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Focus on:
The New You



the BEACON

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New you, new normal

Life certainly is full of highs and lows. Being appointed CEO of Breast Cancer Network Australia last year was a high point of 2011. My daughter starting her first year of university, travelling to Darwin with my husband and seeing the Top End for the first time and many other things were highlights in 2011.

Being diagnosed and treated for breast cancer was undoubtedly the low point.

I had a routine mammography where the radiographer was taking more pictures than I knew would be standard. The doctor then walked in to tell me what I already knew: there was an area that wasn't normal and needed a biopsy, which was organised for later that day. My attitude over the next few days, waiting for results, was not to worry unnecessarily or worry anyone else. I told my husband John there was no need to come with me to get the results as I thought it was likely to be nothing. Of course, as soon as my surgeon walked into the room I knew he was going to give me bad news. Invasive ductal carcinoma.

Surgery was arranged and I rang John to tell him. I needed a second operation to ensure a negative margin, which was followed by six weeks of

radiotherapy. I completed my radiotherapy in October and am now on tamoxifen for five years. So I guess the new me is oestrogen-free!

The day after I received my diagnosis I had a call from the recruitment company looking for a new CEO for BCNA. The serendipity of the timing of that phone call still amazes me. I wondered if I wanted to take on such a role so soon after diagnosis and treatment.

I decided I could, and I'm very glad I did as I really relish the chance to work together with everyone in our network.

I believe the person we are today is the sum of our life experiences. Our shared experience of breast cancer is what binds the network together. That experience, how we respond, live with and adapt to the change in our lives, is as diverse as we are individuals. Yet when reading *The Beacon* contributions in this issue I am sure some of the feelings and experiences described will resonate with you – be it finding your own Everest, leaving paid work, making a 'sea change', changing priorities, not taking anything for granted, getting

fit, finding love or going back to university.

I was impressed by the common theme of finding the freedom and confidence to be true to yourself and to be kinder to yourself.

For me, one thing that hasn't changed is my enjoyment of snow skiing. My husband John and I just love skiing and travelling together. Following active treatment we decided we needed time together and in January we went to Europe and skied from the highest cable car and breathed in the alpine air and the beauty of the landscape, a real treat not taken for granted.

Today, I love even more spending time at home with John and my son and daughter. Nothing that happened last year has changed that.

I hope you enjoy this issue of *The Beacon*.

Maxine Morand
Chief Executive Officer



Maxine enjoying the alpine landscape

Breast
Cancer
Network
Australia





Issue of concern

Why hormone therapy? Tamoxifen and AIs

Your pathology report provides information on the type of breast cancer you have. This information guides your doctors on how best to treat your particular type of cancer.

About two-thirds of breast cancers are hormone positive, meaning that the cancer is 'fed' by oestrogen and/or progesterone. Most women with hormone positive breast cancer will be recommended hormone therapy. These are oral medications that are taken daily for a minimum of five years following the completion of your other breast cancer treatments (surgery, chemotherapy, radiotherapy).

Clinical trials have shown hormone therapies to be very effective in reducing the risk of the cancer spreading to other parts of your body or a new breast cancer developing in the opposite breast. They have been shown to improve survival. Their use is based on the important role of oestrogen as a growth factor for hormone receptor positive cancers. Their impact on women's survival is substantial and ongoing, and increases over time, meaning that the benefits extend well beyond the time that you take them. They are therefore an important part of breast cancer treatment.

Types of therapies

Hormone therapies can be divided into two groups – tamoxifen (Nolvadex, Genox, Tamoxen) and the aromatase inhibitors (Arimidex, Femara and Aromasin).

Tamoxifen is used to treat pre-menopausal and post-menopausal women. It blocks the oestrogen receptor on the cell surface, stopping oestrogen from stimulating cancer cells to grow.

Aromatase inhibitors (AIs) are only used in post-menopausal women. This is to do with the way our bodies produce oestrogen.

In pre-menopausal women, most of the circulating oestrogen is made in the ovaries.

In post-menopausal women, the ovaries stop producing oestrogen. However, it continues to be made in fat cells and the adrenal glands. The enzyme aromatase is needed for this to happen. The aromatase inhibitor group of drugs blocks aromatase. This reduces the amount of oestrogen being produced by the fat cells and adrenal glands, and so reduces the amount of oestrogen available to feed cancer cells.

We know that taking a medication every day for several years is not easy, especially if you are experiencing side effects.

Whether you are pre- or post-menopausal is, therefore, important in determining the appropriate hormonal treatment for you.

Side effects

We know many women experience side effects as a result of the hormone treatment, and that sometimes these can be distressing. For other women, taking these drugs causes few unwanted side effects.

Menopausal symptoms can occur with both groups of drugs, and may include hot flushes, night sweats, heart palpitations, anxiety, sleep disturbance and fatigue. Vaginal dryness, painful intercourse and changes in libido can have a negative effect on sexual wellbeing and are more common with the aromatase inhibitors. There are ways to manage these side effects, including strategies you can try yourself at home and

medications your doctor can prescribe for you. BCNA's *Breast Cancer and Sexual Wellbeing* booklet includes suggestions on managing menopausal symptoms and the impact of treatments on sexual wellbeing.

AIs can also cause joint stiffness and pain, and may increase the risk of osteoporosis.

After menopause, women's bone density declines – so hormone therapy can have an impact on your bone density. Your doctor may refer you for a bone mineral density scan and/or blood tests to measure your calcium and vitamin D levels. You may be advised to take calcium and/or vitamin D supplements if your levels are low. Weight-bearing exercise, such as a brisk walk every day, is also beneficial in maintaining bone health.

Long-term side effects of tamoxifen can include an increased risk of thrombosis (blood clots) and thickening of the endometrium (the lining of the uterus), although the risk of developing these is low.

We know that taking a medication every day for several years is not easy, especially if you are experiencing side effects. Research has shown that 30 per cent of women do not adhere to their treatment as prescribed by their doctor. It is important to complete the full course of treatment to get the

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You can download a copy of BCNA's *Breast Cancer and Sexual Wellbeing* booklet by visiting www.bcna.org.au > Living with breast cancer > Sexual wellbeing, or phone us on 1800 500 258 (freecall) and we will post a copy to you.

Lymphoedema and breast cancer

Lymph nodes are glands in the armpit and other parts of the body that filter and drain fluid that circulates around the body. During breast cancer treatment, lymph nodes are commonly removed by surgery or may be damaged by radiotherapy. This can restrict the flow of fluid from your breast and arm, particularly if large numbers of nodes are removed, which sometimes results in swelling. This is called lymphoedema.

Some women are surprised to learn that they can develop lymphoedema in their breast, as well as their arm, following treatment. The use of sentinel node biopsy (the removal of the first lymph node that a woman's breast cancer may have spread to for testing) has reduced the rate of arm lymphoedema, because of the reduced number of nodes being removed. However, reports suggest that this technique may increase the risk of breast lymphoedema.

Not all women treated for breast cancer will develop

lymphoedema; however, it is possible for lymphoedema to develop at any time, including years after treatment is finished. There are many ways to manage symptoms.

If you have lymphoedema, or are concerned about it, you may like to ask your doctor to refer you to a health professional



who works with people with lymphoedema, such as a physiotherapist. Gentle exercise is sometimes recommended and can often be done at home. If you have a carer or someone who provides support, you may like to take them to the appointment with you so they can learn the exercises and help you with them.

Compression garments (tightly fitted garments worn on the affected area to stop fluid building up) may also be suggested. There is still some debate about how useful they are. Some women find them helpful, while others have told us they did not find any benefit in using them. Garments can be expensive and may need to be replaced often. All states and territories except Queensland and South Australia offer subsidies that may cover some or all of the cost of garments.

For more information, including a fact sheet that details the compression garment subsidies available, visit www.bcna.org.au > Living with breast cancer > Physical wellbeing > Lymphoedema.

Your doctor can tell you if you qualify for a GP chronic disease management plan that provides Medicare rebates for up to five consultations per year with allied health professionals such as a physiotherapist.

Issue of Concern continued.

most benefit from it. If you are having difficulty managing side effects, you may like to talk to a member of your treating team, as solutions can often be found. You can also join the discussion on BCNA's Online Network (www.bcna.org.au) to find out how other women are managing side effects.

Tailored treatment

The best use of hormone therapy – how many years to use it and which drugs or combination of drugs to take – is still being established in clinical trials, mainly because AIs are a relatively new treatment. For this reason, hormone therapy is used in a number of different ways.

Some women take tamoxifen or an AI for five years, while others may switch to an AI after two to three years on tamoxifen. Your doctor may suggest extending your hormone therapy to 10 years, by adding five years of an AI after five years on tamoxifen.

Regular follow-up with your doctor to monitor and deal with

side effects is important and may help you to stick to what is a long-term but very effective treatment. Regular contact with your doctors and other health professionals can also assist you with important general health strategies such as maintaining a healthy diet, weight and exercise regime.

Ask the Expert

Dr Carrie Lethborg



Carrie Lethborg

Dr Carrie Lethborg, MSW, PhD, is the Clinical Leader, Cancer Social Work and Coordinator Psychosocial Cancer Care at St Vincent's Hospital, Melbourne. She leads a team of psychosocial staff and runs a psychosocial research program. *The Beacon* asked Carrie about challenges women face after treatment is finished.

After treatment is finished, many women expect to go back to being the person they used to be, but we know this doesn't always happen. Why is this?

When a woman gets through the trauma of treatment for breast cancer, there can be a desperate and understandable desire for life to 'get back to normal'. It is the normal things, like being able to plan, eating what you want and being well, that can be missed the most. When treatment ends, it can be a shock that the 'normal' you used to have is no longer there. There may be ongoing physical issues, the worry of recurrence, the pondering of what is really important in life, and the aftermath of strained relationships that mean that treatment ending is not the end of the cancer experience. There is what we call a 'new normal'. Many women find it is a better normal in the long run, as they have been able to reflect on the things that are really important to them.

What sorts of changes might women experience?

Going through the trauma of being diagnosed, treated, telling loved ones, receiving care and love, being let down by loved ones and all the other things that women go through can change you as a person. You may not be as carefree as you were, you may be more carefree. You may learn to say 'no' to things and put yourself first. You may be more grateful for life, or fearful of uncertainty. You cannot go through a major life trauma and not be altered by it.

How can women help themselves to come to terms with these changes?

One of the things often missing from the support provided to women with breast cancer is the encouragement of a recovery period. Often friends and family are waiting for treatment to end and consider this to mean that the trauma of cancer is over. Health professionals send women off and tell them to get on with their lives and come back for periodic check-ups. These responses suggest that this is the end of the experience, yet we know that women need to recover emotionally, physically, socially, mentally and spiritually.

Recovery might mean giving yourself permission to rest and manage fatigue, processing the trauma through talking to loved ones, writing a journal,

seeing a counsellor, working on physical fitness, or reconsidering life goals.

I don't think that women need to 'settle' for a reduced quality of life. If there are ongoing stressors, these should be identified and dealt with so that, while you might not be the same person you were, you can still be magnificent! Don't settle for ongoing stress – ask for help and expect joy in your life once more.

How can women manage the expectations of those around them that life will 'get back to normal'?

I am often asked to see couples when treatment is finished. One reason for this is that the partner has been pacing themselves for treatment to end. They have been powerless during the diagnosis and treatment, and just want it to be over. Meanwhile, the woman has been just trying to get through the experience. It is not until she gets to the end that she stops and thinks about what it means for her.

So, just at the time that recovery starts for the woman, her loved ones are ready to 'get back to normal'. This can result in the woman feeling like she 'should'

be over the experience, that she 'should' be less fatigued, that she 'should' be happy and grateful. For the partner or loved ones, there is a sense of bewilderment that 'it's not over yet'.

One of the most helpful things I do with couples and family groups is to get them to tell each other what the experience was like for them and to really listen to each other. Cancer does not just happen to the person with the diagnosis – the trauma is as powerful for partners and loved ones, just in different ways.

What help is available for women who are struggling to adjust?

Social workers, breast care nurses and psychologists are often experts in this area. The Cancer Council's Helpline (13 11 20) and Cancer Connect program, where you can be linked to another woman who has been through a similar situation, are also good resources. Support groups can be great forums for encouragement – it is not uncommon for women who wouldn't have considered one during treatment to find them very helpful during this post-treatment period.

I remember reading at the time [of my breast cancer treatment] that there is a 'new normal'. You don't go back to normal. Your life is changed, that's for sure, but there is a new normal.

Kylie Minogue (ABC AM program, 6 October 2011)

Complementary or alternative: what are they?

I love to meditate. It sets me up for the day ahead and keeps my emotions on an even keel.

We often hear from women who are interested in using complementary therapies and medicines to improve their wellbeing. There are many products promoted to people with cancer, and it can be confusing to know which are effective and good value for money.

Complementary therapies

Complementary therapies are treatments or therapies that are used in addition to conventional medical treatments such as chemotherapy. Examples include massage, acupuncture and aromatherapy.

Many women with breast cancer find that complementary therapies can help to manage some of the side effects of breast cancer and its treatments, including anxiety and fatigue.

Complementary medicines

Complementary medicines are products that are used in addition to conventional treatments. Examples include vitamin and mineral supplements, herbal medicines including Chinese medicines, and homeopathic remedies.

Many people believe that complementary medicines are natural and therefore relatively harmless. However, they can cause unwanted side effects (e.g. skin rashes) and

may also interfere with breast cancer treatments, making them less effective. Vitamin C supplements, for example, can reduce the effectiveness of some chemotherapy treatments.

It is a good idea to speak with a member of your medical team about any complementary medicines you are taking, or considering taking, to discuss any possible impacts they may have on your treatments and health.

Alternative therapies

You may have also heard of alternative therapies. These are used *instead of* conventional treatments. Examples include ozone therapy and coffee enemas.

Unfortunately, very often there is no credible evidence to show that alternative therapies are effective in treating cancer. They may also be very expensive, costing thousands of dollars.

The decision to use an alternative therapy instead of conventional breast cancer treatment is a personal one. However, it is wise to discuss any treatments you are considering with your doctor and family. If you don't feel comfortable raising this with your treating doctor, there may be another member of your treating team with whom you feel more comfortable talking. This may be daunting, but it is important to be well informed about any treatment decisions you make.

For more information, visit www.bcna.org.au > Living with breast cancer > Complementary and alternative therapies.

Screening helps to save lives

A report from the Australian Institute of Health and Welfare (AIHW) has found that the number of women dying from breast cancer has dropped by one-third since the introduction of the BreastScreen Australia screening program.

The national BreastScreen program began in 1991. At that time, breast cancer deaths in women aged 50–69 were 68 deaths per 100,000 women. By 2007, they had fallen to 47 deaths per 100,000 women.

Similar research in the United Kingdom found a 28 per cent decrease in deaths there of women aged 50–69 who attended screening programs.

The AIHW report said that, along with screening, advances in the management and treatment of breast cancer have contributed to the significant reduction in deaths in Australia.

'Over-diagnosis'

You may have seen debate in the media suggesting that pre-invasive breast cancers,

such as ductal carcinoma in situ (DCIS), may be 'over-diagnosed' as a result of screening. BCNA believes that 'over-diagnosis' only becomes an issue if/when doctors are able to determine which of these pre-invasive cancers will become invasive (early) breast cancer and which won't. At present, it is impossible for a pathologist or doctor to know which tumours will spread and which will not. It is important, therefore, that women have regular

mammograms so that breast cancer can be detected early.

BCNA CEO Maxine Morand was diagnosed with early breast cancer in 2011 following a routine mammogram.

'My breast cancer was found early, which has had a big impact on the treatment I have needed and on my prognosis,' she told *The Beacon*.

Finding cancer early gives women a wider range of options in their treatment and improved survival rates.

Breast cancer conference in Sydney

BCNA is delighted to announce that we are hosting a two-day conference for women with breast cancer in Sydney on 25 and 26 October this year. The conference, part of the Sydney International Breast Cancer Congress, will be the first time in Australia that health professionals, researchers and women with breast cancer will come together in one location to listen, learn and debate the key issues in breast cancer.

The conference will be a fantastic opportunity for women to hear from world-leading authorities on breast cancer treatment and care, current research, and other areas of interest.

Program highlights include sessions on: new directions in treatment; managing relationships with partners, family and friends; dealing with menopausal symptoms; sexual wellbeing; and managing fear and anxiety.

With 800 places available, BCNA members are encouraged to take up the early-bird registration offer of \$200 (the standard registration is \$250). Women can register by visiting BCNA's website at www.bcna.org.au and following the links.

BCNA is also pleased to offer financial support to people living outside major cities to attend the consumer program as part of the Australian Government's *Supporting Women in Rural*

Areas Diagnosed with Breast Cancer program. The support will cover the cost of travel, accommodation and registration.

BCNA members and healthcare professionals are invited to apply via www.bcna.org.au or phone 1800 500 258 for more information. Selection will be based on the benefits to attendees' communities and financial need.

Local services online

Have you had a good experience with a breast cancer-related service or support? Let other women know about it by listing it in BCNA's Local Services Directory. This online directory features services suggested by BCNA members.

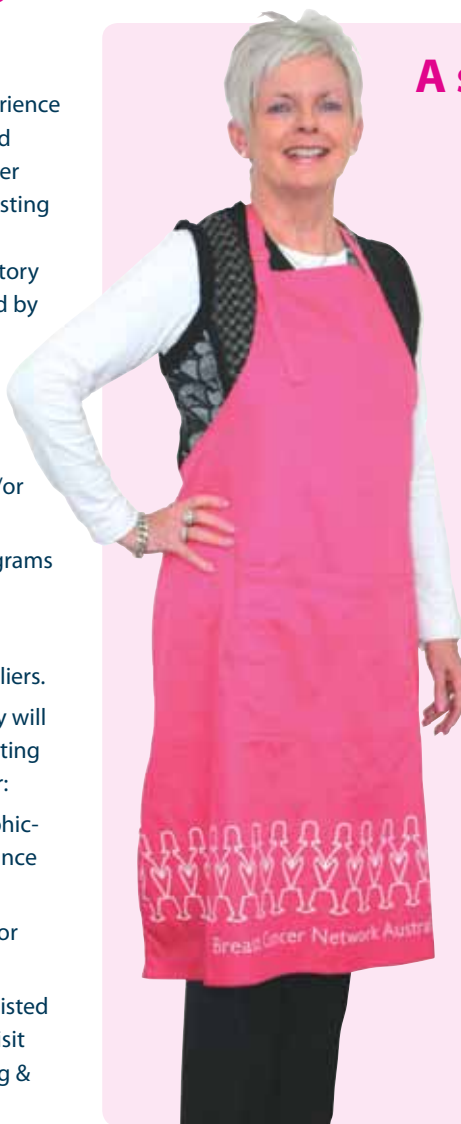
Services you may like to recommend include:

- support or counselling services for women and/or the whole family
- exercise and fitness programs
- specialist lymphoedema massage therapists
- wig and prosthesis suppliers.

Women in your community will then be able to see your listing when they search by either:

- Location – via a geographic-based search using distance from their postcode
- Type – using categories or keywords.

To suggest a service to be listed or to search for a service, visit www.bcna.org.au > Sharing & support.



A special gift idea for Mother's Day

Only \$40 + p&h*! Save \$10!

This gift pack** includes some of our most popular Pink Lady items:

- apron
- two pairs of socks
- key ring
- reusable shopping bag.

To purchase a pack in time for Mother's Day, order via BCNA's Online Shop at www.bcna.org.au > Shop > Shop for Pink Lady merchandise or phone 1800 500 258 by Friday 27 April.

* \$6 postage and handling

** Limited packs available



Find your own Everest

At 9.30 am on 20 May 2011, Sharon and Allan Cohrs reached the summit of Mt Everest. In doing so, Sharon became the first breast cancer survivor in the world to achieve this, and together they became the first Australian-born couple.

In December 2007, as avid mountaineers, my husband and I were preparing to embark on our next adventure to climb the highest mountain in South America, Mt Aconcagua (6962m).

That was until I discovered a pea-sized lump in my left breast. After a mammogram, ultrasound and needle biopsy, I had a nervous two-day wait until I received the dreaded news, 'You have breast cancer'. My world was turned upside down in an instant. Instead of embarking on an amazing adventure, I was about to enter the frightening world of surgery and chemotherapy treatment.

The next months were extremely tough. I was tossed into this unknown world of surgery and oncology visits. I had both breasts and lymph nodes removed and then started the dreaded chemotherapy. I took on my treatment like a climb, taking one small step at a time. Even when I felt weak and sick, I would force myself to keep moving and stay positive. I was determined that I was going to beat this horrible disease.

Throughout my treatment, I dreamed of being in the mountains, relishing the peace and simplicity. I thought about how lucky I was to have a caring husband, great friends and a loving family. It is so easy to

overlook or take for granted the good things we have in our life. I had been given a second chance, an opportunity to treat life as the precious gift it is.

Mountaineering was such an important part of my life before cancer, and it was a passion I was determined to re-ignite. I had posters of my favourite mountains plastered throughout the house while I was going through chemotherapy, giving me the drive and inspiration to get back to climbing.

In 2009 I was told I was cancer free and after that Allan and I trained hard and made a lot of sacrifices. Along with the intense training, I set myself a challenging schedule, climbing

four mountains in the lead-up to Mt Everest in less than two years.

It is incredible how far you can go when you focus and put your mind towards something. I got stronger, both physically and mentally, each time I returned to the Himalayas and climbed a more technical and difficult mountain. I developed confidence and an inner belief, knowing that if I put my mind and energy towards something, that anything was possible – even standing on top of the world.



Sharon and Allan Cohrs on Mt Everest

For each of us, life has a different meaning or purpose, filled with our own individual aspirations and goals. For some, being successful in business or staying fit and healthy is their major driving force. For others, fulfilling a life-long goal, travelling, or spending time with loved ones is what makes life special.

You never know what curve balls life is going to throw at you, and it is how you deal with them that define who you are. I am a stronger person since going through cancer, but have not changed who I am. I still love having a great time with my friends and family, and have learned to cherish those special moments. I have a great sense of optimism and joy for life, and I believe in living.

I now focus my time on sharing my journey, from the lowest times to the finest moments, with people from around Australia, hopefully inspiring and sharing my knowledge that with a positive mind and attitude, people can achieve wonderful things and go on to find their own Everest, whatever it may be.

If you would like further information about Mt Everest and Sharon's journey you can visit her website at www.climbingforacause.com.au.

Sharon, QLD

It is not the mountain we conquer but ourselves.

– Sir Edmund Hillary

The brightest light

Five years ago, I went for my first and last post-50 free mammogram.

A week later, after more testing, I was told by a very dispassionate health worker 'Yes, it is breast cancer. I suggest you go home and talk to your family. If you need any more information the nurse here will help you. Goodbye.' And he was off.

That was a dark day. Since then I have learned that there is nothing black and white about breast cancer or about life in general. Rather, there are a myriad of shades from very dark to glowing light. My brightest light is that I am alive today and that dark day is in the past.

For a bit of relief during my chemo treatment, my husband and I had a short holiday in Warrnambool. In my younger years I grew up surfing the south coast. I have always loved the beach, the sun and the great outdoors.



Ann

After recovering from my treatments I decided to establish a local support group in Daylesford. I was shocked at how many women in our small town had been affected by breast cancer, and how unknown that fact was. Our group registered with BCNA and I attended the 2009 Summit. I was involved with my community. I was happy

but I felt there was something more.

Then last year when we were holidaying in Warrnambool again, we spotted a photo of a fabulous house for sale in a real estate agent's window. That weekend we enjoyed our break by the sea, but said no more about the house. We returned home to Daylesford and got on with our work. We had a successful local business; we couldn't consider a move, or could we?

Before we knew it we were in the car and back in Warrnambool inspecting the house and making an offer. They accepted. That was a very bright day. We sold up everything, packed 20 years into a huge truck and headed for the beach.

Many people asked how I would cope not knowing anyone. 'Won't you be lonely?' My involvement with BCNA had shown me the possibilities. I knew I could go anywhere in

Australia and be welcome. I had a lifelong connection with women throughout the country. One of the first things I did was to join the local breast cancer support group. My new group meets for a casual lunch once a month. I have met women I know will be lifelong friends and have been invited to join a book club and a garden group, and have participated in various creative activities. Every Sunday evening just before sunset I walk along the beach and the cliff tops with some of my friends. I have been warmly welcomed. I feel very much at home.

Breast cancer has changed my life. It was the nudge that made us take a good look at where we were going. We've changed our priorities; the pressures have eased. The ocean invigorates me, and I have been reminded that life holds many possibilities. I feel free and happy. There have been some dark days in my life, but now I focus on the light.

Ann, VIC

So much to live for

In June 2006, at age 37 and with a five-month-old baby, I was diagnosed with breast cancer.

I had the operation and started chemotherapy. As a young couple wanting more children, we went to a fertility clinic to save some eggs and waited five to six weeks for my cycle to come for this to happen. However, I was so anxious about delaying chemotherapy any longer I had an infusaport put in and commenced chemotherapy. The next day I ovulated but it was

too late to save any eggs. I thought we had lost our chance of having any more children.

Part of my treatment meant putting me into menopause for about two years. After that I was eager to have another child and I discussed the possibilities with the IVF specialists, oncologist and surgeon.

To our surprise I was told I may be able to conceive naturally so my husband and I decided to try for a time without IVF treatment to see how things went.

Now 18 weeks pregnant, I am amazed that this was even possible.

I have much to live for and my family is carrying on with our lives as normally as possible. I work, go to the gym, do all the things I did before. Except I am taking things a little easier now as I do still get tired and I try to look after myself better. Luckily for me, my husband has always been very supportive.

I do feel lucky. I am happy too.

Anne-Louise, SA



Anne-Louise with her family

A chance to make my mark

Four years after my diagnosis of breast cancer I ask myself if I am the same person as I was before my diagnosis. Last week I did my annual tests and next week I get my results. How can I possibly be the same when this testing regime is now a part of my life?

I have been through the confusion of diagnosis, the fear producing tests, the cut and thrust of surgery, the awfulness of chemotherapy, the burning radiation and the energy-thieving Herceptin.

No, I am not the same person. I will never take good health for granted again. For the first time in my life, I enjoy and revel in the natural beauty of the world: the magnificent sunset, the cloud

sitting on a mountain, the dingo hurrying across the road.

Since my treatment I have travelled to Guinea in West Africa and Brazil to visit friends.

I have joined Dragons Abreast as a great way to mix with fellow survivors and supporters in a positive and constructive way.

I take nobody for granted any more. I value my time with family and friends. My greatest change is seeing my friends in a new light. They are truly there for me. So many friends were willing to give time to me. I had a friend say to me, 'I'm thinking of you, Anne. I know it's not much but I don't know what else to say.' He was wrong; at that moment of time it meant a whole lot to me.



Anne holding an orphan girl in Guinea

Every day is a gift, a delight, a chance to make my mark. Every day is full of life. I am so pleased

that I am not the same; I am a whole lot better. I feel grateful for the lessons of breast cancer.

Anne, NSW

A greater love and acceptance



Cindy

In October 2008 my mum was diagnosed with breast cancer. I was 37 years old and had just transferred with my job to Brisbane. I was then diagnosed with breast cancer in December 2008 and underwent surgery, chemotherapy and radiation. Then after 18 cancer-free months I was diagnosed with a new cancer in my other breast, underwent surgery and radiation, and am now taking hormone treatment.

I often ask myself how this has changed me; most of the time it seems surreal that this has happened to me. In thinking about it I would say I stress less about the things I cannot change – I say 'yes' more often and sometimes even 'no' more often. I allow myself to cry and feel I sometimes have reasons to be sad. I give my love more freely and try to look for the good in

all. I take time out when I need to and accept the world won't end if I do.

During my journey I have progressed in my career into a management role and most recently I won an award for my achievements. I fulfilled my dream of being in Paris when I turned 40, I found love, and now I go on the fast rides – for me the most significant thing that's changed is that I now believe I can do anything!

Cindy, QLD

The Inside Story is a free supplement to The Beacon which offers more information and stories about women living with secondary breast cancer. To subscribe phone 1800 500 258 (freecall), email beacon@bcna.org.au or visit www.bcna.org.au > Resources.

A new normal

This year is a milestone year for me as it's five years since I was first diagnosed with breast cancer at the age of 27. Two years after my diagnosis I was starting to feel like I was getting back to normal, although I was struggling to remember exactly what normal was. I had a new job, had bought a dream property in the country with my long-term partner, and was planning a trip to South America. I was about to turn 30: party time!

My surgeon sent me for my annual scans. I booked in early because I knew something had



Joanna and baby Isla

changed in my breast. I could feel another lump, but too much good stuff was happening

to really believe it. But, three weeks before turning 30, I was diagnosed for the second time.

I had a double mastectomy and started the whole process again.

Three years on from this diagnosis I think I'm as normal as I could ever have imagined I could be after such a hard five years. I now have a precious baby girl. Our house in the country is almost finished. I haven't been to South America yet and I've become a real homebody. I'll get there one day; I'm not in a hurry anymore.

I now have a new normal, which has just changed all over again but finally for a positive reason.

Joanna, VIC

Finding what is truly important

While I wouldn't wish for breast cancer, it has had its positive side.

For a start it clarifies things: you are very quickly reminded what is truly important to you. My diagnosis was a great reason/excuse to clear clutter from my life. You know – all those things you've said yes to, but are really not happy with. Following my mastectomy in 1995, and my husband Brian's operation for tachycardia, we started making choices for us.

I returned to uni to do a BA in Professional Writing, something I would never have had the confidence to do pre-cancer – and we began planning for Brian's early retirement.

Ten years ago we moved from



Sherrian

Melbourne to Devonport in Tasmania. Cooler, quieter, greener – we love it. We have been fortunate enough to make two trips to America, seeing

places we never imagined we would. (Sorry kids, we are spending any inheritance there may have been! Selfish? Maybe, but we earned it.)

Having been fairly timid I now have much more confidence.

Well – if you can face cancer ...! I have made a niche for myself doing my voluntary work at an aged care facility, even taking a small group for seated tai chi classes. Again, not something I would have had the nerve to do BC.

I find I am far more tolerant in general but much less tolerant of red tape and B#S#!

I have always known it is people who matter, not things, but I have started to realise 'I am a person too'. At last I am beginning to be true to myself, to listen to my inner being (and stand up for it!). I think that is the most important thing I have learnt.

Sherrian, TAS

Finding the true me

I have been living with, not dying from, breast cancer for over five years now. The journey has changed me in many ways and mostly for the better. Here are some of my observations.

- My large breasts have gone but I no longer have aching shoulders.
- My hair has grown back curlier and greyer but it is easier to look after.
- I have neuropathy in my fingers and toes so have less feeling in them – not so good.
- The scarring from surgery and radiotherapy feels numb and tight but I don't feel a lot of pain.
- The chemo treatment brought up old physical problems that I was able to clear with physical and emotional work.
- I have had to use my energy for healing so have set better boundaries and am more discriminating about with whom I spend my time.
- I have a far greater appreciation of how amazing my body is, even though it doesn't look the same.
- I have had the time to pursue my hobbies and do things I love.
- I have learnt to appreciate that both conventional and complementary treatments can work well together.
- I live more in the present and far less in the past and future.
- I chose to look at and discard some faulty beliefs that were running my life.
- I have been humbled by the amount of love and support I have received from so many people; and been surprised

by a few who weren't there for me.

- I have learnt to be proactive in my own healing and question some of the decisions made by others. I feel empowered and stronger.
- Chemo fog is real. My memory and concentration have deteriorated but I'm hoping they will improve.



Robyn

- Doubt is the enemy. I was overwhelmed by all the advice given to me but needed to trust what felt right for me.
- This illness has forced me to be weak, needy, vulnerable and dependent, especially on my husband Greg. He has kept everything as normal as possible and supported me in every area; over and above the call of duty.
- I have been challenged by my own mortality, felt the fear and have found a peacefulness within that I know I will be fine no matter what happens.

If my journey could be put into one sentence it would be: I have found the freedom and appreciation to be more of my true self.

Now to live it for a long time!

Robyn, VIC

Seeking the joy in the everyday



Ros

I was diagnosed with breast cancer at age 42 on the fifth anniversary of my mother's death from breast cancer. Now, a year on, I reflect on how I have adjusted to life as a survivor. In the early days of treatment I recall reading all the literature provided to me and being terrified at the thought that I wouldn't be the same person, physically or emotionally. I wasn't ready to change so dramatically.

The physical changes to my body have been hard to deal

with. My surgeon cheerfully refers to my lumpectomy site as my 'divot'. I don't see it unless I catch a glimpse in the mirror as I am dressing. However, an oophorectomy (for me, a welcome alternative to chemotherapy) brought on instant menopause, with hot flushes, changes to my skin and hair and difficulty sleeping. From a whole-of-life perspective, I have changed significantly. I find I am less prone to stress and anxiety. After cancer, many problems now seem minor,

and I reflect on how much unnecessary drama I created in my life. I am kinder to myself. I do yoga, take holidays, and seek the joy in every day. I have changed my focus at work, and a significant part of what I do now involves helping others through leadership coaching. I enjoy giving back.

All in all, absolutely I am a different person. I believe I am a better person – scars and all.

Ros, TAS

A health record that moves with you

Many women with breast cancer find it challenging to keep track of medical records and health information during their treatment.

From 1 July 2012, the Australian Government will introduce 'eHealth', a system that will allow your health information, such as prescriptions and test results, to be electronically shared by you and the doctors looking after you.

Your eHealth record will be controlled by you. By logging into a secure website, you will be able to manage your personal record and choose the information you would like to share and the health professionals with whom you would like to share it.

This will ensure that your health information is available when and where it is needed. In particular, women living in remote parts of Australia who may travel long distances for medical appointments only to find that records have not been transferred, may find this new system useful.

Whether or not you make your health information available through eHealth is up to you – it will only be available if you register for it. Registrations open on 1 July and we will tell you how to sign up in the next issue of *The Beacon*.

For more information, visit www.bcna.org.au > Living with breast cancer > Practical issues > eHealth.

Pink Footy & Netball Day

This coming Mothers Day weekend (12–13 May 2012) football and netball clubs from around Australia will be turning **HOT PINK** during their matches as they participate in the fourth annual BCNA Pink Footy & Netball Day.

Pink Footy & Netball Day is a chance for clubs to show their support for, and pay tribute to, women from their local communities who have been affected by breast cancer. It's free for clubs to participate, however, registrations are essential.

More than \$130,000 was raised last year with many BCNA members helping out their local clubs on the day.

Pink Footy & Netball Day is a great opportunity for the whole community to put on a show of strength and support for women affected by breast cancer. I loved seeing everyone come down, get involved and cheer on the teams. Kate, BCNA member, VIC

Registrations for Pink Footy & Netball Day are now open

Send us your best photos

In all the material BCNA produces, we try our best to use images of people who have been affected by breast cancer – they may have been diagnosed themselves or had a family member or friend diagnosed.

To keep our publications fresh and up to date, we are asking for your help.

Please send us any photos that you would be happy for



online. Help us keep the ball rolling so we can build on last year's success!

If you have a connection with a local football or netball club and

would like to get involved, visit www.bcna.org.au > Events > Key fundraising events > Pink Footy & Netball Day, or phone BCNA on 1800 500 258 (Freecall).

us to use in print or online. This includes on our website and in presentations, publications and general promotional material.

Photos may be of:

- you, during or after treatment
- your partner and family
- activities such as holidays, family celebrations, sport, fundraising events, etc.
- general day-to-day life.

While we always like to see our

members enjoying life, we know there are ups and downs and would welcome seeing these moments captured as well.

To submit your photos, please email them to photos@bcna.org.au

Please visit our website www.bcna.org.au > Sharing & support > Personal stories > Ways you can tell your story for further information and details for submitting your photos.



Profiling our Member Groups

Ten years on and paddling strong!

Dragons Abreast Illawarra is celebrating its 10th birthday on 29 April 2012. Catherine Holland explains how it started and why people get involved.

Dragons Abreast Illawarra was formed in 2002 after a group of breast cancer survivors were introduced to dragon boating. We are proud to be the third oldest group in Australia behind Darwin and Canberra. We paddle three days a week on Lake Illawarra with the mountains as our backdrop. Our group's motto is 'Friendship, Fitness & Fun!'

Dragon boating is a team activity. By being part of a team we support each other in regaining our sense of wellbeing, self-confidence and control of our lives after a breast cancer diagnosis. Our members come in all shapes, sizes, ages and fitness levels. Being part of the group is exhilarating and lots of fun. One of our newest members writes:

What a friendly bunch of people. They made me feel so welcome. They have a lot of experience and wisdom between them. Some have been paddling for many years and have some great tips, advice and encouragement to share.

After surgery, survivors can become very self-conscious about their appearance. Paddling helps them to rebuild their physical strength and confidence. When you are in the

boat all your cares and worries disappear; you become fitter and stronger over the passing weeks without realising that a change is taking place. Our group is honoured to have received a 'Healthy Cities' award for our continued participation in our local regatta, using the event as a means to show women that there is good quality of life after breast cancer.

Members get involved for various reasons. Some join purely for the social and fitness aspect while others love to participate in regattas. Several of our members have been lucky enough to be part of a combined Dragons Abreast Australia team which has participated in breast cancer regattas in New Zealand (2003), Vancouver (2005), Singapore (2006), Australia (2007) and Canada (2010). Dragons Abreast Illawarra entered a team into the first All Breast Cancer Participatory Regatta 'Abreast in Australia' at Caloundra, QLD, in 2007. We were among 1000-plus breast cancer survivors from sister groups across Australia and six other countries!

We enjoy paddling and socialising with our sister groups. Sometimes they visit us or we travel to them. After a paddle with our sisters there always seems to be some kind of pink party for us to enjoy. Over the years we have formed many

friendships with fellow survivors across the country and we always look forward to meeting up with them when the occasion arises.

We don't just paddle though. We like to get involved in many community activities, whether it is fundraising for our group, keeping ourselves updated on current breast cancer information, promoting the physical and emotional benefits of dragon boating to our community, or supporting those who run events to raise money and awareness of breast cancer.

As with many dragon boating groups, we welcome not only breast cancer survivors but all those affected including family and friends. It is great fun! The physical and emotional rewards vary from person to person but the rewards are many. To find out more please email us at illawarra@dragonsabreast.com.au.



Linking together

Over the past 14 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 total 308.

BCNA also has more than 67,000 individual members across Australia.

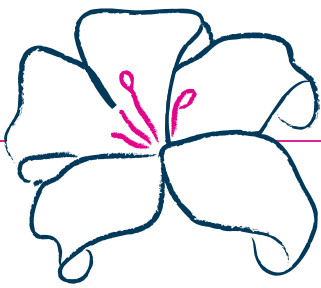
New Member Group:

- Sassy Survivors Inc. Gold Coast QLD

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



Dragons Abreast Illawarra



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:

- Aegis Global Australia, VIC
- Ali Macrae, TAS
- Allan Myers, VIC
- Arthur Pearce, NSW
- Auburn RSL, NSW
- Australian Olympic Committee, NSW
- AFL Cairns, QLD
- Belinda Cliffe, VIC
- Bevis Gibson, QLD
- BP Oakey, QLD
- Catherine Rolston, NSW
- Emma Taylor, WA
- Fireflies Wine Bar, VIC
- Greg Vaughn, NSW
- Hachette Australia, NSW
- Heather Christmas, VIC
- Jason Snoxall and Sydney Survivors, NSW
- Jordie Browne and Ellie Gwyther, VIC
- Justine Walsh, VIC
- Kalgoorlie Women's Tri Club, WA
- Kavi Rao, VIC
- Kay D'Alia, VIC
- Kingswood Golf Club, VIC
- Leanne Sher, VIC
- Loreto College Marryatville, SA
- Margaret Grant, NSW
- Maureen Chan, ACT
- Melba Hyne, QLD
- Michael Sowards and Adam Begg, 2012 Alpine Classic Challenge, VIC
- Peninsula Aero Club, VIC
- Peninsula Private Hospital, VIC
- Pulteney Grammar School – Mandy Hore, SA
- Sandra Western, NSW
- 2011 Sussan Women's Fun Run participants, fundraisers, volunteers and organisers, VIC

- Swan Athletic Football Club, WA
- Tania Harris, SA
- Twin Rivers Country Music Club, QLD

Memorials

We pay tribute to the lives of:

- Amanda Sue Leech
- Christine Elizabeth Norris
- Elizabeth Walker
- Filomena Franceschina Vocale
- Frances Merle Harrison
- Helen Margaret Mackenzie
- Jennifer Ann Griffin
- Joan Agness Ince
- Karina Woolley
- Katrina J Mitchell
- Kenneth Robert John Boylan AM
- Kerryn Dianne Hatfield
- Liliana Irma Willemsen
- Mary Aslanidis
- Mary Dib
- Rachael Joy Tomlinson
- Susan June Patterson
- Theo James Ellard
- Vivian Leung
- Wilma Elizabeth McAllister

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:

- Caroline Thomas
- Debbie Kralik
- Dianne McFarlane
- Houla Giahos
- Karen Barton
- Meg Vanderslink and Michael Dondas
- Meryl & John Kahler
- Sandra Stirling
- Shenae Mathieson and Andrew Hyder

Practical support from Sussan

Proud partner Sussan continues to support BCNA through innovative, beautiful and now very practical gifts.

This month all Sussan stores will be selling a new item – BCNA wash bags. These bags are the perfect way to protect your special items in the wash. They will sell for \$7.95 with \$5 from every sale donated to BCNA.

We are also working with the Sussan team on some beautiful items for Mother's Day, so keep

your eye out for them in your local store!

The team members in Sussan stores love to meet our members, so when you are out shopping, pop in and say hello. It is through the generous support of our sponsors, such as Sussan, that we can continue to provide programs and services free of charge to all our members.

If you don't have a Sussan store near you, shop online at www.sussan.com.au



Three-week sweet treat

It's almost time for the 2012 Pink Bun campaign! Every year we celebrate the incredible relationship we share with Bakers Delight through this campaign, where 100% of the money raised through the sale of Pink Buns comes directly to BCNA. Over the past 12 years of this unique campaign, Bakers Delight has raised a remarkable \$5.5 million for BCNA.

In 2012 we are kicking off the campaign with a special launch in Sydney, where local Bakers Delight franchisee Matt Smallwood is 'Pedalling for Pink Bun'. Matt will be riding a stationary bike in Bakers Delight bakeries around the Sydney area for 10 days to support the Pink Bun campaign.

I'm very excited to be launching this year's Pink Bun campaign. Every year, I am inspired by the women who come into my bakery and tell me their stories. This is my chance to support these women and go the extra kilometre pedalling for BCNA.
– Matt

This year's Pink Bun campaign runs from Thursday 3 May to Wednesday 23 May in all 614 Bakers Delight bakeries around Australia. The Pink Bun campaign raises funds to help BCNA continue our important work and to raise awareness of the support we provide to women affected by breast cancer and their families.

Bakers Delight staff have given us wonderful feedback in previous years about the immense benefit of working together with BCNA members and groups during the campaign and we would like to offer our thanks to everyone who has been involved in previous years. Your efforts are much appreciated.

Some of the ways you can join in the Pink Bun fun this year include:

- Develop a taste for Pink Buns and purchase them – and encourage your friends to do the same!
- For a gold coin donation, write a message of support on a Pink Lady silhouette in your local bakery
- Visit your local Bakers Delight bakery and thank them for their support. To locate your closest store, visit the Bakery locator at www.bakersdelight.com.au/BakeryLocator
- Vote for your local bakery in the best dressed awards at www.pinkbun.org.au

Helping others has never been sweeter! If you are able to support one of the most important events on the BCNA calendar and would like more information email pinkbun@bcna.org.au.



Matt Smallwood in training for 'Pedalling for Pink Bun'



BCNA gratefully acknowledges our partnership with Bakers Delight.





Dates for your diary

10–20 April or 7–17 May: Gawler Foundation 'Life and living', a healing cancer retreat, Yarra Valley Victoria. For more information visit www.gawler.org.au.

Thursday 19 April: BreaCan presents a free session on 'The two of us' for women and their partners, 6.45–8.30pm, Queen Victoria Women's Centre, 210 Lonsdale Street, Melbourne. Bookings are essential. Phone 1300 781 500 or email brecan@brecan.org.au

Friday 20 April: Free BCNA Warrnambool information forum. For more information and to register phone 1800 500 258 (freecall). Places are limited so register early to avoid disappointment.

Thursday 3 May to Wednesday 23 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 12 to Sunday 13 May: Pink Footy & Netball Day Mothers Day weekend. Local football and netball clubs will turn pink to support BCNA. For more information and to find out if there's a game in your local area, visit www.pinkfootynetballday.org.au

Sunday 13 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

Sunday 13 May: Melbourne Piano Trio's Pink Lady Concert, supporting BCNA. 4 pm, Melbourne Recital Centre, 31 Sturt Street, Southbank. \$50 adult; \$35 concession. Book online at www.melbournerecital.com.au or phone 03 9699 3333.

Wednesday 23 May: Free BCNA Bundaberg information forum. For more information and to register phone 1800 500 258 (freecall). Places are limited so register early to avoid disappointment.

Friday 25 May: Free BCNA Cairns information forum. For more information and to register phone 1800 500 258 (freecall). Places are limited so register early to avoid disappointment.

Tuesday 19 June: Free BCNA Lismore, NSW, information forum. For more information and to register phone 1800 500 258 (freecall). Places are limited so register early to avoid disappointment.

Tuesday 23 to Friday 26 October: Sydney International Breast Cancer Congress 2012. For more information visit www.sydneybreastcancer2012.com.

Travelling Pink Lady

In the December issue of *The Beacon* we included a Pink Lady car sticker as a gift to our members. One of our members sent through this photo and message: all the way from Switzerland!

The Pink Lady sticker is now proudly on the back of my car for all to see. Your Pink Lady has travelled half way round the world to get here. The kangaroo sticker on the garage is a souvenir from my trip to your wonderful country. Keep up your good work and best wishes to The Beacon staff and readers for the New Year. – Jan, Switzerland



Seeking stories – Unsung heroes

We are seeking stories for the Spring 2012 issue of *The Beacon* about **unsung heroes**. Who helped you along the way? Who made a difference to your experience, and how? Was it someone unexpected?

A stranger perhaps, or maybe it was your breast care nurse, neighbour, colleague, local hospital staff, or a sales assistant in a wig library or lingerie shop. Please email articles of 200–300 words (about half a page) to

beacon@bcna.org.au by the end of June 2012.

We ask you to also include a high-resolution photo, or post your photo to us and we will scan and return it to you.

Join our mailing list

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



the BEACON

BCNA
293 Camberwell Road,
Camberwell, Victoria 3124
1800 500 258 (Freecall),
(03) 9805 2500
beacon@bcna.org.au or
www.bcna.org.au

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