

INSIDE

Mini-Fields of Women	2
Issues of Concern	3
My Story	11
Reviews	12
Member group profile	13
Thank you	14
Upcoming events	16



the BEACON

Breast Cancer Network Australia's Magazine

Issue 43

Winter 2008

ISSN 1834-5921

What works for you?

Welcome to those of you who are receiving **The Beacon** for the first time.

This issue considers work-related challenges for women. We have aimed to include articles written from a full range of perspectives; from women who gave up work as soon as they were told they had breast cancer right through to women for whom work became a marvellous life-line. As we often remark, the disease affects us in so many varied ways. Often our ability to deal with it successfully depends on our own individual situation at the time.

I am confident you will agree that the stories submitted by our readers provide a powerful, personal and rich source of responses. They offer some great ideas for helping women who are facing challenges that come at them out of nowhere. As always, I am so impressed and moved by our women's honesty and willingness to share their experiences with others.

It also makes me wonder about the word 'courageous' and how easily the media uses it to describe guys playing football or facing tough business decisions. I cannot help thinking most of them would have no idea about the courage needed to face each day, for example, as a single



Women working together: (Left to right) from the National Breast Cancer Foundation Sue Murray, General Manager, and Ros Kelly, Chair; from BCNA Patricia Edgar, Chair, and Lyn Swinburne, CEO; and from the National Breast and Ovarian Cancer Centre Helen Zorbas, Director, and Megan Keaney, Chair.

mother with this disease, along with the associated financial pressures and an uncertain future.

Their stories also remind us that we need to focus on how best we can help women in this situation, whether from the perspective of a carer, a doctor, an employer, a colleague or an advocate. It is BCNA's role to speak up on behalf of those 36 Australian women and men who are diagnosed every single day. There are ways – big and small – to help, and we are passionate about reducing the negative impact on those most closely affected. We hope this issue of **The Beacon** will help readers by providing quality information about the services and systems that exist. As always, we are sure at least

one of the pieces will strike a chord for each of you.

And, speaking of women at work ... our cover photo is a recent example of women working together. There is a fair deal of confusion in the community about exactly which breast cancer group does what. In March, BCNA invited our 'sister' national organisations, the National Breast Cancer Foundation (NBCF) and the National Breast and Ovarian Cancer Centre (NBOCC), to come together to discuss how best we can work together for the benefit of women with breast cancer.

While this will not do much to clarify for the public the specific role each undertakes, it will

ensure that each organisation's efforts complements the others' and that a combined approach from us working together will make us all stronger. You can read about our collaborative national approach and so much more on our website at www.bcna.org.au > About BCNA > Summary of Activities.

*Lyn Swinburne
Chief Executive Officer*

Breast
Cancer
Network
Australia



Mini-Fields of Women 2008

'It is such an important and special day for us. We come together; some old friends and many new faces. If we can just help one newly diagnosed woman and her family then the day has been an incredible success.'

It is now time to plan your 2008 Mini-Field of Women events.

A Mini-Field event is a powerful, yet simple, way to recognise those affected by breast cancer in your local community. It is also an opportunity to promote the information and support available to women and their families through BCNA. In addition, the events are an important way to support Australia's Breast Cancer Month in communities across Australia during October. Help us to make 2008 the biggest yet.



A Mini-Field held in the park at Beaconsfield, Tasmania.

BCNA can help you plan your Mini-Field of Women event. We will also provide you with everything you need in an 'Event in a Box', containing 100 Pink Lady silhouettes, a media release to generate local media coverage,

invitations and helpful hints for running your event.

Mini-Field of Women events can be held in a number of different ways, such as:

- a morning or afternoon tea with a group of friends;

- a picnic in a private garden or a park, with family and friends; or
- a display of pink ladies planted at a farmers market, fete or sporting event.

Start planning your Mini-Field today. Contact Marita on 1800 500 258 (freecall) or email beacon@bcna.org.au to discuss your ideas and to register your event.

We thank Australia Post for its ongoing support of BCNA's Mini-Field of Women events.



Trained and ready to go!

Seventeen women from across NSW came together in Sydney in March to complete BCNA's one-day Community Liaison Training Program. Bringing together motivated and enthusiastic women generates many more opportunities for BCNA to make a difference in local communities.

The day was superbly organised and I was made to feel very welcome. It was an honour to be with such a great bunch of women who all had the same purpose in mind.

BCNA's resources are awesome and the training ensured that we are all equipped to go into the community with confidence and know that we will be helping many women.

*Lee McKerracher
NSW Community Liaison*

Through our *Seat at the Table* program our Community Liaisons represent BCNA at various community events, participate in local BCNA activities and media. They also help promote resources such as the *My Journey Kit* in their local communities.

Many of our Community Liaisons were involved in this year's Bakers Delight Pink Bun Campaign in May. We are extremely grateful to those who supported this successful campaign by strengthening our relationships with Bakers Delight bakeries and promoting BCNA's services for women across Australia.

For more information about our *Seat at the Table* program, visit our



Our newly trained NSW Community Liaisons with BCNA staff in Sydney.

website www.bcna.org.au > Policy & Advocacy > Seat at the Table.



Issues of Concern

Fatigue

Demoralising fatigue almost signalled defeat [on returning to work]. Most days I would go to work, come home at 3.30pm, head to bed and sleep for a couple of hours, get up and cook tea for the family or eat if this had been done, then collapse back in bed exhausted.

*Rosemary Bambery
Taylors Lakes, Victoria*

Returning to work or getting back into the usual household routine is something that many women look forward to once they finish breast cancer treatment. However, fatigue (extreme tiredness) can make this difficult and it is not unusual to end up feeling frustrated and overwhelmed as a result.

Fatigue can be one of the most common and distressing side effects of breast cancer treatment. Importantly, it also tends to be one of the least acknowledged and, therefore, least well managed symptoms. However, women do respond to treatment in a variety of ways and some women are pleasantly surprised that they did not feel too many negative side effects.

Those women who do experience fatigue report feeling that they have little energy or are extremely tired all the time. Others describe feeling like every part of their body is tired or worn out. Rest or sleep may not always help and, as a result, day-to-day activities, such as cooking and cleaning or going to work, can become incredibly difficult.

What causes fatigue?

It is still not clear what causes fatigue following breast cancer treatment. Experts believe it could be a side effect of chemotherapy or radiotherapy. It could also be the result of ongoing pain, anaemia (a lack of red blood cells), or a reaction to the stress of going through cancer diagnosis and treatment. Fatigue is also a common side effect of depression.

Fatigue can last anywhere from three to 12 months after active treatment (such as surgery, chemotherapy or radiotherapy) has finished. Some women even experience continued fatigue, which can become worse over time rather than better.

Managing the impact of fatigue

Some experts state that it is important to be realistic about the impact that cancer treatment has on the body and to allow time for recovery. Building up to the usual level of daily activities, rather than stepping straight back into the old routines, can help. For example, if you break your leg, you would not expect to run a marathon the day after the plaster was removed. The principle is the same for women with breast cancer.

The mind is willing, but the body has other ideas, and for now I'm happy to let my body win!

*Jane Bailey
Allambie Heights, NSW*

Research is also showing that exercise can greatly assist in reducing fatigue. However, it may be the last thing women feel like doing when they are tired. Exercising with friends can help with motivation and make it more of a social event. Being realistic about the level of exercise that is right for you is also really important.

Doctors do not always ask about levels of fatigue and it may be considered to be a minor side effect compared with other treatment-related issues. However fatigue can have a significant impact on the ability to do the usual day-to-day things such as going to work or looking after the family. Discussing fatigue with your doctor is important. Identifying the right level of activity, work and exercise for you may help you manage fatigue and its impact.

Chemobrain

I did struggle with 'chemobrain', which was very frustrating, suddenly not knowing how to do things that I have been doing for years.

*Jacqui Tunbridge
Manly Vale, NSW*

Another side effect some women report during and/or after treatment is forgetfulness and the inability to concentrate and think clearly. 'Chemobrain' or 'chemofog' are terms used to describe short-term memory loss, or problems with concentration and clarity following treatment for breast cancer. Very little

research has been conducted on the 'chemobrain phenomenon' and what does exist is often inconclusive or contradictory. Possible causes include the stress of diagnosis, chemotherapy itself, hormonal changes or the 'natural' ageing process. The jury is also out on the number of women affected and the length of time that it lasts. For some women this is only as long as their treatment lasts, whereas others find the symptoms can continue for a number of years.

Some women report that doing crosswords, sudoku and other puzzles or activities that exercise the mind has helped them to feel more alert and to improve memory. Getting enough sleep is also really important. Physical exercise may help with sleep problems, and avoiding alcohol can also assist with this. Making detailed lists of things you need to do, and using computer and mobile phone based reminders are all practical strategies that can assist. Taking time to relax and wind down may also be useful, as it can help to manage stress and assist you to remain focused.

For further information on fatigue and 'chemobrain' and strategies on how to manage them visit the BCNA website at www.bcna.org.au > Information > Resources or phone BCNA on 1800 500 258 (freecall) and we can send you a list of resources.

No small business

When I was diagnosed with breast cancer I owned a small business and was the major contributor to the family budget. So taking time away from my busy work life was not an option and, in retrospect, I think working through the treatment was a good option for me.

After surgery there were two big decisions I had to make which would affect my ability to work:

1. Whether to have chemotherapy or not. After seeking advice from different doctors and others, I decided not to have the chemo.
2. How much should I use my arm after the full axillary clearance, with all the conflicting information about developing lymphoedema? I decided to use my arm as much as possible. This suited



Christine Mitchell

me, as my work would have been seriously impeded otherwise.

I managed to make my radiotherapy appointments the last appointment of each day,

so I would only come back to work for a couple of hours, then home to dinner (often supplied by friends and colleagues). There were many nights when I was in bed by 8pm.

I was really proud of what I was achieving and the balance I was finding in my life. I realised I didn't want to be self-employed any more. It was high time I took a holiday and it was time to think about what I would like to do, rather than what I had to do. I maintained an early morning exercise regime, as I found this got my energy levels pumping for the day.

Once I completed radiation I headed off to Italy for a holiday, backpacking wherever the wind took me.

Today, three years after diagnosis, I am working for a company in

an area that I love. I probably work as hard as I did in my own business. However, I know there are four weeks holiday each year that I can take and at the end of the day it is not my responsibility to pay employees.

My focus now is working for my own satisfaction and learning new skills. My employer gives me time off each month to volunteer with the *Look Good ... Feel Better** program. Every week is filled with running, swimming, walking, pilates and dragon boat training, and about 45 hours of work, but, hey, life is such a privilege why not get as much out of it as we can.

*Christine Mitchell
Castle Hill, NSW*

* For more information about the *Look Good ... Feel Better* program visit www.lgfb.org.au

Taking care of business

When I was diagnosed with breast cancer in 2006, I was working for a small consultancy firm. I had only been there seven months after moving to Sydney from London. Like many working women, I went for my mammogram in my lunch break. When they said they needed to do a core biopsy immediately, I still went back to work bandaged up and didn't tell anyone.

Once I learned I had breast cancer, I put work on hold to concentrate on restoring my health. My boss said he would keep my job open for me while I got better. However, I had not anticipated that the surgery, IVF,



Cordelia Gover

chemo and radio would take a year out of my career life.

During my treatment I kept questioning how I got cancer, why me and whether I would

really want to return to my old job, which I did not even 100% enjoy. I felt there were more opportunities that I should explore, rather than falling back to my old routine and commuting to an air-conditioned office every day.

I had always wanted to start my own business and felt that this was the chance and my 'wake-up call' to do just that. I was fortunate to have such a supportive husband (emotionally and financially) and the space at home to work from.

I officially resigned and set up my own consultancy company just over a year on from my

diagnosis. The process of setting up the business – from creating a company name, website and designing business cards – helped give me a sense of focus for the future. My first few jobs also gave me back my confidence. I was wanted and needed by people – other than my doctors!

Another year on, and on reflection, leaving my old job was the best move I made. I now have a happy, healthy, balanced lifestyle with freelance work when I want/need it and, most importantly, have the weekends free to spend with my husband.

*Cordelia Gover
Darling Point, NSW*

Why did I go to work?

There were a variety of reasons why I went to work during my breast cancer treatment. I have always worked, so it is a way of life, I even took in work during my two periods of maternity leave. I like the structure of going to work and the sense of purpose it gives me. If I am to be honest, it was also about trying to maintain some level of control when my body had failed me and the treatment was brutal. To be fatalistic, it was also about trying to maintain some distance, so my children would not become overly dependent on me.



Joanne Katsoris with sons George and John.

For me, work was therapeutic. It was a welcome distraction from my negative thoughts. My colleagues were absolutely amazing. They were genuinely interested, but respectful. They allowed me to hide in my office during the days that I felt really unwell. They asked me how I was and listened when I told them. I was disappointed to find that a number of close friends did not know how to deal with my diagnosis and became distant during treatment. As I reached

the end of treatment, I realised how lonely I would have been without the company at work. I am lucky. I was able to go to work because of the additional help that was available. My parents were an enormous help, particularly with caring for my children and with what I affectionately call 'meals on wheels'. We hired a gem of a cleaning lady who also happens to iron and we ordered takeaway when we were not up to cooking

and tried to ignore the things that were not done.

I understand that working while being treated for breast cancer is not for everyone. For many of us, the treatment is brutal and it is difficult to remain focused on the idea that the ultimate aim of treatment for early breast cancer is cure. For me, however, working helped me get through it all, with my sanity, perspective and humour largely intact.

*Joanne Katsoris
Mitcham, Victoria*

Caring for children

The biggest difficulty I had was managing the children, particularly baby Renata. Consequently, she spent a lot of time in child care and she had to learn to go to her father when at home.

*Joanne Brown
Albury, NSW*

While many women find family and friends rally to help care for their children during and after

their breast cancer treatment, sometimes extra help is needed.

The national Child Care Access Hotline (established by the Australian Government) can provide information on child care services in your local area, including privately operated and local government operated child care services. They can also provide information about

government financial assistance for child care.

Contact the **Child Care Access Hotline** on **1800 670 305** (freecall) between 8am and 9pm, Monday to Friday, for more information or visit the website at www.facs.gov.au > Families > Child care > Who to contact > Child Care Access Hotline.

Single mum

Within a day of being diagnosed, I had to leave my three breadwinning part-time casual work positions. It was impossible to contemplate my early morning starts at one job, caring for germmy preschoolers during the day while immune suppressed, and teaching parents at night. Fortunately, I was eligible for single parent benefits, which sustained me through most of the chemo treatment. However, medical and other expenses soon saw me successfully applying for a new permanent position despite being wigged, lashless and browless.

How I managed to complete chemo, then radiation, while learning a new job defies my comprehension now. My two young children were somewhat neglected through lack of energy and had early independence forced on them. However, we all found the strength we needed and are now a healthy, formidable team.

*Jill Hicks
Camberwell, Victoria*



Jill Hicks

Work after breast cancer

I needed to return to work for a sense of belonging, to return to 'normality' and to have an income to pay off medical bills.

*Carol Walker
Wahroonga, NSW*

Continuing to work gave me something else to focus on rather than medical appointments and my illness. It also gave me the opportunity to wear some pretty fancy hats!

*Vanessa Harvey
Grasstree Beach, Queensland*

I had to work through my treatment, as I was on my own. Also, I had no sick leave.

*Catherine McGrath
Annandale, NSW*

I struggled to resume my previous role ... I didn't feel I was coping with the daily stresses it involved.

*Kerry Weldon
Boambee East, NSW*

There is no one solution for all women when it comes to working after a breast cancer diagnosis. Your financial situation and how you feel physically and emotionally may affect how, when or if you go back to work.

Many women experience side effects such as fatigue, pain or lymphoedema after their breast cancer treatment, while others have few side effects.

Working part-time, job sharing or reducing hours may be an option to help manage new energy levels during and/or after treatment.

My school bent over backwards to make this transition an easy one and I returned part time, three days a week, not five, and with reduced hours.

*Rosemary Bambery
Taylors Lake, Victoria*

Did you know?

The Workplace Relations Act 1996 (national legislation in place until 2010) states that it is unlawful to terminate a person's employment if they have a temporary absence from work due to illness or injury. This applies if a medical certificate is presented within 24 hours (if requested), all award and agreement terms are met and only if absences total less than three months in any 12-month period.

For those who are self-employed, asking a staff member to temporarily step up into your role, employing someone to help, or reducing your hours may ease the load.

My immediate work colleagues and management were understanding and enormously flexible. The HR area was great and answered all my questions about returning to work and various options.

*Denise Connolly
Eudlo, Queensland*

As a general rule, it is in your interests to keep the lines of communication open with your employer and to also find out what your entitlements are, including what paid and unpaid leave is available. Supervisors, human resources personnel and occupational health and safety staff should be able to discuss your situation and options with you. Your industry association or

union may also be able to provide information.

The Cancer Council Australia's *Working with Cancer* booklet suggests keeping a diary of meetings, tasks, important conversations and leave taken. It may also be useful to take a support person or colleague with you to keep track of discussions at meetings with your employer. Giving employers as much lead time as possible about the type of leave you may require and how you will inform them of any changes is also helpful.

You may need to provide a 'return to work clearance' certificate from your doctor stating that you are fit to return to work. If you are unable to carry out your normal duties, talk to your employer about alternative 'lighter duties' that you may be able to do. Your doctor can state these duties specifically on the clearance certificate. This is especially important if you are working in an area that requires lifting or repetitive movements.

Many employers are supportive when an employee is diagnosed with breast cancer. If, however, you feel you have been unfairly treated, it is wise to seek advice tailored to your individual situation. Visit our website for a list of helpful organisations, as well as a list of resources about returning to work after breast cancer www.bcna.org.au > Information > Resources or phone BCNA on 1800 500 258 (freecall) and we can send you the list.



Judy Crofton

Running from the fog

After treatment for breast cancer in 1997 I certainly took a new direction in my life. From being a 'domestic engineer' I set up and sold a cafe and then moved from Sydney to Tasmania. Here there are so many activities to join, from African dance to weaving, bush walking to lace making and I've started a university course; all things I would not have done in Sydney.

Unfortunately I had a second breast cancer diagnosis in 2006. I've found that I cannot quite get the enthusiasm for things like I did the first time. I still try to do too many things, but I find that physically I cannot; I get very tired.

The first time, I did not deliberately make a decision to work out what I was going to do. I felt at the time I was 'running from a black fog' and threw myself into the business and some voluntary work. I think I had some degree of post-traumatic stress. I had always been healthy and did not even have a GP. Many, many things have changed.

*Judy Crofton
Deloraine, Tasmania*

Staying on duty

In June 2007, aged 31, I was diagnosed with early breast cancer. As a policewoman, I had generous paid sick leave entitlements. However, I was urged by both my surgeon and oncologist to carry on life as normal. That included continuing full-time work. It was the best advice I could have been given.

Following my mastectomy/reconstructive surgery, I had four weeks off to recover. I returned to work the week I began chemotherapy and thereafter had about a week off every three-week cycle.

My colleagues were a fantastic support for me and I could not have coped without them. Even hardened 'old school' police officers were simply wonderful.

While we had a lot of fun joking about my lack of hair, my



Amanda Ball (centre with pink hat) celebrates the end of her chemo with her work team.

colleagues also understood how I was feeling and what they could do to help me out. I was given less onerous tasks to complete during chemo and my boss was only too happy to alter my hours to fit medical appointments and give me a workload I could handle. She frequently gave me the opportunity to go home when she thought I looked tired

and always offered a shoulder to cry on or an ear to listen.

I found that continuing work provided me with support and, more importantly, something to occupy my mind. On the days that I was home alone I found I was constantly preoccupied with everything about breast cancer and found my mind

frequently wandering to worst-case scenarios. I am sure that I would have been in the depths of depression if I had stayed home alone all day every day.

Although I am still a policewoman, I now have a niggling feeling that I should be doing something else. After 11 years in what I thought was a career job, I am now open to other ideas and would be happy to pursue another career if the right opportunity arose. Work is no longer a priority for me and I have tried to instil the same value in my loved ones and those close to me. Life is too short to spend the majority of it working. Having said that though, I am still trying to work out how to live without the money it provides!

*Amanda Ball
Aveley, Western Australia*

Help your colleagues help you

I was happy for people at work to know I had breast cancer; I just didn't want to be the one to tell them. I gave copies of the Helping a friend or colleague with breast cancer brochure to my manager, so he could give them out. I think they helped my work colleagues understand what I was going through, especially as I went through the different stages of treatment.

*Catherine Ritchie
Kew, Victoria*

Many women say that friends, colleagues and even family members sometimes don't know what to say or how to treat you when you have been diagnosed

with breast cancer. BCNA's *Helping a friend or colleague with breast cancer* brochure helps others understand what women with breast cancer are going through and offers practical advice on how they can provide support. It is based on the experience and wisdom of our members and can help 'break the ice' if colleagues and friends are not sure how to support you.

We are more than happy to send copies to you or your workplace. Phone BCNA on 1800 500 258 (freecall) or visit our website at www.bcna.org.au > Information > Brochures for a copy of the brochure.



Ripped off

At the time of my diagnosis (in January 2007) I had recently changed careers. In 2005 I had left the public service to train as a high school teacher. In 2006 I had full-time work at my local high school. Finally I had found the job that I was meant to do. I loved working with the staff and students. Life was exciting and full of potential.

When I was diagnosed all thought of work ceased. My treatment included a mastectomy, chemotherapy, radiotherapy and now Tamoxifen. Teaching is a job that you have to be well to do. You cannot hide behind a desk or be given light duties. It is full-on and demanding. Teaching also requires a fully functioning immune system, which was something I did not have, so I had to give up work. It was easy to do at the time and what choice did I have anyway? Now though, it has left me feeling a strong sense of being ripped off and cheated by the cancer. Words such as 'anger', 'resentment', 'frustration' and 'powerlessness' come to mind, but they don't come close to how cheated I feel.

During treatment I continued to visit the school. My morale was always boosted when I was greeted by the students. The staff were beyond amazing.



Karen Longmuir with her son Conor and their version of Look Good ... Feel Better.

Their support helped me get through some really bad times and reduced that terrible sense of isolation you get when you are sick for an extended period.

Since treatment has ended, I've been back at school doing relief teaching. I work two to three days a week. At the moment I'm not strong enough physically or emotionally to do more than this. In the second half of the year I hope to be well enough to take on a part-time contract. I don't know when I'll be well enough to work full-time again or if I'll want to.

Cancer has stalled my career and damaged my current and potential income. For most of

2007 that meant no income. We manage on my husband's income, treating mine as a bonus. If not for the cancer, I would have been working full-time since 2006. I'd hate to put a figure on current and future lost earnings and lost superannuation. I'd cry if I did.

On the positive side, I do enjoy relief teaching. I get a lot of the fun without the ongoing responsibility. I also get to fit teaching around my health and fitness needs. I'm staying positive and loving the challenge and variety of teaching. Work is also a wonderful break from being a patient.

*Karen Longmuir
Nicholls, ACT*

Retiring early

Breast cancer inspired a new direction for me and I have certainly reprioritised the importance of paid work in my life. My decision to retire when I did changed my life in so

many ways. While I don't think that breast cancer was the best thing that ever happened to me, I do love the changes it brought with it. I did change from paid to unpaid work and although it

brings me great satisfaction, sometimes the pressure has been great. This year will bring more changes to my life when I cut down on my volunteer work. Exciting times ahead!

Robin Gregory, Mangerton, NSW

Caring for the carer

Before I was diagnosed with early breast cancer I was the full-time carer for my elderly mother.

It has been more than a month since I had the operation. I still have the occasional problem, especially with doing housework. The most difficult part has been not being able to do the laundry and hanging the clothes on the line. My mother tries to help me, even though she is legally blind. She tries her best to hang the clothes on the line.

Being an active and independent person, this has depressed me.

My two older sisters, brother and their children have been able to come on weekends to help me look after my mother and myself. If I did not have the support of my family and friends, I don't think I could have managed what I have been through.

*Lula Giarenakis
Yarraville, Victoria*



Our stars

Good friends and family are like stars. You don't always see them, but you know they are always there.

Caring for others

A diagnosis of breast cancer, for some women, comes at a time when they are also facing the challenges of caring for their elderly parents, an adult child with a disability or another family member. It can be particularly difficult for women in this situation to find timely and practical information and assistance.

Statistics show that women account for 71% of primary carers in Australia. Women who are full-time carers for others,

such as elderly parents or a child with a disability, may need to seek short-term or emergency carer assistance while undertaking treatment for breast cancer.

Short-term or respite care can be provided at home or at facilities such as day centres and may be for a few hours, days or longer periods, depending on the need. Emergency care may include short-term care in-home or in a centre or hostel.

Local councils provide a range of community support services that

may cater for carers, including home help, home maintenance, personal care, in-home and centre-based respite, transport and food services.

The Carers Association, with branches in each state and territory, provides a range of services such as education, information, counselling and support groups, which vary from state to state. The national number **1800 242 636** (freecall*) links to the Carers Association in each state or territory.

Alternatively, visit the Carers Australia website at www.carersaustralia.com.au

The Commonwealth Respite Carelink Centres (CRCC) coordinate respite care, and can give information about local services for carers. CRCC can be contacted on **1800 059 059** (freecall*) 24 hours a day. Eligibility criteria apply and there is usually a fee for centre-based respite care.

* Calls from mobile phones are charged at the usual rates.

Testing the new boss

I received my diagnosis the day I started my new job. It was quite strange, as my first concern was not the diagnosis, but the possibility that I might lose my job. Being single with a mortgage was foremost in my mind when I went to discuss my new status with my manager, just after lunch on day one.

The response I received could not have been better. Not only was I told to ensure that my health was my first priority, I was reassured that my job was safe.

Initially I thought a week or two off work would be okay. This rapidly changed, as I needed three operations resulting in a bilateral mastectomy, followed by chemotherapy. I had two months off work and then returned on a part-time basis, having the chemo week off and then working three days per week on reduced hours in between cycles.

Working kept my mind off the

treatment and my workmates were incredibly supportive while this was happening. What helped me most of all was being told that I could arrange my working hours to suit the treatment and my fatigue levels. This took the pressure off and ensured that I still had some kind of an income while undergoing chemo.

I cannot stress enough how great it was to keep working through the chemo – it was tough and tiring, but I proved to myself that I could still function, get the job done and basically face whatever was thrown at me. On a few occasions I worked from home, which was a fantastic option to have available as sometimes the one-hour train trip into the office was a little hard, but at least I could still contribute online.

I admit I was incredibly lucky to have an employer who was so flexible and supportive. It demonstrated to me that I am



Lee McKerracher (left) with her sister Lynne at the 2007 Field of Women LIVE in Sydney.

working for an organisation that does put its employees first and makes me proud and happy to work there. It has also made me a bit of a workaholic, as I try to give back as much as they gave me!

I have found that since returning to full-time work I am

determined to make my mark, but also to enjoy the ride. There are many things that I had planned for the future and I find I am looking at ways of making them happen now rather than later.

*Lee McKerracher
Raby, NSW*

A country practice

I have been working for a group of doctors in our local community for more than 20 years. I am the Practice Manager and our staff are extremely supportive of each other. In my hour of need I was fortunate to have 20 years of sick leave virtually untouched, so I could continue to get paid while away in the city for treatment, some 600 km from home.

I was 51 years old when diagnosed and all our sons were working and independent. My husband is self-employed and as I was still receiving an income he could afford the time and expense of coming to Adelaide with me for the six weeks of radiotherapy. I was also fortunate



Karyn Speed

to have a good relationship with my doctor, who agreed to give my first four doses of chemotherapy at the regional hospital 50km

away. That hospital now gives chemotherapy on a regular basis, having set up a chemotherapy room during my treatment.

I worked most of the time before and after my time in Adelaide. I would have my treatment on Thursday and then have Friday and Monday off work to recover. I know that working certainly helped me with my recovery and feeling of wellbeing. Since completing my treatment I now work four days a week, having Wednesday off, which makes me feel that I have two weekends.

I believe working, particularly the camaraderie, was an important part of my recovery. I am grateful to my employers and colleagues

for their ongoing support of me and each other and will work for a few years to come. Work is important to me and I manage to keep stress to a minimum by delegating wherever possible. There was a time when I would work on weekends to catch up and try to do more to be 'in control' of things. I have learnt in my absence that the staff can manage very well and I no longer need to 'control'. I am enjoying taking less responsibility and the freedom that flexibility in the workplace is giving me.

*Karyn Speed
Tumby Bay, South Australia*

Money, money, money ...

Breast cancer threw me the biggest challenge of my life, as I faced unemployment and losing all that I worked for since I was 17.

*Rosemary Lee
Elizabeth Bay, NSW*

As if a breast cancer diagnosis is not enough, having to leave your job, either temporarily or permanently, and losing the income that goes with it, can mean a significant financial strain.

My salary is about 40% of what it was before surgery.

*Carol Walker
Wahroonga, NSW*

There are some options that can assist in managing your finances during treatment.

Financial advisers can help with practical advice on budgeting or tapping into financial options for individuals.

Some utility providers (e.g. water, gas, electricity) can delay payments or work out a payment plan. Banks and other lending institutions may delay minimum monthly mortgage repayments due to illness depending on individual circumstances. Some major banks offer a 'repayment holiday' of up to three months.

Centrelink offers some financial and other support services for women who leave the workforce

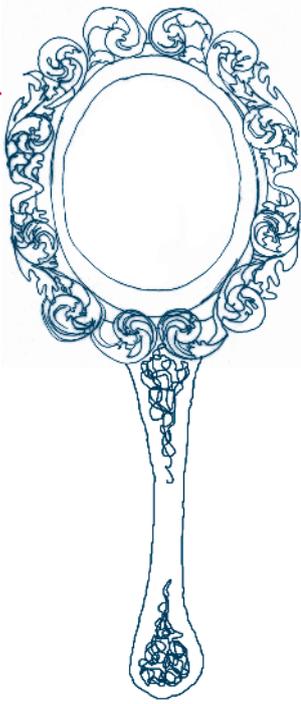
due to breast cancer. Options include carers, sickness and disability, and employment-related income support. Health Care Cards can provide discounts on the cost of medications, travel and household utilities. Centrelink social workers can help with information, referral and support. Navigating the Centrelink system may seem a little daunting at first. The easiest way to contact Centrelink is to phone **13 27 17** between 8am and 5pm weekdays. There is also a multilingual call number **13 12 02**. The Centrelink website is www.centrelink.gov.au

Some state and territory-based Cancer Councils offer one-off

financial assistance to help pay household bills such as rates and utilities. Contact the Cancer Council Helpline on **13 11 20** for more information.

Other options may include accessing pre-existing income protection or other relevant insurance (particularly for women who are self-employed) or accessing superannuation early, depending on individual circumstances.

Your breast care nurse or a social worker at your treating hospital may also have more information about financial support services.



My Story

Taking it as it comes

I was 42 when I was diagnosed with breast cancer in September 2006. I had a full mastectomy and axillary clearance. Four weeks later I started five long months of chemo, followed by five weeks of radiation therapy.

Within a week of my diagnosis, I quit my job. I was the manager of a ladies retail clothing outlet, managing staff with problems of their own, which on a normal day I could deal with. However, my husband, Robert, and I decided I would be better off focusing on my health, without the distraction of work-related pressures.

Like a lot of people in our situation, we had a mortgage, car payments, etc, and now we had 40% less income to work with each fortnight. It was tight, but we managed; after all I wasn't buying new clothes or shoes. I no longer had a need for my four-weekly haircuts and colours, and our entertainment expenses were non-existent. Life just stopped for a while.

My amazing husband was my nursemaid, my hairdresser (he was a wizz with a razor), my

fashion adviser (an easy job might I say), my counsellor and my best friend.

Six weeks after my last radiation treatment we sold our house, bought a caravan and travelled down the East Coast for four wonderful months. During that time I thought long and hard about what was next for me. I could not bear the thought of just going back to work as if nothing had happened. Surely this happened for a reason. I kept waiting for a sign or revelation to hit me, for something or someone to say this is what you need to do. Well it is six months later and I am still waiting.

In the meantime I volunteer at a nursing home one day a week, talking to elderly people who need company and still have so much to offer. I chose aged care because I know what it is like to have to depend on someone else for support. Plus, it feels good to help others. I suppose these days I am more into feel-good stuff, such as yoga classes, attempting watercolour paintings, going for long walks along the beach and generally taking it as it comes.

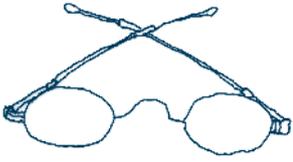
My patient husband has a new job that he loves, but I do worry that I am putting him under pressure to support us both. However, like most men, he denies that he is under any pressure. He does not want me to worry.

My greatest difficulty is imagining what the future holds. After so many years of working hard and having a clear view of my personal, career and our financial goals, now everything seems so uncertain – in flux. I do not want to waste time going through the motions of making money. There are more important things to do. The new me is evolving and I hope one day I will have a better idea of where I am going. Until then I will try to enjoy every day with Robert at my side and a smile on my face. What's that old saying? 'Life's too short', and don't we know it.

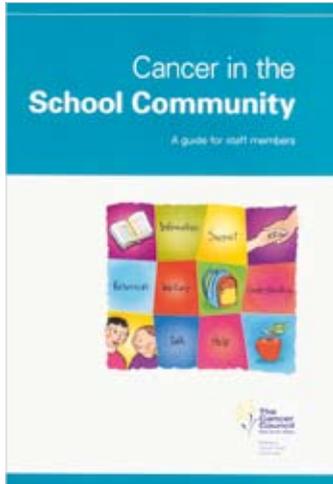
*Sue Hardy
Medowie, NSW*



Sue Hardy with her husband Robert at Cape Hillsborough just north of Mackay, Queensland.



Reviews



Cancer in the School Community

The Cancer Council New South Wales' recent publication *Cancer in the School Community* was of particular interest to me as I am a secondary English teacher who was diagnosed with breast cancer in 2006. The resource is generally well set out. The introduction, although not comprehensive, provides an overview about cancer and its treatments and the quotations throughout the resource from people affected by cancer add authenticity.

Chapter Two 'Talking about cancer' addresses many of the issues faced in a school community when a diagnosis of cancer is made. It concludes with providing information about seeking further information or assistance from the Cancer Council and includes telephone numbers and the Cancer Council's website.

Chapter Four focuses on when a parent has cancer and its possible implications for children and young adults. Suggestions for

practical ways the school can help are offered; although how feasible their implementation would be depends greatly on the broader community and whether the child is in primary or high school. Integrating information about cancer into the core curriculum or planning cancer awareness activities would possibly be more easily achieved in the primary setting. The important message in this chapter is that schools should be guided by the needs of students.

When a staff member has cancer is covered quite well in Chapter Five, although how individual teachers and schools impart the information to students and the wider community is perhaps not considered in enough depth. The implications for teachers in the management of their classes and discussing the situation with their students will be significantly different for primary and secondary teachers and this needs more recognition than the resource allows.

A principal's role in supporting staff members who have been diagnosed with cancer cannot be overestimated. It is from the principal that the rest of the staff take their lead. Chapter Six provides a comprehensive and well-balanced mix of practical strategies to ensure the smooth running of the school, tempered with recognition of the needs of the staff member. This chapter could have been written by my principal. He did everything possible to make sure I was supported, could teach if and when I felt able, and he fully

respected my decision to take an extended period of leave.

Cancer in the School Community should be considered a valuable addition to staff resources in a school community and is highly recommended.

Jan Shore
Euroka, NSW



Working with Cancer

In 2007 The Cancer Council Australia published *Working with Cancer: a workplace resource for leaders, managers, trainers and employees*. The glossy 80-page publication with its accompanying DVD aims to support not only employees who have cancer but also their managers and employers.

The resource contains comprehensive and useful information. I have some reservations about how user-friendly it is, as its information would need to be repackaged by organisations using it, to ensure the right information is given to the right people.

Primarily, it is a resource for employers that provides general

and statistical information about cancer, its impact in the workplace and how to manage/support employees with cancer. It also includes a section for employees diagnosed with cancer with a list of rights, responsibilities and tips, plus several pages of information. The rights and responsibilities are mixed in with tips, which can sometimes be confusing.

The information in the employees section is great. However, it is written in fact sheet format/language, occasionally punctuated by the word 'you' that can make a reader unsure the section is relevant to them.

Above all, a person diagnosed with cancer wants to be accepted in their workplace, whether they need time away to deal with the cancer or want to remain in the workforce. I hope the resource is used by employers and results in better support for employees affected by cancer. However, if not carefully managed, those using the resource could focus unwanted attention on a worker's cancer diagnosis, possibly isolating and overwhelming them, which is clearly contrary to its intention.

Ann Revell
Mundaring, Western Australia

Both of these resources are available from the Cancer Council New South Wales website at www.cancer council.com.au/cancerinschools and www.cancer council.com.au/workingwithcancer respectively. You can also order hard copies by phoning 13 11 20.



Profiling our member groups

Waratah Breast Cancer Support Group

The Waratah Breast Cancer Support Group, established in 1995 in the Wellington and East Gippsland shires of eastern Victoria, is auspiced by the Gippsland Women's Health Service. It meets every two or three months at various towns in the area, including Sale, Bairnsdale, Munro and Wy Yung.

Meetings are fun occasions, with new activities to try and guest speakers from time to time. In the past members have let down their hair (and in one instance their bellies) with belly dancing, African drumming and tai chi. With the assistance of community grants from Wellington Shire, the group also arranges free counselling sessions for women and their families.

'Our cancer journeys make us sisters. When we meet, we give ourselves permission to share the good and the bad. The beauty of a group such as this is that we can be honest; we have the opportunity to share and talk about the bad times. But we must not forget that it is also very important to take time out to pamper ourselves. The latter is often last on our list,' says one of the coordinators, **Marlene Parsons**.



Marea Wright was the inaugural Waratah Princess for a Day.

As a result, Marlene, **Stephanie Crosbie** and **Glenyss Ruff** came up with the 'Princess for a Day' concept – to ensure that the pampering is not forgotten.

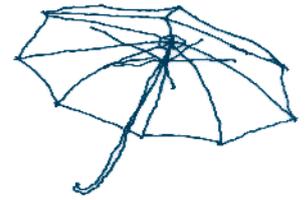
Marea Wright was selected as the inaugural Princess and was duly robed, crowned and sceptred! Marea shared the story of her breast cancer journey with those present. A new 'Princess for a Day' will be chosen at each meeting.

The Waratahs have been involved in various events and fundraisers for breast cancer organisations. They ran a *Mini-Field of Women* in 2003, brought the Pink Lady bus to Melbourne's *Field of Women* in 1999 and are planning another *Mini-Field* this year.

Marlene says that like other support groups, they lose too many members.

'We honour them by celebrating their lives, sharing our memories, laughter and tears and reflecting on the impact they have had on each of us. We have also honoured them by purchasing white silhouettes, which have been planted in BCNA's national *Field of Women* events,' she says.

The Waratahs are proud of the important role the group plays in supporting, informing, representing and empowering the women of east Victoria. Together they have identified and addressed the issues affecting their community and evolved into a strong and united group of women.



Seeking Shelter

BCNA welcomes:

- Camden Haven Dragon Boats, Camden, NSW
- Cancer Support Friendship Circle, Parmelia, Western Australia
- Donald's Wonder Women, Donald, Victoria
- West Cancer Support Group, Airport West, Victoria

We have **196** Member Groups and more than 28,000 individual members.

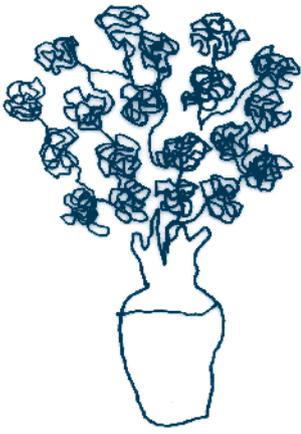
You can visit our website to find Member Groups in your state at www.bcna.org.au > About BCNA > Member Groups.

Member Groups in our focus

We recently appointed **Janelle Woods** to the new position of Member Groups Coordinator.

Janelle is currently working on strengthening our links with BCNA Member Groups across Australia.

If you would like to know more about BCNA Member Groups visit our website www.bcna.org.au > About BCNA > Member Groups, email beacon@bcna.org.au, or phone 1800 500 258 (freecall).



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:

- Cathy and Tom Park
- Courtney & Patterson Pty Ltd
- Cranbourne Football Club
- David Bird
- Gadens Lawyers
- Gillian Walker
- Green Acres Golf Club
- Hush Puppies Clarks/Pacific Brands Footwear
- Kate Knight
- Linette Etheredge
- Sharlene McArdle-Sacco
- Tasmanian Breast Cancer Network – Pauline Watson
- Terry White Chemists – Macarthur Square
- Trudy Harris

Memorials

We pay tribute to the lives of **Zelia El-Hadj, Nancy O’Dea, Maria Scalise and Bruce Studley**. We are 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.

Happy birthday to **Sevim Akcelik, Hannelore Best, Jill Collins, Susan Fishpool, Leanne Pentland and Maree Sandles**.

Congratulations to **Becky Swart and Josh Somerville** on their recent wedding; and **Jocelyn and Neil Clements** who celebrated their 25th wedding anniversary.

Making a difference

Thanks to the many women who took up our invitation in the last issue of **The Beacon** to join our Review & Survey Group. The response has been overwhelming. Since then, many women have completed surveys, and commented on resources and books.

One example of a survey opportunity for our women is a study we are supporting conducted by the National Breast and Ovarian Cancer Centre (NBOCC). The study is about women’s experiences of support and information after their breast cancer surgery.

Another survey, conducted by the University of Queensland, captured women’s experiences of breast cancer follow-up care while living in rural, remote or regional Australia.

It was wonderful to hear from women all around Australia and such a privilege to speak to these women. All of them had such amazing and unique stories to share.

*Jane Masters
The University of Queensland*



Sunday 17 February 2008 saw the national launch of the *Wade in the Water* DVD. The event brought more than 60 choirs and local communities together, raising an incredible \$20,000 for BCNA. Thank you to documentary writer and producer Linette Etheredge who organised this impressive event and raised such wonderful awareness of BCNA throughout Australia. For more information about the *Wade in the Water* events visit www.bcna.org.au > Events > Recent events. Pictured is the South of the River Gospel Choir from Victoria.

If you would like to help make a difference for the women who experience breast cancer in the future, register with the Review & Survey Group at www.bcna.org.au > Policy and Advocacy > Seat at the Table > Get Involved – or email ras@bcna.org.au

All you need is an email address and a willingness to complete a survey from time to time.

Bakers Delight rises for BCNA

More than 620 Bakers Delight bakeries turned pink for their annual Pink Bun campaign in May. Bakeries filled their Pink Lady tins and while we are still counting the proceeds they have so far (mid-May) raised well over \$360,000.

The campaign was a wonderful way for bakeries to show their support for the local women and their families who have been affected by breast cancer. Pink Lady cut-outs with moving messages lined bakery walls and barbecues were fired up to raise extra 'dough'.

Many of BCNA's Member Groups and Community Liaisons participated in the local community activities. These included:

- Bakers Delight Artarmon asked local BCNA members to help with its second annual 'Bid for a Baker' at the Community Artarmon Fair. At their BCNA information stall,



Angie Christie and Caroline Howard at Bakers Delight Lavington, NSW, pinked it up with local personality Steve Bowen (courtesy of The Border Mail).

Community Liaisons spoke to more than 5000 people about BCNA, the local breast cancer support group and, of course, how they could make a donation!

- In Footscray, Victoria, Community Liaison **Jillian Lawrow** spoke with many customers during the bakery's

official Pink Fun Day and helped sell Pink Lady cut-outs.

- In the ACT, all five Bakers Delight bakeries asked their local BCNA Member Groups to help them 'Pink Up' their bakeries, hand out information to customers and organise BCNA Pink Bun tables in the shopping centres to help spread the word.

- With Bakers Delight Morayfield, Queensland, local BCNA member **Jurina Demaine** was able to generate local radio coverage and a very Pink Lady photo in the local newspaper.

Customers were encouraged to visit BCNA's website to vote for their favourite Bakers Delight bakery.

The Pink Lady Awards went to the following bakeries: Dianella (WA), Crows Nest (NSW/ACT), Murwillumbah (Qld), Edwardstown (SA/NT) and Boronia Junction (Vic/Tas).

For images of the wonderfully decorated bakeries, visit www.bcna.org.au > Supporting BCNA > Sponsors > Pink Bun 2008.

A big thank you to Bakers Delight and all the bakeries and to our women who put in such a big effort helping to make this campaign the best so far.



Sandie Wiggins and Wendy Robottom turned pink in Lindisfarne, Tasmania.

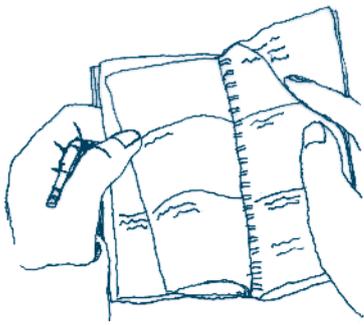


Claudia enjoyed a pink bun at the Albury Centro Bakers Delight, NSW.



BCNA gratefully acknowledges our partnership with Bakers Delight.





Upcoming Events

June 21: BCNA will present a forum for women in Sydney. Featuring guest speakers Assoc. Prof. Fran Boyle and Stephanie Dowrick. There is no charge to attend but please register on 1800 500 258 (freecall) or visit www.bcna.org.au

June 21: Breast Cancer Association Queensland (BCAQ) will hold their annual Rural Breast Cancer Seminar at Charleville RSL Club, Queensland. For more information contact Tracey Plumridge at bcaq@bigpond.com or phone (07) 3666 0614.

July: BCNA will hold a free forum for women in Melbourne in July featuring guest speakers. Visit www.bcna.org.au or phone 1800 500 258 (freecall) for more information or to register.

July: Four weekly seminars for women who have completed treatment for early breast cancer will be offered in July by the Austin Hospital, Melbourne. For more information about these free seminars contact elizabeth.foster@austin.org.au or phone (03) 9496 3715.

July 17: BreaCan Victoria will be holding an information session about Fatigue – To Rest Or Not To Rest? An occupational therapist will talk about cancer-related fatigue and how to manage it. For further information visit BreaCan's website www.whv.org.au/breacan or phone 1300 781 500.

September 20: Organised by BCAG NSW, the *Women for Women with Breast Cancer 2008 Forum* will be held at the Sydney Convention Centre, Darling Harbour. There is no cost to attend. For more information visit www.bcag NSW.org.au

October 25: Dragons Abreast ACT's Challenge Corporate Regatta will feature a BCNA *Mini-Field of Women* at the Canberra Yacht Club. For more information contact canberra@dragonsabreast.com.au

October 27: Australia Breast Cancer Day

November 15: NT Breast Cancer Voice will celebrate their 10th Anniversary Dinner. For more information contact Pat Hancock on pathancock_is@hotmail.com

November 15-16: Gawler Foundation 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.

May 13-14 2009: The UICC 15th International Reach to Recovery Breast Cancer Support Conference will be held in Brisbane. Abstracts are now being accepted. Cost of registration before February 2009 is \$375. Visit www.reachtorecovery.org for more information.

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

The summer issue of **The Beacon** will be looking at **Life after treatment**. We are seeking stories about how your life has changed after your initial journey with breast cancer. What are the on-going, long-term issues for you, physical or emotional? How do you cope with those sometimes dreaded follow-up appointments? Has your life taken a new direction? What are your priorities now? Have they changed since your breast cancer diagnosis and treatment?

Please submit your articles of around 200-300 words (about half a page) preferably via email to beacon@bcna.org.au by the end of September 2008.

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



the BEACON

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