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the BEACON

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Sharing the journey

We all know that when a woman is diagnosed with breast cancer she is not the only person directly affected. It is usually also a scary time for those close to her, and sometimes they can struggle with the news even more than the woman herself. Perhaps we are getting better at addressing the needs of the person with the disease; let's hope so. I do wonder, though, whether we've made much progress in figuring out how to help husbands and partners.

I acknowledge that not all women have partners, not all partners are males, and not all males are husbands. It does seem to be that women have the capacity to reach out to one another, to ask for help, to offer support in a more open way. I keep hearing from women about how their husbands struggled, how no-one asked how they were managing, how they wished there was some real assistance out there for them. Several support groups have been set up over the years, but most have folded within a short time. It seems men do not want to attend support groups. The focus of everyone's attention is the woman (as it needs to be), but the issues and needs of the blokes are often left out.

We need them to be supported. How can they support us if they



Standing together at the Sydney Field of Women LIVE in 2007.

are floundering themselves? Many men consider themselves 'Mr Fix-it' – if there is a problem, they'll fix it. It must be upsetting to face a situation they simply cannot fix.

This *Beacon* closely considers issues concerning partners. Many readers have written glowingly of the phenomenal support they received from their husbands and partners and how their relationships were strengthened through the ordeal; sadly others felt, and were, abandoned when

the going got tough. Our survey results are interesting.

You may have been lucky enough to hear BCNA's Ambassador and breast cancer survivor, **Stephanie Dowrick**, present her words of inspiration and wisdom at one of our forums around the country. On page 8, Stephanie explains how partners and close friends can best support one another after a cancer diagnosis.

Many women say they draw strength from notes, cards and

emails sent by friends and family members, to help support them through their breast cancer journey. Our recently launched *Virtual Field of Women* (www.fieldofwomen.org.au) website offers loved ones a new way to send messages of support to the women or men in their lives who have been affected by breast cancer. You can read more on page 2.

As always, we hope that the articles and information included in our *Beacon* are not only of interest, but also of help to our readers. Sometimes, simply knowing there are others out there with similar experiences and challenges can be a comfort. Some women requested that only their first names or pseudonyms, rather than full names be used, so we have taken that approach throughout this issue. Again, we thank all of you for your generosity in sharing your private thoughts with us in this issue.

Lyn Swinburne
Chief Executive Officer



Breast
Cancer
Network
Australia

BCNA around the country

More than 130 women, family and friends attended the **Lismore NSW forum in May**, where they heard from BCNA CEO and breast cancer survivor **Lyn Swinburne** and local medical oncologist **Dr Adam Boyce**.

Many women came from regional areas around Lismore, some driving for several hours to attend. They appreciated the opportunity to meet with other breast cancer survivors and to learn more about BCNA's work and current breast cancer treatments.

In June, BCNA hosted around 250 women, friends and partners at a forum in **Sydney**. Guest speakers included Lyn Swinburne, medical oncologist and BCNA Board member **Associate Professor Fran Boyle**, who

spoke about the latest breast cancer treatments, and BCNA's Ambassador, author and breast cancer survivor **Stephanie Dowrick**, who gave a wonderful motivational talk.

Have you ever wondered how and why your breast cancer tissue is tested, stored and what that means for your treatment?

BCNA's next forum for women, focusing on pathology, will be held in **Melbourne** on the afternoon of Saturday 11 October 2008.

Associate Professor Michael Bilous, Director of the Tissue Pathology Department at Westmead Hospital, Sydney, will give an insight into breast cancer pathology – how and why breast cancer is tested for hormone receptors and HER2 status, where



A couple at our Sydney forum.

tissue is stored, and the tests that will be available in the future. Melbourne oncologist **Dr Richard de Boer** will explain how pathology results guide treatment options for women.

Stephanie Dowrick will also share her wisdom and inspiration.

The venue, Melbourne Grammar School, Domain Rd, Melbourne, has limited seating, so **please book your place as soon as you can**. Bookings can be made online via our website at www.bcna.org.au > Events > BCNA forums.

www.fieldofwomen.org.au

BCNA's *Pink Lady* has been planted in cities and towns around Australia. She has come to life on the MCG in Melbourne and Telstra Stadium in Sydney and now she is on the world wide web.

Our new *Virtual Field of Women* website (www.fieldofwomen.org.au) offers family, friends and colleagues the opportunity to leave messages of support for anyone who has had a breast cancer diagnosis, recently or in the past.

Women tell us that messages from loved ones can be a wonderful and powerful support, especially following a new diagnosis. The *Virtual Field of Women* helps loved ones send messages to anyone around the world.



Sporting legends David Neitz, David Schwarz, Steve Moneghetti, and Raelene Boyle, and actor William McInnes were among the first to leave messages of support to their loved ones at the launch of the Virtual Field of Women. To view the messages visit www.fieldofwomen.org.au

As with the *Field of Women* event that launched BCNA in 1998, the site allows you to leave:

- a blue man message for a man diagnosed with breast cancer or
- a white lady tribute to those who have lost their lives to breast cancer.

It costs \$20 to leave a message. The money raised will help ensure we can continue providing free resources, such as our *My Journey Kit*, to those affected by breast cancer.

We are excited about this new and unique way of linking people together, however we need your help to spread the word. Inside this **Beacon** is a *Virtual Field of Women* flyer, please pass it on to a friend or family. If you would like more flyers, contact BCNA on 1800 500 258 (freecall) or email bcna@bcna.org.au.

- a pink lady message for a woman diagnosed recently or in the past



Issue of Concern

Breast cancer's effect on couples

I think we have made it through the tough times and our relationship is getting stronger again.

He was always supportive, but when it came to discussing the possibility of not surviving, he did not want to discuss it.

Being in a relationship during the trials and tribulations of breast cancer can be filled with complexities, challenges, heartaches – and unexpected joys. To understand the effect breast cancer had on women's relationships with their partners, we invited 100 of our members, randomly selected from our Review & Survey Group, to complete a short survey. A number of themes emerged from the 64 responses we received.

Strength

I feel I have become stronger in myself since diagnosis and treatment, and my attitude to all things including relationships is more live for the day and enjoy it, or don't do it.

Many women felt that their partnership was strengthened, which resulted in, among other things, increased communication and feelings of closeness, particularly at the time of diagnosis.

Support

He loved me. Cared for me. Let me cry.

Not surprisingly, many women told us that practical and emotional support from their partners was of great assistance. When asked what helped the most, many said it was when their partner looked after the children, went to appointments or looked after the household.

Women noted that it was helpful when their partners listened to them, took an interest in research about breast cancer, provided emotional support and did not try to 'fix' things. Around 63% of women said they felt their partner was always supportive.

We found that feelings of closeness and increased communication tended to be strongest for most at the time of their diagnosis. In contrast, the time during treatment was often reported as a time of increased stress on the relationship.

Some women felt that their partners did not help enough in practical ways, such as with childcare or housework. Others felt their partners were not emotionally available or avoided talking with them about their fears. Twenty-six per cent of women who responded to the survey said their partner was not able to support them as much as they had hoped.

Our survey findings suggest that some women felt the levels of support from their partners fluctuated during their breast cancer journey. Significantly, nearly 40% of women commented on feeling their partner's support diminished after their active treatment, such as surgery, chemotherapy and/or radiotherapy, had finished.

Women consistently commented that their partner, and others, expected life to get back to 'normal' once treatment was over. This was often identified as a source of frustration and stress. Many women also reported a decrease in communication or feelings of closeness at this time.

Separation

He left when I had early breast cancer ... I recently remarried.

From time to time we hear from women about the detrimental effect breast cancer has on their relationships. In the survey we asked women if their relationship had ended during their breast cancer experience. Six per cent of those surveyed indicated that their relationship broke down between 12 months and two or more years after their treatment ended.

The impact on partners

I think there was more stress for my husband in dealing with my diagnosis than what I felt.

Throughout the survey, some women commented that their partners felt stressed and distressed while they went through breast cancer, which reduced their ability to support them.

We also asked them where their partners found support for themselves. Overwhelmingly, women told us that their partners looked to family and friends, followed by printed information or a breast care nurse for support.

These findings demonstrate there is a need for more recognition of partners' experiences and their role in supporting women with breast cancer.

The findings also suggest that more support for women and their partners at all stages of the breast cancer journey would be useful to help couples manage during and after this challenging time.

You can read the full survey report at www.bcna.org.au > Policy & Advocacy > Research reports and surveys or phone us on 1800 500 258 (freecall) for a copy.

My rock

We are the Jarretts, Patricia and Ed. Nine years ago we retired to our beautiful Caves Beach, for what we thought would be a life of pleasure and fun. Instead, after 50 years of marriage, we now truly understand love, strength, loyalty, hope, faith and trust.

The deadline for submitting this article for **The Beacon**, 30 June 2008, will be a momentous day for us. It is the day that Patricia faces the trauma of the surgical removal of her left breast; a breast that has succoured three children and has been an important part of her anatomy for 71 years.



Patricia and Ed celebrating their 50th wedding anniversary.

At this stage, I wonder how will she cope, how will we cope? How can we cope? The answer has been laid in stone over our 50-year journey together

and particularly reinforced approximately five years ago when I had colon cancer surgery, followed by six months of chemo. Patricia was 'the rock'. Then, two years ago, I had a heart bypass. Again, Patricia was 'the rock'. It now breaks my heart to see my rock become a small frightened worried pebble (but only for a week or two).

The other day, as we sat holding hands on our balcony, gazing at the ocean, we talked about the cancer and the operation. We spoke openly about the bad news of having cancer and the good news for detecting it early. All of

the strength that she has given to me was given back to her. To my wife, my lover, the mother of my children, my best friend, and she, no **we**, will handle this part of our life's journey together. We know the surgery is necessary, we know about chemo, we know that it is another challenge to our loyalty, love and trust in one another. We know we shall complete this journey and return to our balcony and gaze at the ocean and quietly thank God. This time I shall be her rock.

*Ed
Caves Beach, NSW*

A new perspective

Our journey began in 1988. On Margaret's 44th birthday, the specialist told her the lump in her right breast was malignant. After having the lump removed we have had 19 years of clear mammograms.

In all this time I have been to every visit and check up and have found it the only way to understand what Margaret has been through and support her. Having a specialist who includes us in all discussions has also helped. On one occasion the nurse doing the mammogram also allowed me to see what Margaret was going through during her mammogram.

After 19 clear years, 2007 saw the return of a worrisome lump in the mammogram. Subsequent

investigation found it was necessary to remove the breast.

Margaret's outlook during this time has been great.

It's funny how people have different fears when it happens. My greatest fear when it was decided to remove the breast was the possible bad scarring and that the cancer had got into the bones, while Margaret's greatest fear was losing her hair if she needed chemo. Thankfully everything has come up clear.

The reaction of our twin grandsons has put it all into perspective. When one of them learnt that Grandma had lost one of her 'boobies' he wanted to retrieve it and give it back!

*Terry
Traralgon, Victoria*



Margaret and Terry

Mr Fix-it

From the time a lump was found in my wife's breast I suspected it might not be good news. I took a fairly clinical approach to it though and assumed that if it was diagnosed as cancer we would just deal with it.

Nevertheless, it was still a shock when Jane and I went to her local GP to hear her diagnosis. The cancer had spread to her lymph nodes. The seriousness of Jane's situation was brought home to me there and then. All the specialists we have seen since, however, have been positive about Jane's outcome, which has taken a little of the pressure off.

Probably the biggest frustration for me, and Jane, is that I have not 'been there' for Jane all the time. Most of Jane's support needs are emotional, not physical. I am good at the physical, but apparently I am hopeless at the emotional.

Being a typical man I am a 'fixer' and the thing I find most frustrating as Jane progresses through her treatment is that there is little or nothing I can do that actually helps.

In the main, we are totally reliant on the care and treatment provided by the specialists. We don't seem to have any say in the treatment offered or decisions to make about the treatment, which leaves both of us feeling helpless.

Jane has been critical of me for not doing more research about her cancer and complementary treatments. The truth is that I have done a lot of research, but so much of what I have read is negative and alarming and leaves me feeling very distressed about the possible outcome. I cannot imagine life without Jane and so,

in a funny way, I try to ignore the negative information that I read and try to get through each day as normally as I can.

I am learning, however, that this is not what Jane wants and that she wants a lot more of my emotional support – something that I find hard to do but something I am slowly starting to learn. We still have a long journey ahead of us with the reality being that the journey will never be over and that cancer will always be part of our lives. Our challenge is learning how to live with that fact and not allowing it to totally consume us so that, at some point, we can recommence as near-normal a life as possible.

*Clive
Allambie Heights, NSW*



Clive and Jane

Tips for couples

A diagnosis of breast cancer can be incredibly confronting and stressful for couples. These suggestions may be useful for you and others you know.

Providing support

Often women who completed our Partners' Survey mentioned that they most valued the times their partner just listened and did not try to 'fix' things. They also valued talking about fears and hopes for the future. Other types of support mentioned were more practical, such as: reading about breast cancer research and therapies together; attending appointments together; showing understanding about fatigue; asking friends and family for support; and being prepared for the time after treatment, when things may not automatically return to normal.

Talking to someone

Some couples find it helpful to see a counsellor to talk through issues. GPs can give referrals to a psychologist, psychiatrist, occupational therapist or social worker. A Medicare rebate is available for up to 12 counselling sessions if you have been referred by a GP.

Relationships Australia also offers counselling for couples and individuals. They can be contacted on **1300 364 277**. For more details about other counselling services in Australia, visit our resource page at www.bcna.org.au > Information > Resources or phone us on 1800 500 258 (freecall) and we will post you a copy.

Ask the Expert

Dr Jane Turner is a practising psychiatrist and researcher specialising in breast cancer. Based in Queensland, she has vast experience with women with breast cancer and their partners. We asked Jane questions about the challenges for couples living with breast cancer and her suggestions for working through them.

What are the main challenges for partners of women with breast cancer?

Distress for both men and women increases with a cancer diagnosis. However, once a woman starts active treatment (surgery, chemotherapy and/or radiotherapy), her distress will often decrease, in part because she's doing something. Her partner, on the other hand, can feel like a passive bystander, and their level of distress can be high. This can be particularly challenging for those men who tend to respond to problems by trying to fix things. However, breast cancer is something that they cannot fix, which can leave them feeling out of control.

Doctors may assume that the partner will provide support to the woman, but in some instances they are not able to because they are feeling overwhelmed too. Men often say things to me such as, 'She's the one with the cancer. I have to hold it together'.

A partner may also be doing additional domestic tasks, which could be an added stress. The problem is that he may be still trying to earn a living at the same time as taking on the



Dr Jane Turner

additional role. Partners need to be acknowledged and supported, along with the woman who has breast cancer.

Another challenging time for partners may be when a woman has finished her active treatment. Her partner may think, 'Okay then, back to business as usual', as a way of protecting himself and moving on. However, often she can feel that her life has changed, which can mean that her priorities are different.

How do you ask for, and get, the help you need from friends and family?

Being really specific and concrete about the type of help you need from friends and family can be a good start. The person who has been asked often feels better with a specific request because they know they are doing something that is valuable. People can only respond in a way that is helpful to you if you tell them what you need.

Do relationships often break up because of breast cancer?

I don't think they necessarily break up because of breast cancer, but the stress can sometimes be the straw that breaks the camel's back. However, I hear a lot of people say that they become a lot closer, despite the difficulties.

What are some of the positive outcomes for relationships?

Well, I think a lot of people let go of stuff that does not matter. They say things such as, 'I no longer worry about having immaculate grouting between the tiles. I realise now that that's less important than having time with my partner or my children'. They will often become more proactive in things that they think matter.

How do you keep communication open between yourself and your partner?

Often I hear women say, 'I'm really scared of what will happen', and he'll say to her, with the best possible motive, 'You'll be fine love', because he may be worried about talking about things that are upsetting. My experience, however, is that most people who talk about their fears feel liberated. It actually takes energy to keep things inside. When it is out in the open, it is often a great relief.

My other advice is to be assertive about what you need, both from your partner, and from others. I often say to women, 'Look, you may not like the script, but you're in the director's chair. If you can't be selfish now, then I don't know when you can'.

Our share

I had been widowed 8½ years before I was diagnosed with breast cancer.

I had just met Peter who was a widower of three years. His wife had died of breast cancer. My husband had also died of cancer.

We had been seeing each other for six months when I discovered I had breast cancer.

I said I would understand if Peter wanted to 'part company'.

He stayed around; however he was not much support for me as far as appointments and treatment were concerned.

Luckily I had lots of really good friends and relatives who helped us both out.

Nevertheless, Peter and I are still together 11 years later.

Four years ago Peter was diagnosed with bowel cancer. I think he now realises how he did not support me through my journey, as I have been there for him all the way through his troubles.

Last year he had another bout of it, so he needed to have chemo and radiation once again.

We have both had our 'share' of cancer.

June
Perth, WA

More stories

Visit our website at www.bcna.org.au > Stories to read more personal stories from women and men about how breast cancer has affected their lives.

If you would like to submit a story to be considered for **The Beacon** or our website send it to beacon@bcna.org.au

Falling in love

In 1991 I was diagnosed with inflammatory breast cancer and not given a good prognosis.

I was a single parent and my son had been married a month earlier, so I was on my own.

I was, as we all are, devastated to say the least. A good friend and support person of mine confided in a good friend of hers, Graeme. He was touched by her sadness and thought if this was how she was feeling, how must I be feeling? So he came around to offer his support as a friend, should I ever need it.

As it turned out, we became good friends and support for each other. Over time, this friendship turned into love.

Graeme was advised against getting involved with me by one of his friends and a family member because I might die.

This hurt me deeply, although I could understand their concerns.



Michelle and Graeme on their wedding day, with their grandsons Riley and Tane.

Graeme responded by saying he could get hit by a bus and die before me, so he was not going to live his life worrying about what might happen.

This beautiful man stood by me every step of my treatment – during chemo, a mastectomy,

more chemo and then radiotherapy, a blood clot in my lungs and everything else that went wrong. Not once did his support, loyalty and love falter.

Graeme told me that going to all my treatments and seeing all the other cancer patients only

helped him realise that we were not alone and there were a lot of people worse off because they had no one to support them.

Some people lost their partners, because their partner could not cope. However, Graeme never contemplated leaving. In fact, he asked me to marry him.

I know how lucky I am to have Graeme in my life. My life is completely different since my diagnosis; the only thing that is still the same is I still work as a nurse. Every other aspect has changed for the better. Breast cancer has given me a life that is so happy and fulfilled, which I will not take for granted. I honestly believe the love and support I get from my husband is what made the difference to how my health is today. As Graeme says, he fell in love with me, not my body.

*Michelle
Waikerie SA*

New beginnings

I was first diagnosed with breast cancer in January 1990. Initially I had a lumpectomy, followed by ray treatment and recovered well with the help and support of my husband. We had three children at this time.

In 1992 the lump recurred and I had a mastectomy.

Although my husband seemed to be coping with the situation well, in 1996 he decided that he needed to make a break for himself.

This, I feel, was caused by the continuing uncertainty about my future.

His mother had died of Hodgkin's lymphoma when he was 13 and I feel he had never really dealt with this.

He has since remarried.

Although I continued in good health, with no recurrence of the initial cancer, I was diagnosed with breast cancer in the other breast in September 2006, again followed by a mastectomy.

Genetic testing has revealed that I carry the BRCA2 gene. I have subsequently had my ovaries removed.

I am currently not in a relationship and help care for my 81-year-old mother, who survived breast cancer in 1998.

I do not work, but help as a volunteer swimming coach over summer.

This year I began studying for a diploma in fine art.

*Robyn
Wodonga, Victoria*



Are we in this together?

Stephanie Dowrick describes how partners (and close friends) can best support one another after a cancer diagnosis.

There is no 'right time' to discover you have cancer and there is no 'right way' to respond. Many of us have a picture of the ideal patient in our minds – and believe we fall far short! This ideal patient is brave (of course). She does not complain (hmm!), weep at the wrong time or shout 'Why me?'. She is good-natured, even while throwing up. And she has tireless circles of friends and family whose care and affection she always welcomes.

The truth is, of course, quite different. Cancer happens in lives that are already complex. Serious illness brings new complications and is as likely to drive people apart as to bring them closer. That picture book 'ideal patient' may have the perfect partner, but in the real world ordinary human beings must discover day by day and bit by bit how best to meet a situation they would never have chosen, one that brings all kinds of fears and sorrows, but also some quite unexpected opportunities.

Take it for granted that you can not predict your response to a cancer diagnosis or treatment – and nor can your nearest and dearest. Do not judge yourselves against unrealistic ideals.

Step up your communication skills. Establish a clear understanding that you will be honest about what you are feeling, rather than either one of you 'acting out' your fears or resentments by withdrawing, arguing, belittling, criticising,

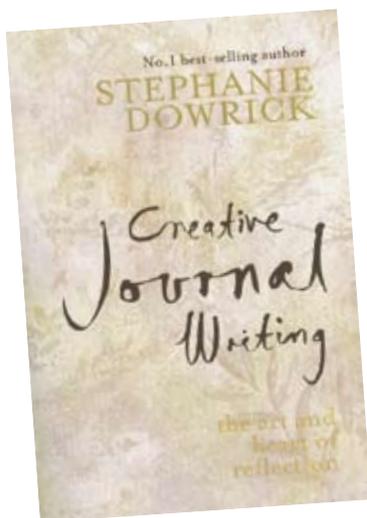


Stephanie Dowrick

getting drunk, never leaving the office ...

No matter how close you and your partner or support person are, recognise that you **both** need other people in your life to listen, encourage and care.

Assume that fear itself can make people behave badly. Intelligent professional help can work



*Creative Journal Writing is reviewed in the current issue of **The Inside Story**, our four-page **Beacon** supplement for women living with secondary breast cancer. The review is also on our website at www.bcna.org.au > Books and reviews. If you would like to subscribe to **The Inside Story**, visit our website or phone 1800 500 258.*

wonders, especially when old fears are newly triggered (for example, you or your partner may have lost a sibling or parent as a child).

Speak up frankly about your needs. Think about them. Write them down. Be straightforward about what you can and will ask for. When you do not get all you want, look for help from others also rather than blaming. 'Blaming' will undermine what you **are** getting.

Take it for granted that you will feel globally vulnerable – not just about your illness. This is not the time to fix other people's problems or put up with behaviour that is toxic or confusing. You literally cannot afford that stress. Again, professional help can work wonders, as can clarifying your thoughts and responses through journal writing.

Make it a top priority to spend real chunks of time alone and together that is not about 'managing' your life or illness but doing and experiencing what you most enjoy. Remain engaged with the world around you. Find what gives your life its special sweetness. Bring those moments to the forefront of your life.

Finally, speak up often about *what's going well*. Encourage and embrace it. Your life is precious.

*Stephanie Dowrick is a breast cancer survivor, a proud BCNA Ambassador and the author of a number of life-changing books including **The Almost-Perfect Marriage**, **Creative Journal Writing** and **Choosing Happiness**.*

Inner strength

My partner was very distressed by my breast cancer diagnosis. His mood deteriorated quite rapidly and he needed medication to help him cope. He accompanied me to various doctors' appointments and recorded important details to help in the decision-making process. However, when, in conjunction with my specialists, I decided to have a bilateral mastectomy and my ovaries removed, he was in total disagreement. My priority was to increase my survival rate, but he felt this treatment was unnecessary. This conflict caused an enormous tension between us.

Fearing that our 20-year relationship would not survive, we were encouraged to speak to a counsellor who specialised in cancer. Explaining my situation and reasons for my treatment decisions to a person outside the relationship helped reassure my partner.

Hanging in there when the road was rough and forgiving, when necessary, has made our relationship stronger. I have become a more confident person and my partner has a new appreciation of my inner strengths. I would love to discuss with him what happened, now everything has calmed, but he cannot bear to be reminded.

Surprisingly, he has accepted my new appearance extremely well, which, in turn, helps me. We are closer and more intimate than before the diagnosis. We have a renewed appreciation of our relationship, having faced a life-threatening storm and survived.

Margie
Carlingford, NSW

Understanding

Until a little over two years ago, I paid little attention to any news or publicity about breast cancer. I had never been touched by breast cancer, nor had I really come into contact with anyone who had been touched by it, either directly or indirectly. Now I have a personal interest since I met my partner Jo, who is a breast cancer survivor.

I did not know Jo at the time of her diagnosis and treatment (eight years ago). I sometimes think it would have been better to have been around, to know what it was like for Jo and to have been her partner during that time.

I came into Jo's life and truly felt overwhelmed by a sea of pink (Jo is involved with Dragons Abreast Australia). For many, many months the only people I met from Jo's circle of friends were breast cancer survivors.

We would often socialise with large groups of women and I often felt I did not fit. I was not a 'member of the club'. I did not want to qualify for membership, but I felt like I did not belong in a group of people that all had something in common (apart from me).

Practical help

Sometimes it can be helpful to take time out during your breast cancer journey.

A couple of suggestions found on www.breastcancer.org are to delegate tasks to your husband or partner, so you can take some time for yourself. Using 'Caller ID' to screen phone calls when you do not feel up to chatting, is another helpful suggestion.



Jo and Adrianna

Nevertheless, it has been a positive experience. Things have changed significantly for me over time. Because of the people I have met, I have discovered so much about myself and have a different opinion now about what is important in life. It was not a conscious decision, but I just realised that I felt differently about things. I did not need to know anymore what it was like to have cancer. All that mattered was that I had met, and continue to meet, some amazing and inspirational people who have made a difference to me and my

outlook on life. I am lucky to have a large circle of fun and positive people in my life and to have such a wonderful partner who inspires me in so many ways.

Jo and I participate in a new group for breast cancer survivors and their female partners. I have found it really beneficial to be able to be among other partners who are female, to be able to talk and share experiences, but at the same time, enjoy each other's company and have some fun!

*Adrianna
Brisbane, Queensland*

Help with the housework can be particularly welcome. While your partner, family or friends may be able to assist, local councils can sometimes provide childcare, meals and general home help. The Cancer Helpline 13 11 20 can direct you to local support services.

If you and your partner need to get away from it all,

The Otis Foundation offers accommodation retreats in a rural settings free for women living with breast cancer and their partners and families. The Otis Foundation has five accommodation options, located at various picturesque sites across Victoria and one in Thredbo, NSW. To book, phone (03) 5444 1184 or visit www.otisfoundation.org.au.

In all his wisdom

I feel like I did not get the support I needed from my husband. I guess in a strange way this was his way of dealing with the whole thing.

A couple of incidents stay etched in my mind. Just days after my diagnosis, one of the comments my husband made was, 'Why is this happening to me?'. Hello, who is it happening to? Another time my then 16-year-old son was pestering us (as kids do) to buy him a motorised scooter. I was totally against it but he kept on insisting. My husband in all his wisdom and anger told our son, 'This is not important, do you realise your mum could die'. Great, well handled.

I went through eight chemo treatments and despite my many requests, my husband only came to one of them with me. His excuse was he could not stand to see me in those conditions. He really had no idea. My last four chemo treatments I was sedated each time, as I had a severe reaction.

I got through my nightmare because of my beautiful children and my parents. They took every step with me, attended every doctor's appointment with me. They sat with me through every chemo and drove me to my daily radiotherapy treatments. God bless them.

*Sue
Sydney, NSW*

Breast care nurses helping couples

Breast care nurses can play an important role for couples when a woman undergoes breast cancer treatment.

Women tell us that they often found their nurses extremely helpful when it came to discussing the impact of breast cancer on relationships.

We asked breast care nurses **Jenny Macindoe** from Victoria, and **Jennie Copley** from the Northern Territory, how they support women and their partners after a breast cancer diagnosis.

Both agreed that a big challenge for couples is keeping communication channels open during this stressful time.

Jenny Macindoe notes that 'Most women need a lot of emotional and psychological support when they have breast cancer. Partners are sometimes at a loss as to how to give support. Women often feel that they shouldn't have to say what they want – "that he should just know". Consequently, women often seek support from their friends, and partners can feel shut out'.

For women in the Northern Territory, the 'tyranny of distance' also challenges relationships. Jennie Copley says, 'We don't have a radiation oncology unit in the Northern Territory, so women need to travel interstate for five or six weeks at a time to have radiotherapy. Partners sometimes

can't go with them because of work or family commitments. In these instances, the partner usually ends up "holding the baby" and the woman is left without much support'.

Both nurses encourage couples to focus on listening skills, to be patient and to talk about how they are feeling.

'I generally encourage men to hone their listening skills. If their partners are having a hard time or being snappy, to try and understand why, and be patient', Jennie says.

'It helps if women can talk about what they need. More often than not, their partners aren't mind readers,' Jenny adds.

Sex and body image

So we can't have kids, so we don't make love any more ... 'we have each other' was my daily overall message.

Talking about sex and intimacy is not always easy. It is bound up with how we imagine ourselves physically and how we feel about ourselves emotionally. It can be even harder to grapple with following a breast cancer diagnosis.

Some women tell us that they were worried about what their partners would think about their body following surgery. Others talk about how they simply lacked energy and desire due to fatiguing treatments or changed hormone levels. Experiencing physical pain during sex as a result of treatment for breast cancer is also not uncommon.

Partners can find it hard to talk about sex and may sometimes withdraw from making sexual requests, so as not to pressure their partner.

If the underlying reasons behind these changes are not discussed they may lead to misunderstandings that can affect intimacy over time. Talking openly with your partner about any fears you may have around sexual activity, intimacy and body image may help. Letting your partner know how you feel – when you are ready to have sex, what level of intensity you prefer, or if they could do something differently can also help.

Encouraging your partner to talk about how they feel is also

important. They may be worried about hurting you or appearing too eager.

Taking it slowly to start with can help. It may be easier to start with cuddles or a sensual massage.

Consider speaking with a member of your treatment team, such as a breast care nurse, for more information about the effect of treatments and fatigue following breast cancer.

The Cancer Council Victoria's *Sexuality and Cancer* booklet has useful information and tips. It is available by phoning (03) 9635 5000, or you can view it online at www.cancervic.org.au > About cancer > Living with cancer > Sexuality and cancer.



Reach to Recovery

The international breast cancer support conference, Reach to Recovery, will be in Brisbane on 13-15 May 2009.

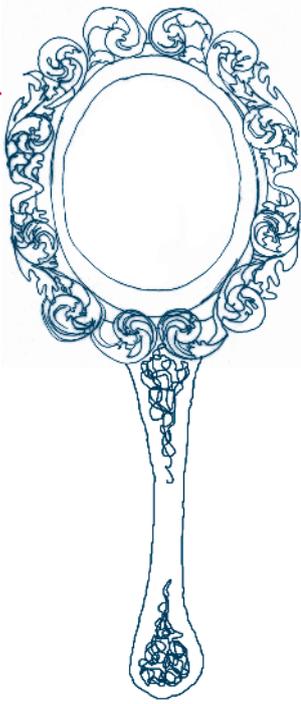
This is the first time in its 15-year history that this event will be held in Australia.

BCNA is supporting this international conference, which will connect women affected by breast cancer from around the world with a focus on survivorship, capacity building and peer support. The program will include case studies, presentations, international speakers and workshops, as well as indoor and outdoor activities that offer new challenges and exciting opportunities for personal growth.

The early bird registration fee of \$375 closes on 12 February 2009.

Women are encouraged to submit presentation abstracts for the conference by 11 November 2008.

For more information, visit www.reachtorecovery2009.org



My story

The shed

We had been married for more than 40 years and produced four children who brought with them challenges, joys and pain. We thought we had weathered it all.

When he came with me for my first call back, to assess something 'unusual' on the mammogram, he sat in the waiting room. The waiting room looked like Bourke Street on a Saturday morning. Frantic! Women were in and out of the room. Each one leaving with a big smile, 'Have a wonderful Christmas. Have a great new year'. With the fear gone from their faces, they looked forward to the future with certainty. They would disappear out the door and he was still sitting there patiently waiting.

Perhaps he was growing a little more concerned, as I would appear every now and then to say, 'I am having the needle biopsy now'. I would leave him and disappear behind the secret doors for another test, and then another – small needle biopsy, large needle biopsy (with 'gun'), pathologist report, surgeon examination, radiologist all

gentle and so precise. The breast care nurse hovered throughout, popping out to tell him what was happening.

Then home to wait for another week.

A week later he was sitting stoically again, but this time with me beside him, waiting to be called in to hear the outcome.

The surgeon on duty gently pronounced the dreaded words to us. The rest washed over us like a tide returning to the sea. We left in a daze of dates, organisation and horror. Three weeks to wait until I was able to

be operated on. Christmas was here and operating theatres were closed until a week after the new year – three weeks stretching endlessly ahead.

A grandson was born on Christmas Eve. What joy and happiness that brought to an otherwise bleak Christmas for us all.

My daughters and son were on the phone daily, but what can a man do and say to ease this dark and lonely time? Men my husband's age are not trained for these occasions.

My wonderful girlfriends gathered with comforting words and strong embraces.

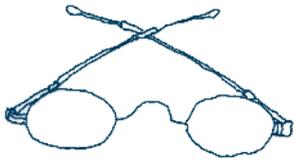
What does a man do? He retreats to his backyard and paints the shed. This was the shed that I had asked, pleaded with him to paint, for 10 years. It was 35°C outside yet he painted and painted. One coat, two coats. Then back to the shop for more paint. The shed sparkled. No words were ever said. We did not need words.

The shed looks just grand, nearly three years later.

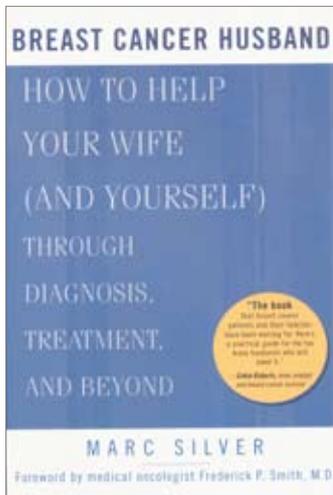
*Annie
Bendigo, Victoria*



Annie and her husband Rob with the lovingly painted shed.



Reviews



Breast Cancer Husband

by Marc Silver. Holtzbrinck Publishers, 2004 (paperback), 319 pages, RRP: \$29.95.

BCNA Review and Survey Group member **Alison McRae** with her husband **Roderick** reviewed **Marc Silvers'** book **Breast Cancer Husband**.

Alison: This book would be most helpful to the husband or partner of any woman who experiences the shock of being diagnosed with breast cancer.

At this devastating time there is a good deal of information and guidance available for the woman herself but, to date, not a great amount of information for the partner, who himself is also feeling quite devastated at the diagnosis that has the capacity to change their lives.

Even though it is more than six years since my surgery, I found, as a cancer survivor, the information

contained in the book interesting and informative. It was enlightening to read of a number of things that I was not aware of at the time of my diagnosis.

I shed a few tears while reading the first few chapters; it brought back the memories of the time of my diagnosis. I felt such empathy for the women mentioned in the book. Reading those first chapters about how the husbands were reacting also brought back memories of my own wonderful husband at the time of my diagnosis. He was in hospital awaiting a heart transplant and was distressed that he could not 'be there' for me (He underwent transplant surgery during the time of my radiation but, sadly, did not survive).

I really enjoyed Marc Silver's sense of humour when writing about such a sombre subject. After my emotional reaction to the first chapters, I was laughing at his sense of humour. It was a welcoming light-heartedness; it engendered a positive mental attitude and would be good for recently diagnosed women and their husbands or partners to read.

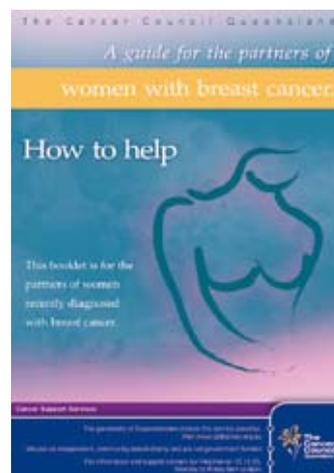
Roderick: I found the book helpful, especially as it has been written by a husband who has been through the experience of his wife having breast cancer.

Had I been in the same situation, I feel it would have helped me to understand what my wife was going through (I was not married to Alison when she went through breast cancer, but my eldest sister died of breast cancer aged 59,

and another of my sisters is a breast cancer survivor of some six years).

The author communicates extremely well and talks on an ordinary man's level. His writing holds the interest of the reader. The book is well set out and I particularly liked the summary points at the end of the chapters. These helped to enforce what was said in the chapter.

Alison and I would recommend this book to any woman of any age who has been diagnosed with breast cancer, and especially to any husbands or partners. It is a book that couples could read together, to help them understand the feelings and emotions of each other as they face this diagnosis together.



How to help

The Cancer Council Queensland recently updated its booklet *How to help: A guide for partners of women with breast cancer*. It was reviewed by **Rodney Booth**, husband of BCNA member, **Sue Booth**.

Overall, the booklet reads quite well and I found a number of similarities between my experiences and Sue's. After your partner has been diagnosed with breast cancer there is a general feeling of being out of control, with your other half in the hands of well-meaning strangers. It is an uncertain time with no guarantee that all will be well, even after successful surgery, chemo and/or radiation.

Often it felt, and still feels, like you are on the outside. The partner is relatively useless, as he or she is not experiencing the physical trauma associated with treatment and has only an inkling of how it might feel to experience the threat of a shortened life span. The only option is to be there, do whatever you can, attend as best you can and hope like hell you have a long time together.

The booklet deals well with how you might assist during diagnosis and treatment. It does not touch on longer-term issues; that may need to be a separate document.

A general comment is that partners may be female, which the booklet does not really acknowledge. Overall, however, it would be a useful resource for women and their partners.

The booklet is available from the Cancer Council Queensland's website at www.cancerqld.org.au > Resources > Breast Cancer. You can also order a copy by phoning 13 11 20 if you are in Queensland or (07) 3258 2200 if you are phoning from another state or territory.



Profiling our member groups

Kim Walters Choices Program

Queensland BCNA Member Group **Kim Walters Choices Program (Choices)** celebrates its 10th anniversary this year.

The program was established in memory of **Kim Walters**, wife of former Brisbane Broncos rugby league captain **Kevin Walters**. Kim died of breast cancer in 1998 aged 30.

Kim's vision was to establish a service that would provide help and support for other women with breast cancer.

Choices is managed by breast care nurse **Janine Porter-Steele** and offers a holistic approach to care, including specialist nurses, peer support coordination, staff and volunteers with personal experiences of breast and gynaecological cancers, counselling and physiotherapy services.

It provides a wide range of services, free of charge, to women with breast and gynaecological cancers, including individual support from breast care nurses and women's health nurses; support groups; complementary therapies, including art classes and meditation; exercise programs; a wig library; rural



Women support each other at the Sister After Stretch – Craft Support Group.

support workshops; and a lymphoedema clinic.

The support groups for women with breast and gynaecological cancers include: Secondary Breast Cancer and Gynaecological Cancer Group; Sisters After Stretch – Craft Support Group; Younger Women's Group; Women Who Partner Women Group; and Inflammatory Breast Cancer Support Group.

Each group meets monthly, most alternating a social meeting with an information meeting. Choices provides peer support training

to volunteers from each group, teaching them communication and listening skills and how best to support the women in their group.

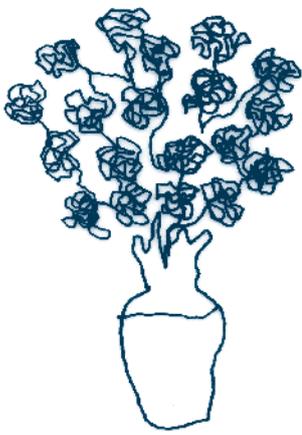
The Younger Women's Group has approximately 250 members. Depending on what is planned for the evening, usually 20 or more attend each of the monthly meetings. Most of the women maintain contact with the group in some way – coming along to meetings or phoning when they feel they need the extra support.

The Women Who Partner Women Group was established at the beginning of this year. Already the group has 20 members, including one couple who are both breast cancer survivors.

'As we know, men and women have different reactions and needs, and we find that the women partners are really pleased to find someone they can relate to and share their stories with,' Peer Support Coordinator **Leonie Young** says.

Women and men who visit Choices will find a range of helpful books, information booklets and CDs, Internet materials and DVDs.

Choices is based at the Wesley Hospital in Brisbane. It is a not-for-profit organisation, funded by donations from the public, corporate sponsorship and its own fundraising events, which are held throughout the year. The programs are available to anyone in Queensland irrespective of where they had their surgery and treatment.



Thank you

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

- Alison Irving
- Australia's Open Garden Scheme
- Barham Raiders Football Club
- Betty Amsden
- Brighton Grammar School
- Clayton RSL
- Coles Group
- David Sonenberg
- Deborah Wastell – Terrace Tearooms
- Diane Grady
- Dunlop Flooring
- Elspeth Davey
- Gadens Lawyers
- Gillian Walker
- Joan Staples
- Kitchen Aid – Peter McInnes Pty Ltd
- Lillian Moroney
- Margaret Illman
- Margaret Tierney
- Merlvic Schrank Pty Ltd
- New England Wool Expo
- Panton Hill Football Club
- Peter Madsen
- Ron Bonighton
- Rural Press Ltd
- Sonia Finlay
- Taryn Lupton
- Thornlie Christian College
- VSI Pty Ltd
- Waverley Park Hawks Auskick
- Yarra Bend Ladies Golf Club

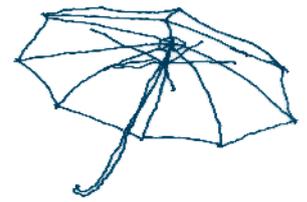
Memorials

We pay tribute to the lives of **Alison Lewis, Dorothy Busby, Frank Ahern, Jennie Sherlock** and **Muriel Grace Pollock**.

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

Celebrations

Thank you to those who celebrated a special occasion with donations coming to BCNA in lieu of presents. Congratulations to **Nola Hargraves** and **Frank Ward** on their recent wedding. Happy birthday to **Sam Van Gastel, Susie Amundsen** and **Vivien Brass**.



Seeking Shelter

BCNA welcomes the following new member groups:

- The Hunter Breast Cancer Foundation, NSW
- Lismore & District Breast Cancer Support Group, NSW
- Port Pirie Cancer Support Group, SA
- Treasure Chests, Blue Mountains, NSW

There are now 198 BCNA Member Groups and more than 29,000 individual members across Australia.

You can visit our website to find a Member Group (support group) in your state or territory at www.bcna.org.au > About BCNA > Member groups.

New e-Bulletins

BCNA's new-look e-Bulletins are now in circulation. Each issue includes the latest breast cancer news, information about relevant events and conferences, and updates on research in four key breast cancer areas, familial breast cancer, young women, women living with secondary breast cancer, and those living in rural and remote areas.

You can subscribe to BCNA's e-Bulletins by using our online form, available at www.bcna.org.au > Information > e-Bulletins or by emailing policy@bcna.org.au



BCNA member Wilma Bott and friend Sandra McGowan rallied the support of the members of the Barham Raiders Football Club in NSW to celebrate Ladies Day with a fundraising event for BCNA. The day was a great success, raising funds of more than \$2000. Pictured are Wilma and Sandra with club president Robert McCaig and team members.

Sussan's staff moved by BCNA members

Breast cancer survivors **Nikki Dwyer** and **Susan Crawshaw** attended Sussan's Annual Conference in August.

Nikki and Susan shared their inspirational stories with the 250 Sussan store managers at the function.

The conference gave us the opportunity to thank the Sussan team for their ongoing support of BCNA. Since our partnership began, just two years ago, they have raised more than \$290,000.

Sussan presented Nikki and Susan with a \$65,000 cheque for BCNA

from the sale of BCNA Mother's Day bags and our Pink Lady pins.

Pink Lady pins are still available in Sussan stores across Australia. If you are close by, please pop in and thank your local store for their ongoing support.



Pacific Brands extends its support

In 2005 our partnership with Pacific Brands began through our *My Care Kit* program, which provides more than 130 free *My Care Kit* bras each week to women after their breast cancer surgery.

What began as a financial commitment to a unique service

for women has grown into a strong partnership. We thank Pacific Brands for recently increasing its financial support to help fund our state forums, policy work, as well as the *My Care Kit* program.

Pacific Brands, an Australian company, owns brands such

as Berlei, Tontine and Dunlop Flooring, which all support BCNA.

Importantly, thousands of Pacific Brands employees are playing an important role in the partnership, especially through promoting our *My Journey Kit* and *Hope & Hurdles Pack*.

An invitation for you

Ever thought you would like to get involved in something that really makes a difference?

Your breast cancer experience can help researchers make life easier for other women with breast cancer.

Join our Review & Survey Group now.

Once you are registered with us, we will send you emails from time to time, inviting you to complete important surveys. There is no obligation – you can decide which opportunities interest you and if you want to be involved.

One of our recent surveys asked *Review & Survey Group* members about the cost of follow-up mammograms. Another research project asked women about their views and experiences of high-cost drug treatments.

The surveys are not too long and are about the issues that are important to women with breast cancer.

More than 500 women have joined this year, and many have already contributed their ideas and opinions.

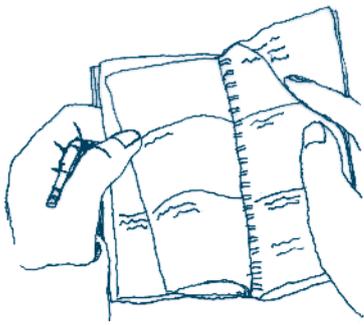
Interested? To complete the online registration form, visit www.bcna.org.au > Policy & advocacy > Seat at the Table > Get Involved – or email ras@bcna.org.au

We would love to hear from you.



BCNA gratefully acknowledges our partnership with Bakers Delight.





Upcoming Events

September 20: *Women for Women with Breast Cancer 2008 Forum*, organised by BCAG NSW, will be held at the Sydney Convention Centre, Darling Harbour. It is free to attend. For more information visit www.bcagnsw.org.au

October: *Mini-Fields of Women* will be held around Australia. Visit our website www.bcna.org.au > **Events > Mini-Fields of Women 2008** to find the location of your local *Mini-Fields*.

October 5: BCNA, in conjunction with the National Breast Cancer Foundation and the National Breast and Ovarian Cancer Centre, will hold a combined Memorial & Thanksgiving Service in both Melbourne and Sydney at 2pm. Visit www.bcna.org.au > **Events > Events and activities** or phone 1800 500 258 (freecall) for more information and to register.

October 11: BCNA will hold a forum in **Melbourne** at the Nigel Peck Centre, Melbourne Grammar School, 1-4.30pm. The theme is 'pathology' and will feature guest speakers (see page 2 for more details). There is no cost, but seats are limited. Please register online at www.bcna.org.au > **Events > BCNA forums**.

October 19: Dragons Abreast Australia's inaugural Corporate & Social Dragon Boat Regatta will be held at Cockle Bay, Darling Harbour, Sydney. For more information, visit www.dragonsabreast.com.au or email regatta@dragonsabreast.com.au

October 25: Dragons Abreast ACT's Challenge Corporate Regatta, featuring a BCNA *Mini-Field of Women*, will be held at the Canberra Yacht Club. For more information, visit www.dragonsabreast.com.au or email canberra@dragonsabreast.com.au

October 27: Australia Breast Cancer Day

November 15: NT Breast Cancer Voice's 10th Anniversary Dinner. For more information email Pat Hancock at pathancock_is@hotmail.com

November 15-16: Gawler Foundation's Annual Conference, *Profound Healing – Sustainable Wellbeing* will be held at the Hilton on the Park, Melbourne. The cost to attend both days is \$270 (other packages are available). For more information visit www.gawler.org or phone (03) 5967 1730

March 28-29 2009: Tasmanian Breast Cancer Conference will be held at the Hotel Grand Chancellor, Launceston. For further information about guest speakers and the program, contact Karen Forster at kforster@netspace.net.au or (03) 6273 4422.

May 13-15 2009: The UICC 15th International Reach to Recovery Breast Cancer Support Conference, Brisbane. The early bird registration fee before 12 February 2009 is \$375. Visit www.reachtorecovery2009.org for more information. Also see the article on page 10.

Would you like to be on the mailing list for *The Beacon* or *The Inside Story*?

Telephone 1800 500 258 (freecall), email beacon@bcna.org.au or fill in this coupon and send it to: **Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.**

- Yes, please send me: **The Beacon**, BCNA's free quarterly magazine
 The Inside Story, a four-page supplement on living with secondary breast cancer, mailed with **The Beacon** to those who request it.

Name:

Address:

State: Postcode: Phone: ()

Email:

Have you had a diagnosis of breast cancer? Yes No

If yes, what year were you diagnosed? What year were you born?

Have you had a diagnosis of secondary breast cancer? Yes No



PaperlinX proudly supports women with breast cancer by generously donating the paper for **The Beacon** and **The Inside Story**.

Printing kindly supported by Vega Press.



Your stories

'I never thought I would ...'

We are seeking stories for the 2009 autumn issue of

The Beacon about the things you never thought you'd do, if you had not had breast cancer.

Tell us if you have made friends you may otherwise never have met, taken up a new activity, travelled to new places, or had experiences that you could never have imagined, as a result of your journey with breast cancer.

We welcome your article of around 200-300 words (about half a page) preferably by email to beacon@bcna.org.au by the end of December.

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



the BEACON

Layout: Substitution

BCNA

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Camberwell, Victoria 3124

Freecall 1800 500 258,
(03) 9805 2500

beacon@bcna.org.au or
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