through Whyalla Pink Spirits

Linking together

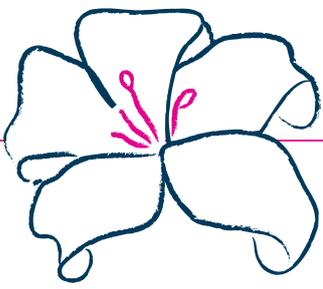
Over the past 13 years a key part of BCNA's mission has been to **link** Australians personally affected by breast cancer.

We welcome new Member Groups to our network. They now make a total of 305.

New Member Groups:

- Blackwood Valley Breast Cancer Support Group – Blackwood, WA
- Central Burnett Cancer Support Group – Mundubbera, QLD
- Choices – Young Women's Group – Toowong, QLD
- Cobram Breast Cancer Support Group – Cobram, VIC
- Hervey Bay Young Women and Mother's Support Group – Hervey Bay, QLD
- Indigenous Cancer Support Group – Geraldton, WA
- Indigenous Women's Breast Cancer Support Group – Perth, WA
- Inflammatory Breast Cancer – Toowong, QLD
- Life Force Cancer Foundation Support Group – Edgecliff, NSW
- 'Man Up' – Men's Cancer Education Forum – Camberwell, VIC
- Maryborough Breast Cancer Support Group – Maryborough, QLD
- Nathalia Breast Cancer Support Group – Nathalia, VIC
- PYNKS Support Group – Perth, WA
- Secondary Breast and Gynaecological Cancer Group – Toowong, QLD
- Strathpine Coffee Club – Strathpine, QLD
- Tamworth Breast Cancer Support Group – Tamworth, NSW
- Western Buddies Breast Cancer Support Group – Altona Meadows, VIC
- Women Who Partner Women – Toowong, QLD

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



Happy birthday Raelene!

On 1 July 2011 at Crown Palladium, Melbourne, Olympic legend and inspirational BCNA Board member Raelene Boyle kicked up her heels with Prime Minister Julia Gillard, Health Minister Nicola Roxon and Victorian Premier Ted Baillieu, along with the who's who of Melbourne. The spectacular party celebrated her 60th birthday and 15 years of survival since being diagnosed with breast cancer in 1996.

The night was truly a celebration of Raelene's achievements and an opportunity for us all to say thank you for the contribution Raelene has made to BCNA.

The event was a black tie affair but the hot pink of BCNA was proudly on display and matched the brightness of the mood in the room.

Paying tribute to the guest of honour, Prime Minister Gillard said: 'Your life has touched many people and this little gathering tonight is a snapshot of the wider esteem in which you are held. Esteem that was born in your career on the running track and grows with every day that you devote to this strong passion of yours – helping women as they journey through breast cancer.'

Interviewed on stage by MC, Eddie McGuire, and with her characteristic irreverent humour, Raelene's candid reflections on her life and its challenges had the 1000-strong crowd in the palm of her hand. There was no question Raelene Boyle is grateful for her good health.

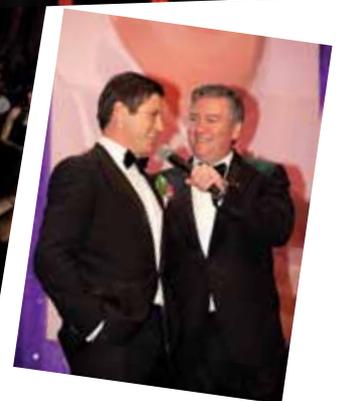
Auction items were fiercely contested on the night, and more than \$430,000 was raised



to help BCNA continue to support all Australians affected by breast cancer.

The event was generously sponsored by BHP Billiton, Nissan, NAB, Virgin Australia, Paspaley, Dacou Gallery, Focus on Furniture, 50 Kaliber Films, Maha Bar & Grill, and Crown.

Special thanks to Channel 7, Nine Network Australia and Channel 10 for providing the wonderful footage of Raelene used on the night. Also to our event contributors and to the generous support of many organisations and individuals for the range of silent auction items.



To see more photos from the night, visit www.bcna.org.au > Events > Key fundraising events > Raelene Boyle's 60th

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:

- Bell Charitable Fund, VIC
- Brasher Family Foundation, VIC
- Camden Survivors of Breast Cancer Inc., NSW
- Colleen Unger, QLD
- Drillpro Services Pty Ltd, QLD
- Dunlop Flooring, VIC
- Emma Murphy, NSW
- Ernst & Young Foundation
- Gold Cup Carnival Pink Ladies Day Mt Gambier – Tracy Bald, Julie Campbell & Committee, SA
- Green Acres Golf Club, VIC
- Helen Douglas, WA
- Jellis Craig, VIC
- Joan Staples, NSW
- Kate Krzys, SA
- Kembla Grange Pink Lady Family Race Day – Bakers Delight within the Illawarra and South Coast, NSW
- Kew Football Club – Scott Norman, VIC
- Lloyd and Dorothy Morris, VIC
- Lynn Brewster, VIC
- Margaret Illman, SA
- Merlvic Schrank Pty Ltd, VIC
- Ming Tak Ng, NSW
- Nissan Motor Co. (Australia) Pty Ltd
- Peter Madsen, ACT
- Peter McInnes Pty Ltd
- Rotary Club of Kew – Jill Forsyth, VIC
- Sacred Heart Parish Diamond Creek – Pat Guatta, VIC
- Sandra Munday, QLD
- Sarah Money, QLD
- Sophie Clark, VIC
- Stuart Rodger, NSW
- Sydney Women's Baseball League – Cassandra Boyle, NSW
- Sylvia and Tom Stock, NSW
- Theo Marinis, SA
- Think Pink Charity Golf Day Bonnie Doon – Jane Esposito, NSW
- Tontine Group
- Toshiko Budgen, QLD
- Yates Australia
- Yvonne Waddington, NSW

Special thanks to the participants, fundraisers and organisers of: *The Sun-Herald City2Surf*; *Run Melbourne*, and the 2011 Gold Coast Airport Marathon.

Memorials

We pay tribute to the lives of:

- Jeanne Norling
- Gwenda Painter
- Janet Pascoe
- Jennifer Ramsay
- Donna Vitagliano

Celebrations

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

- Lynette Dayman
- Cathy Jennings

An affirmation a day ...

In October, our long-time sponsor Sussan is launching two gorgeous boxes of affirmation cards – Love and Inspiration – that they have produced especially for BCNA.

'We asked breast cancer survivors, their friends and families to submit quotes on BCNA's website,' says Colleen Callander, CEO of Sussan.

'They could be about a personal journey, words of wisdom or just some kind words. We ended up with a final selection of 24 heartwarming quotes.'

Illustrator, Meredith Gaston, was honoured to be part of this unique project and donated her time to hand-illustrate the cards in her unique, whimsical style.

The launch of these cards follows Sussan's recent generous donation of \$120,000 to BCNA.

The affirmation cards are a lovely gift and will be for sale throughout summer for \$14.95. Sussan will donate \$10 from each box to BCNA.



BCNA gratefully acknowledges our partnership with Bakers Delight.





Dates for your diary

September Yoga and breast cancer with Annette Loudon. Various dates and locations. For more information visit www.bcna.org.au > Events > Search for an event

18 September Blackmores Sydney Running Festival. BCNA has been chosen as one of the supporter charities for this festival. If you would like to register to participate in the event and to fundraise for BCNA visit: www.sydneyrunningfestival.com.au

28 September Breacan forum on Lymphoedema, 12–1.30pm, BreaCan Resource Centre, Queen Victoria Women's Centre, 210 Lonsdale St, Melbourne. Judy Purbrick, Senior Physiotherapist, will talk about lymphoedema and its association with gynaecological and breast cancer. For more information or bookings phone 1300 781 500.

October Mini-Fields of Women will be held around Australia. Visit our website www.bcna.org.au to find a Mini-Field near you or to register your own.

October Combined Church Service for people affected by breast or prostate cancer, 2 pm, St James Church, 173 King St, Sydney. Date to be confirmed: for the final date check www.bcna.org.au > Events > Search for an event

2 October Combined Church Service for people affected by breast or prostate cancer, 2 pm, St Michael's Uniting Church, 120 Collins St, Melbourne.

8 October Free BCNA Coffs Harbour Forum. Register an expression of interest on 1800 500 528 (Freecall). Partners and carers welcome.

8 October Free BCNA Melbourne Forum. Register an expression of interest on 1800 500 528 (Freecall). Partners and carers welcome.

24 October Australia's Breast Cancer Day 2011.

30 October Melbourne Breast Cancer Bra Walk raising money for BCNA. The walk is 2.5 km, starting and finishing at Federation Square. Pram and wheelchair friendly. For more information visit <http://brawalk.gofundraise.com.au/>

31 October – 4 November A Quest for Life residential program for men and women living with cancer. Bundanoon NSW. For more information visit www.questforlife.com.au or phone 1300 941 488.

10–12 November 16th Reach to Recovery International Breast Cancer Conference, Taipei, Taiwan. For more information visit www.reachtorecoveryinternational.org.

19–20 November Gawler Foundation's 2011 Profound Healing and Sustainable Wellbeing Program, Melbourne. For more information visit www.gawler.org.

4 December Sussan Women's Fun Run 2011: 5 km and 10 km run or walk supporting BCNA. Catani Gardens, St Kilda, Melbourne. Cost: \$60 Adults, Junior \$50 (early bird entry fees available for entry before 28 October). For details and online entry visit www.supersprint.com.au. To raise funds for BCNA visit <http://swfr2011.gofundraise.com.au>.

Seeking stories – The new you

Many women tell us that, after breast cancer, they never quite return to the person they used to be.

How did you adjust to life 'after' breast cancer? What have

you learned throughout your journey? In what ways has your life changed? For better or for worse?

Please email articles of 200–300 words (about half a page) to

beacon@bcna.org.au by the end of December 2011. We ask you to provide a high-resolution photo, or post your photo to us and we will scan it and return it to you.

Join our mailing list

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