No woman should be an island

Simon and Garfunkel will be touring Australia later in the year. The lyrics from their 60s hit 'I am a Rock, I am an Island' speak of a man hoping to avoid pain and suffering by cutting himself off from others who might come close. For most of us, stepping away from our family and social groups is not something we would choose.

Certainly a ripple effect occurs when a woman is diagnosed with breast cancer. Yes, the spotlight falls on her, but the effects are also felt by her partner, family members, friends and workmates, and this is not always acknowledged. We know that those close to us can often find the situation excruciatingly challenging. It seems many men feel it's their role in life to 'fix' things that are broken. Yet having their wife or another loved one diagnosed with breast cancer is something they cannot simply fix!

Families can be tricky entities at the best of times. A coherent, supportive family can make recovery so much easier for a woman, but the pressure on families when a cancer diagnosis is made can also influence family dynamics, tip balances and change the way we relate with one another. Let's face it, there is no manual to show us how to behave or what words to use at a time like this.

This issue of The Beacon considers the effects of breast cancer on those around us. As always, it is full of powerful pieces written from a range of perspectives by our members. Some talk of life-affirming relationships established and developed, even new friendships made as a result; others remind us that we might risk losing those close to us because they simply cannot cope.

The diagnosis can also have direct health implications for our children and other family members. One article speaks of difficult decision-making by daughters who are discovered to be carrying gene mutations for breast cancer.

One of the things I find disturbing is that many of the stories we received spoke of a sense of guilt; the guilt of passing on a mutation, of disturbing happy family life, of feeling guilty that a sister or a daughter has been diagnosed and not them. We are all complex individuals who look for affirmation and support. The stories remind me how counselling and professional assistance could help many of us deal with the feelings and challenges we are experiencing.

It is also fantastic to read of the positive support received from husbands, parents, children and those closest to the women and to know that many now feel their relationships have been enhanced and strengthened through this shared trauma.

I am reminded of the old saying, 'We cannot direct the wind but we can adjust the sails.'

Lyn Swinburne
Chief Executive Officer

Mothers and daughters – Melanie Peggell with her mother Christine Paroz who was diagnosed with inflammatory breast cancer in 2005. Melanie is one of the many daughters who have shared their stories about how their mother's breast cancer journey has affected them and their families. You can read Melanie's and other stories on our website at www.bcna.org.au > Stories > Family and Friends.
BCNA forums travel on

BCNA’s forums so far this year have brought together almost 800 women and their supporters in Sydney, Bendigo and Canberra.

At our most recent April forum in Canberra, around 300 women and their supporters gathered at the National Library of Australia. BCNA CEO Lyn Swinburne, Olympian and breast cancer survivor Raelene Boyle, medical oncologist Associate Professor Fran Boyle and breast cancer survivor and author Dr Stephanie Dowrick all spoke on living well beyond breast cancer.

Similar issues were explored when 200 women and their supporters met in Bendigo in March. Forum speakers included Dr Mark Warren, Lyn Swinburne and Raelene Boyle. Women came from as far as Swan Hill and Deniliquin in NSW, with a busload of women arriving from Avoca.

As reported in the last issue of The Beacon, our Sydney Forum in February focusing on the topic of pathology was an outstanding success, with 300 women participating, and a further 300 on the waiting list. For this reason, another pathology forum will be held in Sydney on 12 September 2009. BCNA is also working with the Royal College of Pathologists of Australasia to develop a Breast Cancer Pathology fact sheet later in the year.

To see an overview and photos of each of our forums, go to www.bcna.org.au > Events > BCNA Forums or phone 1800 500 258 (freecall). See Upcoming Events (page 16) for registration details.

Prostheses reimbursement update

This issue of The Beacon includes a flyer with common questions and answers about the Australian Government’s Breast Prostheses Reimbursement Program that began in December 2008.

This program, through the Medicare system, reimburses women who have had a mastectomy as a result of breast cancer up to $400 towards the cost of each breast prosthesis.

We have heard from many women who are delighted with this new program. However some women have told us they are finding it difficult to meet the upfront cost. We have alerted the Government to this issue, and we will continue to monitor the situation over the coming months.

Some breast cancer support groups have responded creatively to help women in need in their local areas, by lending women the money which they repay once they receive their reimbursement.

This is a great example of one of the many ways that support groups can provide practical support to women with breast cancer in their local community.

BCNA Chair retires after 10 years

We acknowledge with gratitude the extraordinary contribution made by Patricia Edgar over the past 10 years. Patricia is BCNA’s Founding Chair and has played an invaluable role in steering Chair and has played an invaluable role in steering us from our baby days to today, where we link together and represent more than 35,000 women with breast cancer across Australia.

Patricia was diagnosed with breast cancer back in 1988 and has often remarked that in those days breast cancer was rarely talked about openly. We have come a long way!

Jocelyn Newman has also retired after seven years on BCNA’s Board. We thank these outstanding women for their leadership and commitment to BCNA.

In the next issue of The Beacon we will profile BCNA’s new Chair, Marg O’Donnell.
Mothers, daughters and the gene connection

When a mother with daughters is diagnosed with breast cancer, she may find herself wondering: ‘Is there a chance that I can pass this onto my daughter?’ Many women may have heard of the terms ‘strong family history’ and ‘breast cancer gene’. What does this all mean?

What does having a ‘strong family history’ mean?

Australian women have a one in eight risk of developing breast cancer before turning 85, which makes it relatively common. This means that many women may have one or two relatives over 50 who have been diagnosed with breast cancer just coincidentally, and not because they are related.

Family history becomes more important the greater the number of relatives diagnosed with breast cancer on the same side of the family. As a guide only, a woman with a strong family history might have two or more first-degree (mother, sister, daughter) or second-degree (grandmother, aunt, niece) relatives on the same side of the family who have been diagnosed with breast cancer.

A father’s family history of cancer is just as important as a mother’s family history.

The risk is stronger again if two or more relatives have other characteristics associated with increased risk, such as being diagnosed before the age of 50, being of Ashkenazi Jewish descent or having ovarian cancer.

Women with a strong family history of breast cancer with or without ovarian cancer are considered to have a higher risk of developing breast cancer and possibly ovarian cancer.

How many breast cancers can be linked to inherited genetic factors?

Only 5-10% of breast cancers can be linked to strong inherited genetic factors.

What can you do if you have a strong family history?

If women are concerned about their risk because of family history, they should consult their doctor. If it appears that there is a moderate or high risk of developing breast cancer, women can be referred to a specialist genetic cancer service or family cancer centre.

One option may be to consider genetic testing to see if there is an inherited predisposition to breast cancer. More about the role of genes is explained in the box on this page. Coming to a decision to have genetic testing is not an easy one, and there are many things to consider.

Family cancer centres provide assessment, specialist information, advice and counselling, and a plan to monitor women’s health.

To find a family cancer centre, phone the Cancer Council Helpline on 13 11 20.

If a genetic mutation to breast cancer is found, what can women do to reduce their risk?

A family cancer centre counsellor can discuss risk-management options. For some women, these might include closer monitoring, annual mammograms from a younger age, or having a breast MRI (magnetic resonance imaging).

Nothing completely eliminates the risk of breast cancer for anyone, but surgery is considered most effective in reducing cancer risks. Surgery can include removing both breasts (bilateral mastectomy) and/or ovaries and associated fallopian tubes.

Coming to a decision to have risk-reducing surgery is often a complex and tough one for many women. Making use of experienced genetic counselling and taking the time to make a decision that is right for each individual, is important.

To find out more, go to www.bcna.org.au > Information > Fact Sheets > Family History and Hereditary Breast Cancer. We also have a list of resources about family history and breast cancer, at www.bcna.org.au > Information > Resources or phone us on 1800 500 258 (freecall).

Genes and breast cancer

The cells in our bodies constantly divide and reproduce. This growth is controlled by genes. If something goes wrong with these genes and ‘faults’ occur, cell growth can be affected, which may cause cancer. Faults can either be acquired during a person’s lifetime or be inherited from a parent.

Two genes associated with breast cancer are BRCA1 and BRCA2. These genes protect against abnormal breast cell division. Faulty mutations can be inherited from either biological parent and are associated with a risk of breast and ovarian cancer.

Scientists tell us that a very small proportion of breast cancer – 5-10% – is due to inherited gene faults. Those with an inherited mutation are rare, but they make up an important group because of their potentially very high risk – 40-80% – of developing the disease.

It is useful to remember that no one inherits ‘breast cancer’, although a small number of women inherit a genetic risk or ‘predisposition’ to the disease.
Carolyn Howard is a senior clinical psychologist working in the cancer services area at Northern Sydney Central Coast Area Health. She supports women and men with cancer, their partners and family members. She talks to The Beacon about the concerns of those around a woman with breast cancer.

When women are diagnosed with breast cancer, they go through a process of psychological and emotional adjustment. The same applies to those around them, including their partner, family, work colleagues and friends. These people may also experience emotions like shock, disbelief, fear, anxiety, sadness, frustration and anger.

Often people around the woman will wonder, ‘what do I say, what can I do?’ Many feel concerned about saying or doing the right thing. Unfortunately, this can lead to withdrawal, and them not saying anything at all.

I think it is important that family and friends do not just make assumptions about what a woman needs. I suggest to them, if you do not know what she needs, just ask. It is okay to say, ‘I don’t know what to say to make this better’, or ‘Can you tell me what some of the things that might help you right now are?’ Possibly you could make some suggestions such as, ‘Do you need me to take you to an appointment’, or ‘Can I do some shopping for you?’

It is good to actually acknowledge and be honest about what it is you are feeling. Often women are grateful for that.

A lot of the time, women’s partners will wonder whether they are able to offer the support that their partner needs. Cancer doesn’t happen in isolation. Partners will often confide to me: ‘Here’s someone that I care about, but there is nothing I can do to fix the problem’.

There are also the practical considerations as well, for example with getting young kids to school, and cooking and cleaning. Often it forces the family to ask for help, which can make some people uncomfortable.

Asking for what you need in a time of great stress is difficult. Sometimes what holds women back from asking for help is their own self-expectations. They think, ‘I don’t want to burden people’.

I often ask them to reflect on the fact that if their friends were in the same position, they wouldn’t hesitate to do the same for them. It is about allowing yourself to receive. Research shows that social support is a huge buffer for psychological distress.

Sometimes well-meaning people come out with platitudes, ‘Don’t worry, everything will be fine’. That can make women feel very isolated and misunderstood. Often they can feel that a door has been closed to her to talk about how they are really feeling.

For women who have completed their treatment, this is also often a time when they feel very vulnerable and alone. Family and friends often just assume that everything is back to normal. Just because treatment has finished, it doesn’t mean that the experience is over, and women still need support.

Helping a friend or colleague

I didn’t know how to ask for help, so I found the Helping a friend or colleague with breast cancer brochure a good ‘ice breaker’, especially for friends and work mates who were finding it hard to know what to do or say after I was diagnosed.

Catherine, Victoria

Many women say that family, friends and colleagues sometimes do not 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 providing support. It is based on the experience and wisdom of our members and can help ‘break the ice’ if friends and colleague are unsure how to help.

We are 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.
In 2000 my parents retired and moved to Geelong. Shortly afterwards Mum was diagnosed with breast cancer. I was shocked – how was I going to cope without her? So many thoughts went through my head, but I had to be strong for my parents, as Mum was the one who had this disease.

Mum had a full mastectomy, removal of all of her lymph nodes and a breast reconstruction. She had six months of chemotherapy, her ovaries removed and medication for five years.

I went with Mum while she had her chemotherapy and visited her oncologists. While she was having her chemotherapy I would sit there reading every health magazine on the shelves and any other information I could get my hands on. I knew that I had a high risk of getting cancer especially with the existence of breast and ovarian cancer on the maternal side of the family – my grandmother and now my mother. I started to think about what I could do to avoid this fate.

Mum and I went up to the Peter MacCallum Familial Cancer Centre for genetic testing. Fourteen months later they had found a mutation in our genes. I saw a series of cancer specialists to see what treatment was available to me. I decided to have a prophylactic (preventative) bilateral mastectomy, which I had in 2003, and in 2004 I had a prophylactic hysterectomy.

I felt there was little information to help me make this big decision, apart from talking to a psychologist and specialists at the Peter Mac. However, after first watching my grandmother and then my mother going through cancer, and with Mum always having in the back of her mind the big question ‘did they get it all?’ I am confident I made the right decision.

The plus side is that I should never get breast, ovarian or uterine cancer. I really wanted children but the odds of getting cancer were too high, so this option was the best choice for me.

I am 44 and have not had breast reconstruction as yet. It is far too expensive and besides who really needs them! Everyone says ‘Gee you were brave to make that decision’, but as women we are always making tough decisions. The best thing to come out of all of this is that it has only made me even closer to my mother. I appreciate her more each day. Mum is going strong and I hope to have her around for many more years.

Janelle, Victoria

Below is an extract of school work by my son Matthew. The topic was ‘Managing change and how it impacted on you’.

‘Change is the law of life,’ said former US President John F. Kennedy. It is inevitable for anyone and everyone. Every day people throughout the world experience change. Either for good or for bad, change is a memory builder, character builder and emotional strengtheners which will continue to build and shape us until the day we die.

I have had many events in my life which I believe have changed me for the better. In late 2003, when I was at the doctor’s with my Mum, she was delivered a curve ball in the shape of breast cancer. This dramatic event caused not only my life but my whole family’s life to be turned upside down. Watching my Mum fight this awful disease, being injected with various sorts of treatments, witnessing her body changing on a day-to-day basis and then come out of the battle victorious. This changed me by opening my eyes to the broader picture of life and taking on board a new motto for life, ‘Life’s too short for stuffing around’.

I owe so much to my children. Going into my sixth year of living with breast cancer, I have no sign of the illness returning. I truly believe Matthew and Laura have had a huge impact on my outcome. They made me a stronger person throughout my nightmare, which I doubt I could have endured without them.

Pat, NSW

A son’s thoughts

Janelle with her mum Beverly.

Pat with her daughter Laura and son Matthew.
Sharing my daughter’s journey

My daughter Jen rang me from northern NSW on 31 March 2008 to tell me she had breast cancer. Among the chaotic thoughts that filled my mind was how I wished it was me.

I was 74, widowed and retired. Jen was 39, her life filled by Bill, her loving partner of 19 years, her passionate commitment to her job in juvenile justice and above all by her beautiful, lively sons, five and three.

I flew north from Sydney to be with her and found her determined to get on with all possible treatment to be free of the cancer. ‘Whatever it takes’, she said.

I stayed with the family for most of the next seven months and shared Jen’s memorable journey. We both like to seek out all available information regarding anything that concerns us and we had a lot to learn about breast cancer.

Jen has always lived life at top speed, involved in numerous community activities, as well as the tight family-work-home triangle. We became part of a team aiming to ensure that life remained as normal as possible, particularly for the boys.

We planned each day around Jen’s appointments and treatments (all involving a three-hour car journey), tri-weekly school runs and Bill’s work. I found I had the dual role of urging Jen to rest and helping the boys to accept this change. I was at times ‘Dragon Mum’ and ‘Dragon Grandma’, frequently fearful, anxious and sad. Jen’s strength and courage lifted us. Also her many friends, whose love and practical help with meals and having the boys to visit warmed us all.

I am so grateful for the time I spent with my grandsons, sharing their lives completely, almost like another parent instead of a visiting grandma. We know each other so well now and my love for them is beyond measure. Above all, the love and pride I feel for Jen has a new dimension. I watched her come to terms with the overwhelming diagnosis, finding ways to cope, including meditation. She thought a lot about her life and priorities and the inevitable stresses involved. We shared many thoughts at this time across the broad picture.

I treasure two gifts from last year apart from my memories. When I came home in November I was deeply anxious, feeling I had left Jen on the edge of a precipice. My seven months with her had occupied me entirely and now I had to let go. She gave me a copy of the CD Learning to Relax, produced by the Queensland Cancer Council. This was new to me. I had always relaxed easily in my garden or with a book, but I find the CD very effective. Secondly my family gave me a digital photo frame for Christmas. Some of Jen’s photos show her uncovered head, shorn of her striking long red hair, particularly on her 40th birthday in September, big smile, arms high in the air, celebrating with her family.

Joan, NSW

A bittersweet journey

My journey which began in November 2007 has been a bittersweet experience. Bitter has been the change in family relationships, and sweet has been finding close and supportive friends.

My husband and I moved to Queensland five years ago to be closer to our grandchildren. We had to start the process of making new friends. We both lawn bowl and so we joined the local club and made acquaintances, some of whom became friends. It was after my diagnosis, surgery, chemotherapy and radiation that these newfound friends became our support group emotionally and physically. Without these people the road to recovery would have been so much harder. They were there with kind words, thoughts and deeds for myself and my husband. I have been extremely fortunate to meet these people.

I also had great support from my younger daughter who has had a changed outlook on life and I think become closer to her own daughters as a result.

The bitter part has been the drawing away of my eldest daughter who has not coped with my cancer. Her reaction has been one of not how I was feeling, but rather how it affected her. If I was tired after chemo and did not feel up to talking, I was accused of having no time for her or my grandchildren. Our relationship deteriorated as she then seemed to ‘have no time’ for myself or her father.

I will always have feelings of disappointment and regret but life is precious and I hope to live the rest of mine to the full.

Jane, Queensland
In October 2008, my beautiful 21-year-old daughter Karlee was diagnosed with breast cancer. Within a matter of weeks, she had a lumpectomy, then a mastectomy, including removal of 17 lymph nodes – four of which were cancerous. Our lives were changed forever.

I was always a ‘worrywart’, paranoid about car accidents. When Karlee and her two younger brothers started driving, that was my greatest fear. It never entered my mind that any illness – least of all cancer – could affect one of my children. Up to that point, I could always make things better – a kiss and a bandaid on a scraped knee, a hug and some kind words after a fight with a friend; but not this time. I was useless, powerless and helpless and absolutely terrified.

For the first few weeks, I could not stop crying, and without the love and support of family, friends, and workmates, I could not have continued functioning. I think I went through every possible emotion in the first few months. – anger, denial, bargaining with the universe to take this away. It could change on an hourly basis.

What has inspired me the most is Karlee herself. Throughout this ordeal she has been so strong, brave and positive. She is what keeps me going; family and friends are in awe of her. She has dealt with this disease with more dignity than someone twice her age. With her fantastic attitude and sense of humour, she has made it so much easier for the rest of us.

We had always been close, but our bond is even more special now. The overwhelming support that has come from family, friends, and even strangers has renewed my faith in mankind. I have been touched and moved to tears by the kind words and gestures we have received. Karlee knows she is loved so much, by so many. We will continue to fight this battle with her, by her side, together. And we will win – of that I am sure.

Janeen, Queensland

The year 2007 wasn’t our best year. My mother was diagnosed with early stage Alzheimer’s in August and I was diagnosed with breast cancer in December, just 10 days short of retiring.

We had no family in Melbourne, the closest living in Brisbane and the others in New Zealand and Japan. It was left to my husband to advise family and friends of both my diagnosis and my mother’s situation.

It was not long before the phone was ringing and the emails flowing. Friends I had known for years but had been remiss in keeping in touch with set up a roster system so someone would ring me weekly. My half-brother and aunty whom I had not seen for 20 years called and emailed me regularly. The phone calls and emails were like a lifeline during my chemo and radiotherapy treatment.

In July last year I managed to catch up with my three closest friends in New Zealand, the first time we had all been together in more than 23 years. Even without the hair they still recognised me!

Only last week my husband and I flew back to New Zealand, along with my mother, to catch up with my half-brother, aunty and their partners.

I seriously underestimated the bonds of friends and family. Even though we had not seen one another or been in touch for years it just did not seem to matter.

If it had not been for my diagnosis I would not have renewed those wonderful friendships or had a relationship with my half-brother and aunty. Imagine all those great get-togethers I now have to look forward to.

Trudy, Victoria
In December 2001 I was heavily pregnant with my son when we found out that Mum may have breast cancer and would require a biopsy for confirmation.

The day after my son was born, Mum had her biopsy. It was surreal how such joy can be overshadowed with such worry.

I will never forget getting the phone call confirming my Mum had breast cancer.

Mum underwent a lumpectomy followed by radiotherapy. It was difficult to help her. She is absolutely my best friend and to feel so helpless was heartbreaking. This lady who had always been my tower of strength was suddenly vulnerable and weak.

The next year she had cancer in her other breast and had a mastectomy. When I visited her in hospital I would sometimes just see her staring at my son. I know she was wondering whether she would see him grow up.

I have been involved in some great things such as the formation of a Pink Lady on the MCG in Melbourne. I also love getting my copy of The Beacon. All of these things not only helped my Mum but they are such a help for the family – they definitely help me to cope.

I know Mum’s situation affects me, and at times I find it difficult to understand what she has gone through, and in fact what my father has gone through to try and be beside her every step of the way.

My beautiful Mum is one of the bravest women I know. I will never take her for granted. I am so proud of her and it makes me very humble to call her a ‘survivor’.

Susan, Victoria

My Mum is the most amazing person I know. She is my mentor, my guide, my source of happiness; she is the person I can trust when I need help, when I need company; she is my gorgeous mother.

Last year she found a benign lump that was surrounded by abnormal cells and, although advised not to take any action, she researched it and in July she underwent a precautionary double mastectomy and reconstruction. She said she would rather lose her breasts than her life, and I will always look back in awe at her courage and optimism.

Cancer was found in one of her removed breasts, so Mum began chemo. It took a while to comprehend what this meant. My Mum has always been there for me and now I wanted to be there for her. However, some days I could see her battling the pain and exhaustion and all I could do was just admire her for everything that she was.

I always tried my best to make her smile and let her know that to me she was still my same Mumma and that although she had no hair or eyebrows she was still beautiful. We would play with different scarves and joke about the ‘chemo chic’ look. I would constantly have to remind her that no one was expecting her to stay in perfect shape considering what she was going through. People say that the most important thing in life is the value of your relationships and I value my relationship with my mum more than anything.

Hannah, NSW
Mum’s and my journey

When Mum was diagnosed with breast cancer I knew this would be a difficult time, the most difficult I would ever go through. But I knew we would get through it.

During this time I got closer and closer to my Mum, just by helping her and being with her which helped me understand what she was going through. Because of this, I have formed a special bond and friendship with her that I never thought I could get.

During the radiation, chemo and Herceptin Mum was lethargic and tired. She would get upset a lot and that would affect all of us. During this time there were so many times I just wanted to cuddle up to her and cry, but I knew I had to be strong.

Not only was I helping Mum, but she was helping me, by seeing the positive side of it. Mum made me look at the world differently. She made me see that there were worse things in life than only an apple for lunch. She made me open my eyes to the beauty of the world.

Now the hard times are over and I know that we won!

Nicola (aged 13)

My story!

When I was diagnosed with breast cancer at the age of 44, my first thought was for my three children and the effect that this would have on their lives. There was and still is, a sense of guilt attached to the disruption and fear that is caused by all of the surgeries, treatments and the unknown.

Thankfully, being their mother made me a tower of strength, as I was determined to be there for them and to still be part of their everyday lives, for example school events, sporting events, graduations, etc, as I had always tried to be.

The weeks dragged on, a year had passed, then good news came at last

Mastectomy cancelled, cancer at bay, my heart cried out that special day

Support and love my family gave kept us strong and somewhat brave

For my sister now life is brighter, overwhelmed with her courage, she is a fighter

I spare a thought now every day for families affected in this way.

Nicola and Michelle.

For my sister Sandra

Cancer touched my life last year, my sister diagnosed, my heart in fear

The initial shock was no not you, feeling helpless, what do I do?

Anger and sadness with me each day, praying her cancer would go away

Surgeons, oncologists and all the rest, emotions soaring put to the test

The bravery and courage she always showed, in hospital, doctors and the chemo road.

The loss of hair, then the wigs and hats, pneumonia, fevers, not good stats

To see all this just broke my heart, the scans blood counts a major part

At night in silence I would weep, anxiety and worry crept into my sleep

Chemo her friend, not her foe, was it working we did not know

My thoughts and emotions all were scattered, beating the beast was all that mattered.

The weeks dragged on, a year had passed, then good news came at last

Mastectomy cancelled, cancer at bay, my heart cried out that special day

Support and love my family gave kept us strong and somewhat brave

For my sister now life is brighter, overwhelmed with her courage, she is a fighter

I spare a thought now every day for families affected in this way.

Debbie, NSW

Sadly, I was not able to be as emotionally strong as I wanted to and, unfortunately, it is usually the family that is most affected by this. Being open and honest about my feelings helped them understand what I was going through. There were times when I could not cope with their emotion as well, and thankfully, my husband was there for them during those times and I know that this has created a closer relationship between them and him.

To me, this has been a wake up call. My family has once again become my main focus as, before I know it, they will have moved onto their own lives. Whereas life was so hectic and busy, I have now slowed life down a little, am trying to become more relaxed, eating and cooking healthier, and I am looking after myself better, so that as well as being there for them, I can also have fun with them. I love being their Mum.

Michelle, Queensland

www.bcna.org.au
Blessed with the help of my angels

I am a 45-year-old single Mum with two daughters, Kelly 13 and Jamie 11. They are my inspiration and motivation to stay healthy and happy at all times.

I also have the privilege of working with a terrific group of people, of varying ages, and from all walks of life at a McDonald’s Family Restaurant in Sydney. Adam, 23, is the manager.

When I was first diagnosed with breast cancer, and lost my hair to chemotherapy, he decided to show his support for me and had his own head shaved.

The year 2007 was stressful, as it saw the end of my 13-year marriage, so 2008 was to be the start of a new chapter in my life. However, my regular two-yearly mammogram and ultrasound on 4 January showed a tumour, and so I began chemotherapy on 31 January.

My life became an endless round of treatments, side effects and specialist appointments. I have always been a strong independent person, relying on no one but being the first person on the scene when a friend was in trouble or needed help. Now it was time for me to accept help, to be humble and simply say ‘thank you’. From the beginning I asked God to send me ‘an angel a day’ and they arrived.

Here are a few of my angels. Fiona, a school mum, became my ‘chemo angel’. She would take me to each chemo treatment. Jan-Marie, another school mum, became my ‘appointments angel’. Gracie, a colleague became my ‘grocery shopping angel’. Karyn, another colleague became another ‘appointments angel’. Noreen, a lovely lady from church, became my ‘hospital angel’.

I work with many teenagers at McDonald’s and they would shower me with hugs and kisses whenever they saw me. They also sent text messages that usually arrived just when my spirits were down.

Whenever I told someone of my diagnosis for the first time, I made a point of staying positive and cheerful, and when asked what they could do for me, I would simply reply, ‘make me laugh’. That is precisely what everyone did for me. I remember my first appointment with my oncologist. I entered the room laughing and joking, and he sat across the desk from me, shook his finger at me and said ‘You keep that attitude and I’ll work with it!’

Most people go through their lives and never really experience the true meaning of friendship or they may only have one or two friends. I have the privilege of saying I have many friends, each one very dear to me, each one part of my ‘angel team’. And no, my house is not full of feathers!

Lucy, NSW

Healing with the help of music and new friends

I was diagnosed with breast cancer in December 2007. My sister Shirley whom I dearly love was diagnosed with bowel cancer three weeks later.

I lost my husband at the age of 25 leaving me with a small son aged 4 who tragically died in 1977. I thought that nothing else could possibly happen to me, so the news of my cancer was a real blow to my system. I told my sister this little devil inside me isn’t going to beat me. I have great faith and with the help of my dear sister and many friends I coped.

I had four cycles of chemo which brought me to a standstill, as I experienced all the possible side effects, and five sessions of radiotherapy. The most devastating aspect of treatment was losing my lovely hair. Fortunately it is just starting to grow.

In 2007 I was introduced to the beautiful music of Andre Rieu. I have a pen pal in the US who is also a fan. Unbeknown to me, she put on her website that I was suffering the effects of chemo. I could not believe the outpouring of compassion from Andre fans all over the world. I received cards and gifts from Germany, Holland, France, Canada, the US and all over Australia. The love of my sister, friends and Andre’s beautiful music helped me through my cancer.

Wilma, NSW
Our story

Inspired by her optimism

Breast cancer is associated with older women, not my beautiful 28-year-old friend Kirsty.

She was over for lunch last July, and said ‘I found a lump last night. Here, feel’. She took my hand and pressed it into her left breast and I felt the hardness, the firmness of a basketball. I chewed my bottom lip. What do you say?

The next morning we met on the city-bound train heading to the breast cancer clinic. Kirsty was her usual bouncy self, laughing and telling stories. The train trip whizzed past and before I knew it we were on the 7th floor of a city building.

Kirsty had initially not wanted me to come in with her, insisting it would be a waste of my time as it would just be quick. I suggested that if it was quick then we would treat ourselves to spending the day shopping and lunching. Several hours into the morning and we were both glad I had come.

Test after test. Needle aspirations, scans, mammograms … After four hours I found myself in a room alone.

A kindly nurse popped her head in and enquired if I was Kirsty’s sister. When this happened a second time moments later, I began to doubt that shopping would be on the agenda.

The news was terrible. I will never forget the crumpled face of the lovely doctor who came to tell us. Kirsty and I had just finished laughing at one of her outrageous stories when the door opened to reveal the doctor who had obviously been crying. She shook her head and said ‘It’s not good’.

It was well after lunch time when we left the building and headed down the street. I was lost for words. Kirsty hooked her arm into mine and started skipping and laughing saying ‘Oh wow’.

It was this immediate positive reaction to something so horrific that will stay with me for the rest of my life. Kirsty has the amazing ability to see the best in everyone and every situation. And diagnosis day was no different.

I found myself quickly moving into practical mode. A friend who was in a similar situation, suggested that patients need different friends for different agendas. They need emotionally supportive friends, practical friends and good time friends to make life as normal as possible. The weekly chemo sessions, which could have been terrible, were instead viewed as quality friendship time.

I loved having a Mad Hatter’s tea party for her where friends came wearing hats as she was about to lose her hair.

What makes it easy is Kirsty’s ability to communicate so effectively. One might expect if you have cancer you withdraw from your friends and interests to cope in silence or with the support of a chosen few. For Kirsty the door was wide open.

Anyone who wanted to support, talk, share, or understand, was made to feel welcome. The school where Kirsty is a much loved teacher has a strong community which banded together to offer meals, gifts, cards, prayers, a book for school families to write in and some financial assistance. All of this was gratefully accepted and appreciated by Kirsty. She wasn’t going to pretend she would ‘go it alone’. That in itself was a huge education for everyone around her as they realised they could be a part of her journey too. Not everyone got it quite right but as usual Kirsty just laughed it off saying that they meant well.

Two particular stories stick in my mind. One was a card a mum at the school wrote which said ‘I know how you feel as I lost my young aunt to breast cancer last year’. And another mum giving some advice ‘Just have them cut off. Both of them!’

Kirsty wrote emails that informed us where she was at in her journey and this again was an extremely effective measure to help her friends feel comfortable and informed.

Walking Kirsty’s cancer journey has been wonderfully insightful and a real privilege to support a truly incredible person who has faced her illness with confidence, courage, determination and, more than anything, optimism.

Chantelle, NSW
Reviews

Positive: Finding life in the midst of cancer
by Sally Collings, Harper Collins, 2009 (paperback). 271 pages. RRP $27.95

This book has 42 chapters; each with a story of either a particular person’s journey with cancer or the thoughts and views of people from all different walks of life about what ‘positive’ means.

I found the book interesting, although at times it was confronting due to the number of people who had recurrences, some many years later. I would recommend it to both survivors and their families, as it covers many different types of cancer journeys – people all going through the same turmoil and struggles in their day-to-day lives.

The sections that had family members’ points of view were interesting, as I have often wondered just how deeply having cancer affects other family members.

I guess the parts that I read with more interest were the breast cancer survivor sections. However, it was very interesting to also read about how people were affected by other types of cancer. I feel that in the end it came down to the fact that most people faced the same problems and feelings, no matter what type of cancer. Without a doubt, everyone who wrote chapters in Positive certainly turned many negatives into positives.

Parts of the book made me feel very sad, while other areas were a reality check for me. The word ‘positive’ has in the past often annoyed me, owing to the fact that so many people say to you ‘you must try and be positive’.

I had not thought about, or realised, that to be positive also means that you are able to talk about your true feelings and positively let people help you on your journey (as was explained in the chapter by Dr Jane Turner).

The book encourages you to reassess your life. You must decide what is really important to you and let go of the unimportant things. This also is a ‘positive’ thing to do, to help you to focus on your recovery without cluttering your mind with unimportant issues.

I think the most valuable lesson to be learned from this book is – if you can discuss how you feel with your family and friends, everyone will benefit. Family and friends need to know that you too are sometimes scared and unsure of what the future holds.

Reading Positive has made me aware of how fortunate I am to have such a wonderful support group surrounding me. For this I am truly grateful.

Jo Chapman
BCNA Review & Survey Group Member

I am married with two sons, aged 11 and 20. While reviewing the handbook we found it provided us with a tool to give us grounds for discussions about feelings and coping strategies. A lot of information that I have sourced in the past is not aimed at a young person’s perspective and sometimes finding the right angle to allow discussion can be difficult.

I especially like the format of the book and the easy-to-find sections. This handbook is not confronting or technical, and it is a good source of information that can be referred to as needed.

I highly recommend it. I feel it should be made easily available and wish it had been around 12 months ago when I was diagnosed.

Amanda Di Rosa
BCNA Review & Survey Group Member

Now What … ?
Dealing with your parent’s cancer

Cancer is not just a journey for the diagnosed, but also a collective journey for the family members and friends of the diagnosed. Now What … ? is a handbook that is written for young people aged between 12 and 24 years, who are affected by the impact of their parent’s cancer on their lives. It is written in a straightforward, easy-to-understand format.

NowWhat … ? is a free resource published by CanTeen, an Australian organisation for young people living with cancer.

To order a copy you can SMS 0429 838 151, phone 1800 669 942 or visit www.nowwhat.org.au.

The latest issue of The Inside Story (our supplement for women living with secondary breast cancer) features other CanTeen services and resources available to young people dealing with their parent’s cancer.
In this issue of *The Beacon* we profile a different type of BCNA Member Group. Unlike many of our Member Groups, which are support groups for women with breast cancer, the Tasmanian Breast Cancer Network operates to assist all Tasmanian women with breast cancer through advocacy and information.

The Network advocates for improved local services for Tasmanian women, informs women about breast cancer-related issues, promotes BCNA at various events around the state, and acts as a reference point for Tasmanian support groups.

Tasmanian Breast Cancer Network President Karen Forster says many of the Tasmanian Network’s core group of 20 members have been involved in breast cancer advocacy for several years. Some were instrumental in the then National Breast Cancer Centre’s Consumer Advisory Group before BCNA came into existence.

A number of the Tasmanian Network’s members have completed BCNA’s advocacy training and represent us on committees across Australia. They also sit on consumer advisory groups with other organisations, including Cancer Australia and the Department of Health and Human Services Tasmania. Their local advocacy work includes lobbying members of state parliament for improved services, most recently better access to public diagnostic mammograms through the state health service.

The Tasmanian Network’s members are also involved in local support groups across the state and use these contacts to galvanise support for their advocacy work. While not a fundraising organisation, the Tasmanian Network does receive donations from local businesses and groups who recognise the importance of its work.

In April this year, the Tasmanian Network used some of this money to fund the Tasmanian Breast Cancer Conference. The theme was ‘Closing the Gap – sharing, caring and information’. Guest speakers included medical oncologist Tabitha Healey, breast cancer survivor and BCNA Ambassador Dr Stephanie Dowrick, BCNA CEO Lyn Swinburne and geriatrician Dr Jane Tolman, who spoke about the effects of chemotherapy on women as they age. Around 170 women attended the free two-day conference, along with several local Breast Care Nurses and allied health professionals.

Much of the Tasmanian Network’s work is on behalf of BCNA. ‘We are the public face of BCNA in Tasmania,’ Karen says. She and fellow Network member Pauline Watson regularly speak to groups across Tasmania about BCNA’s services and programs.

The Tasmanian Network also represents BCNA at state events such as Agfest, which draws up to 90,000 people. Karen says this is an excellent way to get the BCNA message to rural women.

In 2003, the Tasmanian Network hosted BCNA’s regional Field of Women in Hobart. Its members also help local support groups organise their annual Mini-Field of Women events.

Now in its 11th year, the Tasmanian Breast Cancer Network is as strong and busy as ever. It always welcome new members – phone BCNA’s office on 1800 500 258 (freecall) if you would like to be involved and we will put you in touch.
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:

- Ashburton Bowls Club, Victoria
- AFL Cairns and all clubs that took part in Pink Footy Day
- AFL Canberra and all clubs that took part in Pink Footy Day
- Bell Charitable Fund
- Cal Wilson
- Catherine and Gregory Collyer
- Collins Food Group
- Country Energy, NSW
- Diana McCormack
- Hastings Cove Retirement Village, Victoria
- Kate Cuss – Arbonne Australia
- Meyer Cookware Australia Pty Ltd
- Netball Victoria and all clubs that participated in Pink Footy Day
- Pratt Foundation
- Ritchies Stores Pty Ltd
- Sharyn Owen
- Simon Watts – Ray White, Darwin
- The Central Hotel, Collinsville, Queensland
- Victorian Country Football League and all clubs that took part in Pink Footy Day
- Virma Robson and the Peninsula AeroClub

On Sunday 5 April 2009, Helen Carmody and Gill Stapleton completed the Paris Half Marathon. Inspired by the breast cancer journeys of close family and friends, Gill and Helen not only ran the marathon, they raised more than $4,000 for BCNA through sponsorships. Congratulations Helen and Gill!

Memorials

We pay tribute to the lives of Deb Martin, Dianne Mary South, Dianne Volkering, Heather Price, Joyce Dickson, Mary Holmberg, Richard Manthorpe and Ruby Carroll.

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

Celebrations

Happy Birthday to Cathy, Michael and Rhys Van Gastel, Deborah Sandler, Oma Van Volenburg and Sue Ewin, who asked to have money donated to BCNA to celebrate their special day.

We welcome the following new groups who have linked into our Network by becoming a BCNA Member Group:

- Biggenden Bosom Buddies, Qld
- Bribie Island Cancer Support Group, Qld
- Can-Hope Cancer Support Group, Tas.
- Dragons Abreast, Crewsaders, Bunbury, WA
- Esperance Breast Cancer Support Group, WA
- Heathcote Breast Cancer Support Group, Vic.
- Hunter Soiree, NSW
- Illawarra Breast Cancer Support Group for Young Women, NSW
- Inverell Breast Cancer Support Group, NSW
- Mt Isa & North West Queensland Breast Cancer Support Group, Qld
- Valkyrie Care Group Inc. – Bendigo, Vic.

We now have 218 Member Groups and more than 35,000 individual members across Australia.

You can visit our website to find a Member Group, including support groups, in your state or territory at www.bcna.org.

Become a BCNA Member Group?

We are always keen to recruit new BCNA Member Groups from around Australia. As a BCNA Member Group, you can:

- have your group promoted on BCNA’s website;
- fundraise for your group by selling our Pink Lady badges and keeping half the profits (i.e. $2.50 per badge); and
- be invited to join us at special national and state-based events/activities and training.

This year we will bring together one representative from each of our Member Groups to strengthen ties between our Member Groups and BCNA. We will also run sessions about the latest advancements in breast cancer treatment and care, and workshops to assist groups to continue to support women with breast cancer.

If you are in a group that is not yet a BCNA Member Group and would like to be, you can contact Janelle our Member Group Coordinator at membergroups@bcna.org.au or on 1800 500 258 (freecall) for more information or visit www.bcna.org.au > About BNCA > Member Groups.
During October all around Australia, BCNA Member Groups and members gather together in their communities to show support and pay tribute to those affected by breast cancer.

We call these events Mini-Fields of Women. They are wonderful visual events that centre around the display of 100 of our Pink Lady silhouettes, to represent women diagnosed with breast cancer.

BCNA supplies you with the silhouettes, the decorations, opportunities to leave messages and even invitations to help you spread the word. They all come in an 'Event in a Box', which makes it easy to stage and pink up your community.

Everyone adds their own touches so we end up with a wide variety of styles and settings — picnics in parks, family barbecues and lunches at hotels and displays at farmers markets and local gyms.

“We were thrilled with our Mini-Field. It was a great day. It really united our community — we will do it all again next year.”

— Heather, NSW

So get the ball rolling and plan a 2009 Mini-Field in your local community.

It’s easy. Just:
1. Pull a small group together.
2. Set a date.
3. Email Marita at minifields@bcna.org.au or phone 1800 500 258 (freecall) to get help with ideas and to register your event, or visit our website www.bcna.org.au > Events > Mini-Fields of Women 2009.

How special it was to see the Bakers Delight team dressed in pink with their warm smiles and so many pink buns for sale.

The 2009 Pink Bun Campaign had all the right ingredients for an excellent result — commitment, passion and a combined sense of purpose from Bakers Delight staff, customers and our members.

We are so grateful to all franchisees and staff at Bakers Delight bakeries for their overwhelming support. At the time The Beacon went to print we were still counting the money raised. Keep an eye out on our website to see the final result.
Upcoming Events

June 29: BreaCan Victoria will run a free workshop entitled ‘Bringing Death to Life’ 12pm-2pm at the Queen Victoria Women’s Centre, 210 Lonsdale Street, Melbourne. The workshop will provide opportunities for women to have an open discussion about issues surrounding life and death. For more information and to make a booking, phone BreaCan on 1300 781 500.

July 15: BCNA will be holding a forum in Darwin. For more information and to register, visit www.bcba.org.au > Events > BCNA forums.

September 4-6: Canterbury Girls Secondary College, Mangarra Avenue, Canterbury, Melbourne, will host a Girls Bust Out Art Biennale. Come and see hand-painted and decorated busts by students of the school, as well as top artists and celebrities. These artworks are created with inspiration and enthusiasm to continue awareness of breast cancer. Proceeds from the event will support the work of BCNA.

September 12: BCNA will present a forum in Sydney on the topic ‘Insights into Breast Cancer Pathology’. The forum will feature guest speakers Assoc. Professors Michael Bilous and Fran Boyle, and Dr Stephanie Dowrick. There is no charge to attend, but please register on 1800 500 258 (freecall) or visit www.bcna.org.au > Events > BCNA forums.

September 20: Blackmores Sydney Running Festival. BCNA has been chosen as one of the supporter charities for this festival. There are four events: Blackmores Sydney Marathon, Blackmores Half Marathon, The Sunday Telegraph body+soul 9km Bridge Run and The Sunday Telegraph 4km Family Fun Run. If you would like to register to participate in the event and to fundraise for BCNA, visit www.sydneyrunningfestival.com.au

October: Mini-Fields of Women will be held around Australia. See page 15 for more details.

October 3: BCNA and Australian Society of Breast Disease (ASBD) will present a forum on the Gold Coast on the topic ‘Living Well After Breast Cancer’. There is no charge to attend but please register on 1800 500 258 (freecall) or visit www.bcna.org.au > Events > BCNA forums.


November: BCNA will hold a forum in Geelong on the topic of ‘Living Well after Breast Cancer’. Date and venue to be confirmed, so please visit our website closer to the time for more details www.bcna.org.au > Events > BCNA forums.

Visit our website www.bcna.org.au > Events for information about recent and upcoming events held by or for BCNA in your state or territory.

More stories and feedback from our readers

You can read more personal stories from women and their families and friends on our website at www.bcna.org.au > Stories.

Due to the limited space we have in The Beacon and The Inside Story we are unable to publish the feedback we receive about previous issues. We have set up a new web page at www.bcna.org.au > Information > Our magazines > Feedback.

If you would like to give us feedback about our magazines email beacon@bcna.org.au or write to BCNA, 293 Camberwell Rd, Camberwell, Victoria 3124.

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 visit www.bcna.org.au > Information > Our Magazines to subscribe to The Beacon and/or The Inside Story.