



The Beacon

Breast Cancer
Network Australia
newsletter



The impact of breast cancer is felt throughout a family unit. Read Kerry's amazing story on page 8.

How do families cope with a breast cancer diagnosis?

When I was told I had breast cancer in 1993 the news affected not only me, but also my family and the people who cared about me.

The news had huge ramifications for my husband, two young children, parents, brothers and close friends.

We struggled through the ensuing weeks and months as best we could, trying to make some sense of it all and hoping desperately that things would work out okay.

The help and support given to me was wonderful. Apart from worrying about my children, I was probably too self-absorbed at that time to think much about how everyone else was coping.

Looking back on my experience and speaking with other survivors, I realised that we often overlook the issues and needs of those closest to us.

In a recent national survey by the National Breast Cancer Centre, women identified a great need for better support for their partners and families.

Sometimes resources are there, but we don't know about them at the time.

This issue of *The Beacon* looks at some of these issues. As well as stories from the women themselves, we have included articles by partners, children and parents, who have generously shared their feelings and experiences.

We have also included some useful resources developed with these people in mind. It is important that we know what is available, both for our use and so that we can recommend them to others.

When we are advocating for improvements in services, we need to remember the needs of family members.

– Lyn Swinburne

This issue of *The Beacon* has been extended to 12 pages. We were thrilled to receive so many articles. Unfortunately, we could not include all of them and some of the articles here are only excerpts. You will find the full stories on our web site: <http://www.users.bigpond.com/bcan>

If you do not have access to the Internet, write to us, including a stamped, self-addressed envelope and we will send you the full article.

The Network in cyberspace

By the time you read this, our web site should be ready and out there in cyberspace.

Find us at <http://www.users.bigpond.com/bcan>

Thank you to those who have helped with this, especially **Brenda Meyers**, who created the web site, and **Duncan Edwards**, who will help us manage it.

Duncan volunteered his help after

reading his mum's copy of *The Beacon*.

He is 21 years old, a computer programmer by profession and lives in the inner Melbourne suburb of Richmond.

At last we will have somewhere to put all those stories, book reviews and photographs for you to read and look at.

Even stretching *The Beacon* to 12 pages is not enough!

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State Round-up

NEW SOUTH WALES



We are gradually making progress with invitations to act as consumer representatives where decisions about breast cancer are made.

This year, NSW women will have an opportunity to acquire the skills we need for good 'repping'. The NBCC has promised a consumer advocacy and training course in August. No dates yet, but let us know of your interest (there were about 20 interested early last year).

The 'Cancer: We Care' conference in Sydney on July 13 to 16, for cancer patients, carers, volunteers and health professionals, will offer three afternoon sessions about consumer advocacy.

A Field of Women committee has been established and we are looking at some scenic Sydney sites for a 'satellite' field.

Contact: Sally Crossing (02) 9436 1755 or crossings@bigpond.com

SOUTH AUSTRALIA



ACTION for Breast Cancer SA has established several breast cancer support groups and held a group co-ordinators meeting to network and discuss issues and procedures.

A support group for women with secondaries is being set up centrally, but ACTION is also planning two trips to rural areas to help establish further groups.

ACTION, with the help of the National Breast Cancer Foundation and others, is identifying a target for fundraising activities.

A brochure introducing ACTION and its activities to potential members was to be finalised in May.

Contact: Carlene Butavicius (08) 8272 2895

TASMANIA



The Tasmanian BC Network is an informal group set up in July last year, not long after our state forum. We are now considering a constitution and incorporation.

Several members have expressed interest in undertaking the science and advocacy training program to be held in Tasmania later in the year.

Contact: Pat Mathew (03) 6492 3257 or mathewp@southcom.com.au

VICTORIA



Women with advanced breast cancer now have their own support group. The Anti-Cancer Council of Victoria started the group on April 13. Its aim is to provide a forum for women with advanced breast cancer to discuss issues of concern and gain support from other women in a similar situation.

The group will meet every fortnight from 10 to 11.30am at 100 Drummond Street, Carlton. For more information, phone Sue Bottomley on (03) 9635 5133 or Jan Pignalosa on (03) 9635 5393.

Contact: Sue Lockwood (03) 9878 0736 or lockwood@bigpond.com

THE ACT



With some 'persuasion' from Bosom Buddies vice-president, Bev Higgins, local tradespeople have donated their time, skills and materials to build a house which will be raffled at this year's fashion parade.

In other news:

- Jan Murphy has started an education program for Year 12 students;
- two Bosom Buddies will take part in the YWCA training program for Encore, an exercise program funded by the Avon Foundation; and
- a web site is being developed.

Contact: Anna Wellings Booth (02) 6247 8470 or wbfamily@interact.net.au

NORTHERN TERRITORY



On March 27, Prof. Neil Pillar from the Lymphoedema Clinic at the Flinders Medical Centre conducted two workshops – one for health professionals and one for the public.

NT Breast Cancer Voice organised and financed this event. We are also:

- fundraising to send two members to the Sydney conference in July;
- preparing a 'My Journey' poster presentation for that conference;
- gathering information for our breast care nurse submission; and
- preparing a list of books on breast cancer and encouraging local libraries to stock them.

Contact: Susan Tully (08) 8927 3327 or tullynt@msn.com.au

QUEENSLAND



Following our conference, we in Queensland have a new 'collective attitude' to this disease.

This is particularly evidenced in the spirit and enthusiasm shown by breast cancer advocates. Leonie Young and Janelle Gamble have just returned from the Brussels Advocacy Conference.

At home, Sylvia Walters has submitted three articles to country newsletters, to let rural women know how advocacy groups will focus on their needs and help make their voices heard.

The articles were:

1. Leonie Young's paper to the Brussels Advocacy Conference.
2. A summary of the conference recommendations for rural and regional women.
3. A survivor's story.

This will promote the need for essential services for breast cancer patients and their families in the bush.

Contact: Leonie Young (07) 3341 7570 (ah) or Janelle Gamble (07) 3353 4151 (bh) or medusa_998@yahoo.com

WESTERN AUSTRALIA



The free, state-wide clinical psychology service for women with breast cancer and their families was threatened with closure when funding was reduced from its original 12-month contract to six and then three months.

The psychologist found it difficult to work under this scheme and resigned.

On the day she was leaving, five women from Action on Breast Cancer demonstrated outside her office building.

We also faxed the Ministers for Health and Women's Interests and the media, and received a large response from TV, radio and the newspapers.

By 4pm, the hospital released a statement saying that the position would be funded for 12 months with the prospect of on-going funding.

Contact: Carol Bishop (08) 9381 2070 or carol@cancerwa.asn.au

To highlight an activity or a project, contact your state representative and have it included in the next 'State Round-up'.

Taking the field to the world

Six Australian women travelled to Belgium in March to take part in the 2nd World Conference on Breast Cancer Advocacy in Brussels.

On the morning of the first full day, seven international consumers gave presentations about breast cancer advocacy initiatives which had taken place in their part of the world.

From Australia, **Jenny James** showed slides and the Field of Women (FOW) video to the nearly 300 women present.

The video, made by Melbourne filmmaker **Sue Smith**, made a great impression on the audience, many of whom told us it moved them to tears, including Her Royal Highness, **Princess Astrid** of Belgium.

For some of us, our greatest thrill at the conference was to meet **Dr Mary-Claire King**, the researcher who discovered the BRCA1 gene. She congratulated us on the FOW and asked for one of the silhouettes we had taken over with us.



Jenny James, Dr Mary-Claire King, discoverer of the BRCA1 (breast cancer) gene, and Lyn Swinburne in Brussels with a silhouette from the 1998 Field of Women.

In her presentation, Dr King spoke about her reliance on the women in the advocacy movement to motivate her to continue her research. A wonderful thought for us to bring away from the conference – that we inspire *her!*

Sally Crossing's report on the Brussels conference is available from BCNA. Please send a stamped, self-addressed envelope. Copies of the FOW video are available from the Network for \$20, postage included. It is a moving and lasting record of that unforgettable afternoon.

National meeting of Network members

'Cancer: We Care' conference organisers have generously allotted a large room so that we can call together Network members for a national meeting. It will be held on:

Thursday, July 15, 1999

11.30am – 12.30pm

Australian Jockey Club,

Randwick Racecourse, Sydney

We will give members an update on:

- the network's development and activities since our last national meeting in October;
- a financial report; and
- plans for this year's Field of Women.

We know it will be impossible for many of you to be in Sydney, but we're hoping that several interstate members will already be planning to attend the conference.

We would love to see as many of you as possible.

Field of Women 1999, Sunday, October 17

Great news! **AMP** is to be our Field of Women (FOW) sponsor for 1999.

Both the Network and AMP are excited about the prospect of working together to make a difference for women and their families.

This year, the main field of 10,000 pink and 2500 white silhouettes will be in Melbourne. We have lots of great ideas about where the field might be, including launching it at the MCG.

We hope to plant it in a major city park for several days, so that people will be able to come along and read the messages.

To keep our focus as a national group, we will also be having mini fields (perhaps 100 pink silhouettes) in all the other capital cities as well.

There will be many opportunities for you to be involved.

We need sponsors again for the messages for our silhouettes. This is the best way for us to maintain the

Network's activities and spread the word. *The Beacon* in September will include a couple of brochures asking readers to help us find sponsors.



An impression of last year's Field of Women in Canberra by Julie Burdis, an artist from Alice Springs.

For those of you who are keen to be really active, we will be developing kits for you to use. Women in areas away from the capital cities should find these particularly helpful.

These kits will contain ideas and information packs, the FOW video and all you will need to help promote the Network in your community.

If you live in Melbourne, we will be looking for lots of volunteers to help beforehand, as well as on Sunday October 17 and the following days.

We need volunteers for our FOW committees in each of the capital cities. Already we have a list of 40 breast care nurses who have volunteered to help.

Don't be shy! This is your chance to get involved. Don't leave it up to others!

Please contact your state's representative (see contacts on State Round-up, page 2) and offer your help. **WE NEED YOU!**

The needs of families

The mother ... Real pain and endurance

I am a 60-something year old woman trying to explain to my 35-year-old male supervisor that I must take time off to travel to Brisbane from Canberra to see my 31-year-old son, who has Chronic Fatigue Syndrome (CFS).

Last week I took a week off to be in Sydney while my 33-year-old daughter, a breast cancer survivor, had a surgical procedure. She has an allergy to certain anaesthetics, the administration of which has proved life threatening in the past.

My supervisor half jokes that I seem to have considerable problems with the health of my adult children.

I have neither the time or energy to explain the facts to this triathlon-competing, fitness freak.

His reaction again showed me the ignorance of people who have not experienced the trauma of a family member's debilitating or life-threatening illness, especially when it is a child.

What I want to say to this fellow goes something like, "Hey buster! You think you know what pain and endurance are all about because of your sporting feats.

Let me tell you plainly that real knowledge of pain and endurance – mental, as well as physical – belongs to young breast cancer survivors, and other survivors of life-threatening and/or debilitating illness. And this knowledge belongs to their parents as well."

My 31-year-old daughter's voice on the telephone, always so full of confidence and enthusiasm, breaking up as she began to say aloud for the first time, "I have breast cancer", gave me the worst day of my life (until then).

The anguish a mother feels when her child is in pain or trouble is undiminished

Judith would like to contact parents of young women with breast cancer around the world. She hopes to form a network that will enable their daughters to fulfil dreams of travelling by offering hospitality, accommodation and assistance.

Anyone interested in helping Judith realise this great idea should phone (02) 6239 7438 or e-mail her at Judith.Maher@atsic.gov.au

by years. Motherhood is never over, so we suffer and endure with our children.

How warily a mother must tread at this time, conscious that she neither wants nor has the right to take over the life decisions of an independent other. Yet she cannot avoid being keenly anxious that the best medical information be obtained and the best medical advice recognised and acted upon.

A daughter's breast cancer informs a parent's life from then on – every month survived without a recurrence that coalesces into a year and then another year. Every new medical problem encountered, obstacle overcome and goal achieved will all be keenly felt.

Just as certainly, there will be deep pride in the daughter who has learned to live a meaningful life with her constant companions – the shadow of early death, the sense of bodily mutilation, the fear of relationship rejection, the particular constraints on everyday activities.

She is among life's finest adornments – a treasure beyond measure.

– Judith Maher, ACT

The husband ... Taking it one day at a time

Before I discuss the effect my wife's breast cancer has had on me, I will reflect on how we met.

I was playing indoor cricket when I met Janice.

I was 37-years-old and looking for a good time, not a life-time commitment.

The old cliché 'love at first sight' might seem over the top, but that is what happened to me.

In the next two months, I proposed marriage three times and was knocked back twice.

It was also in that two months of loving and making love to Janice that I noticed the lump in her breast.

How did I feel once Janice's breast cancer was diagnosed?

Every male has been hit in the groin at least once in their lives. When I was told of Janice's cancer, that feeling of being hit was magnified 10 times. It was not a physical pain, but an empty, gut-wrenching pain.

After the initial shock of 'Why Janice?' came 'What can I do?'

I know how to splint limbs, stem arterial bleeding and start a heart beating, but I could not do anything about her cancer.

After Janice's mastectomy, I became a full-time personal nurse, both in and out of hospital, which also helped me cope.

After the operation came the chemotherapy treatment, which destroyed Janice's self-esteem.

My insistence that the treatment was

for her own good and that our relationship had not changed fell on deaf ears.

The only thing that got us through was my catch phrase, 'One day at a time'.

I think of my wife's cancer as a minor interruption of our lives.

The one thing breast cancer has done for me is to make me realise that life does not last forever, but love does.

Men have a role in breast cancer awareness. We have to be more vigilant in encouraging our partners to have the necessary tests, even if it does start arguments.

My beautiful wife gave birth to our first child early this year – Malcolm Lindley – and, yes, Janice does breastfeed him.

– Warren Penny, WA

The daughter ... Who do we turn to for comfort?

My mother was diagnosed with breast cancer four years ago. I was 20 years old, still living at home and going to uni.

The biggest shock came when the test results came back.

I saw my strong, capable, powerful mother lying in a hospital bed in shock and very distressed. It was the first time I had seen my father with tears in his eyes, looking distraught and helpless.

I swung into reassurance mode, trying to find out the extent of the information we had been given about the 'lump'.

Afterwards, I ploughed ahead, pretending it really wasn't happening to my mother and it was all going to be all right.

When it looked like she was going to recover and recover well, I suddenly felt consumed with horror and grief, as if she had been given a far worse prognosis. Feeling selfish and guilty followed this – that I should be so overwhelmed when other people's mothers were being given a short time to live.



Mother and daughter, Sally and Alex Crossing.

I finally fell into a heap at the university counselling centre.

Mothers are the ones we turn to when we need comforting. Who do we turn to when we don't want to burden them with our thoughts while they are having to deal with their own concerns about life and death?

When everyone in the family is worrying, it seems easier to discuss the practical side of treatment than how terrified we are that something could go wrong.

We never received contact or information from a counsellor or counselling service, from the time Mum was diagnosed to when she finished her radiotherapy. I had the university counselling service, but didn't think to go there until my mother was almost well.

If something ever does go wrong in the future, I hope that next time I'll be able to talk to someone a little earlier!

I went with my mother to last year's conference in Canberra and was so proud to be there and part of her workshop.

Although the BC word has become part of my family's everyday language I still avoid thinking that the actual BC may return to us.

I am not concerned for myself at present, as I can think of too many different ways to die. This may sound callous, but as with any disease and its precautionary measures, all you can do is follow them.

– Alex Crossing, NSW

The husband ... Positive, open and supportive

Gill's diagnosis six years ago reversed our lifestyle roles. I had been the one in need of all the support and care over the previous six years due to an accident – all of a sudden I was the one hanging out the clothes and doing the vacuuming!

Even though we thought the worst, I had to accept the fact that breast cancer had been found and to try and think positively and be strong for Gill.

When we talked about it, I found Gill was being strong for me – and for our children and their children.

Talking about this helped us come to grips with what was happening. We also faced the fact that breast cancer was not something we had control over.

Our family has always been close and this new trauma was no exception to the support we gain from each other.

Worrying about it made us feel worse, so we searched high and low for information about breast cancer, finding that

there was not a lot available, even those few years ago.

No-one we knew had had breast cancer. BreastScreen SA was helpful, but was only able to send us several photocopied articles. Riverland Women's Health Service was also helpful and supplied Petrea King's 'Spirited Women' – positive and informative.

Gill had a lumpectomy and we got on with our lives.

Another tumour was detected in the same breast 5½ years later and removed. Two months later, Gill had a full mastectomy and reconstruction.

The breast care nurse at Queen Elizabeth Hospital was fantastic and kept me informed all the time while I was home in the Riverland and Gill was in hospital. We have been able to contact her at any time since.

I have been present with Gill during all her visits to specialists and treatments. I have asked as many questions as I could,

even getting them to draw diagrams if I didn't understand. All the specialists have been very giving and informative.

I decided to support Gill in all her decisions, finding that I also agreed after asking questions of those who knew the answers. If anyone wants to know how to make a nipple – I'm an expert!

I would strongly support the idea of generating husband/partner-specific information and can see the benefit of an occasional 'husbands/partners' support group meeting, even though several of us have been attending most of the Riverland Support Group meetings, which we thoroughly enjoy – laughs, friends and information!

Gill's prognosis is good and I think the three main factors that have helped me through these six years have been:

- thinking positively;
- talking openly; and
- supporting the decision making.

– Harold Nelson, SA

Issues of concern ...



Living with cancer and living with children

Young people who have a parent with cancer can be described as “a hidden high risk group whose problems are minimised by (understandably) overwhelmed parents”.

One of the first considerations for parents is in telling their children about the cancer, the treatments and the associated side effects. To tell, to tell all or to tell some, are often the hardest questions for a concerned parent.

I often hear young people say that they are not being given information, not being told what to expect, do not know what's going on or know that there's more to the story than is being told.

They will also mention their parent's concern for them, protectiveness and inability to speak the words, let alone to their children.

These 10 points from a 1986 American Cancer Society publication explain why young people should be given information about their parent's cancer:

- children have a right to know about major events in the family;
- denying something is wrong is a breach of trust;
- children know when something is wrong and their fantasies are usually worse than the reality;
- not telling suggests the situation is too horrible to talk about;
- children may find out from someone else and be given wrong information;
- children may feel isolated, left out and unimportant if not told;
- children may reach wrong conclu-

sions from their observations or develop misconceptions (e.g. they're responsible for their parent's illness);

- informed children can be a comfort to parents and no energy has to be wasted on secrets;
- children have an amazing ability to cope if given support – even very sad truths are better than the anxiety of too much uncertainty; and
- involving the child shows trust in their ability to participate, which enhances self-esteem and allows for a growth experience.

Once you've tackled the task of informing your children, you'll then need to **be aware** of the effects that the information will have on them.

Also be aware of what else they have on their plate – it may not seem significant to you but all things are significant to children – especially adolescents. Are there exams on, a new relationship, pressure at school or with friends, etc?

Being aware of your child's day-to-day happenings will go a long way towards helping you know how they are coping.

Some points to be aware of in regard to your children:

- there will most likely be altered household roles and increased responsibilities for your children;

The Network has found a useful web site for young people who have parents with cancer at http://rex.nci.nih.gov/NCI_Pub_Interface/guide_for_kids/kidscontents.html

- your children may mask their true emotions and feelings to protect you;
- there may be threats to your child's security (staying with friends/relatives, decreased physical/psychological availability of parents, etc); and
- your children may experience changes in mood or socialisation, there may be regressive or anxious behaviour, physical symptoms, changes in school performance, and anti-social or attention seeking behaviours.

Once you have told your child and are aware that they are coping, you need to establish and maintain the best possible path for the whole family.

Open and honest communication: Encourage your child and help them to find someone to talk to. It does not have to be you and often, it is best if it is not you. Think as laterally as possible – school counsellor, a relative, a friend, other young people in the same situation – help them identify one person for them. Even if they don't access this person, there is security in knowing that they can, if they want/need to.

Emotions: Don't be scared of crying, laughing or any other display of feelings in front of your child (bearing in mind, that you may have to explain it to them).

Ask for help: Your children will need to continue with their after-school activities, weekend sports and socialising. Ask for help with driving to and from, etc. Maintain the normalcy of the daily routines as much as possible.

Above all, remember your children are strong. Generally, they will cope if you allow them to. Inform, be aware, support and nurture them, as well as yourself.

Follow your instincts as a parent and if you can't reassure yourself, if you're unsure, talk to someone who can help.

–Kerry Abramowski

Kerry is a qualified social worker and Project Officer on the Adolescent Program in the Anti-Cancer Council of Victoria's Patient Services Development Unit. Contact Kerry for information about the programs she runs for adolescents whose parents have cancer on (03)9635 5134 or e-mail kerrya@connexus.apana.org.au The full article is on our web site.

Pregnancy after breast cancer

You're thinking of starting a family? I recently had a baby after breast cancer. I was 28 years old at diagnosis, and had surgery, chemotherapy and radiation.

I am 31 years old with two beautiful children – a 10-year-old daughter and a seven-month old baby boy.

Becoming pregnant after breast cancer is nothing short of a miracle! However, there are a few things women should consider before trying to become pregnant after breast cancer.

An important point is whether your tumour was oestrogen negative or positive.

This is definitely something to discuss with your breast specialist, as your tumour may need to be treated with hormone therapies and this can affect your chances of becoming pregnant.

How long should you wait?

In my opinion, regardless of your type of treatment, I think it is wise to wait 18 months or so.

This is not only for a full recovery from the treatments, but emotionally and physically you will be better equipped to



Julie Nicholson and her "little miracle" – Finn.

enjoy the baby if your mind, body and spirit are all in top shape!

Another consideration is the chance of becoming pregnant after chemotherapy. Women can save their eggs before chemotherapy, but it varies between states and even hospitals. Speak to your specialist if you feel this might be for you.

After being told that it was unlikely the chemotherapy would affect me, I had temporary menopause for five months. For some women this is permanent, even in their 20s and 30s!

Some women have asked about genetic counselling. This might be considered if breast cancer seems to run in your

family. For information about genetic counselling, try ringing your state Cancer Council for a contact number.

I have been successfully breast feeding with one breast and my baby continues to thrive. However, I have been advised by my specialist to stop once the baby is 12 months old, as I cannot have mammograms while I am feeding.

I have found that the best bra for both pre-birth and after is the Berlei maternity bra (style #848), which is recommended by the Nursing Mothers Association.

The cups are elastic, so they mould to both breasts and are comfortable.

If you are contemplating pregnancy after breast cancer, get as much information as you can, so you can make an informed decision. You should also go to your specialists armed with questions and they should be able to guide you through your decision.

Believe me, a baby after breast cancer is the most precious thing. My little miracle fills my heart with so much joy, more than I thought possible.

Good luck and happy trying!

– Julie Nicholson, Armidale, NSW

Meet our representatives ... Gerda Evans

Gerda Evans represents women on two important groups – the NHMRC Panel reviewing the draft Guidelines on Familial Aspects of Cancer, and the Kathleen Cuninghame Consortium for Research on Familial Breast Cancer (kConFab).

Gerda has experienced breast cancer as a chemotherapy nurse and through her own personal experiences. She is one of three sisters; all three have been diagnosed with breast cancer.

Her nursing career was in large teaching hospitals, which demanded and delivered high standards of care. As a patient she received excellent care and believes all women deserve such standards.

She was concerned by the number of women who seem to be critical of their breast cancer management, and



Gerda Evans and some of the men in her life – her sons Sebastian, Chris, Ben and Dom.

thought her training and experience could be helpful to the Network as a 'liaison' between patients, doctors and nurses associated with breast cancer.

Her recent involvement with the committees has been positive and she encourages other women to become patient representatives to help the various groups understand each other.

Most of Gerda's life revolves around her men! She works with her husband in his Melbourne psychiatric practice and they have four sons.

In their spare time ("That's a joke," she says!) they enjoy catching up with family and friends (over a bottle of red or three), reading, films, walking and bird watching.

My Journey

It never rains, it pours, in our household

I am sitting down to write this article while my six-month-old twins, Katie and Damian, sleep. Jonathan and Patrick are at school, and Emily is due home from preschool at any minute.

It has done nothing but 'pour' in our house for the past 12 months – but let's begin at the beginning!

When an ultrasound in April 1997 showed I was expecting twins, I was so surprised that I laughed and cried at the same time. I'm not sure why I laughed, but it seemed so ridiculous, I already had three beautiful children. And I cried at the sheer enormity of what I imagined was to lie ahead.

This was the calm before the storm.

In July 1997, I read an article in 'The Canberra Times' about a woman who had been diagnosed with breast cancer during her pregnancy. It motivated me to carry out a BSE and I discovered a small lump in my right breast. I kept an eye on this lump for a few days, trying not to think it could happen to me.

After all, I had started my family young, breast fed my babies and had no family history of breast cancer.

Unfortunately, and despite many reassurances that this was unlikely, I was told my lump was breast cancer.

Being 23-weeks pregnant was a complication nobody relished. It limited



Along with her husband, Tom, Kerry Glover had five reasons to survive her breast cancer diagnosis and treatment – her children – Jonathan, Patrick, Emily and the twins, Katie and Damian.

the type of treatments available to me and made everything more complicated.

After much discussion with my surgeon, I was booked into hospital for a biopsy the next day.

The results confirmed a high nuclear-grade duct carcinoma and evidence of spreading into the lymph channels. It was decided that the best treatment was a modified radical mastectomy.

The morning of my admission to hospital, I put a final coat of paint on the chest of drawers I was painting for the babies' room. I didn't know if I would be

able to use my arm after the operation and had a feeling of needing to get every thing organised before I went to hospital.

Fortunately, they gave me a bed in the antenatal ward. I didn't think I could cope in the surgical ward, as I had only been to hospital to have babies. I was familiar with many of the staff and they made my stay comfortable.

The support and comfort from my family and friends at this time was unbelievable! Some friends coming to visit in the hospital were told by the ward clerk to "follow the crowd".

When the woman you love has breast cancer

When a woman has breast cancer, the burden on partners can be overwhelming. Not only is there the emotional impact of a partner facing a life-threatening illness, but often the turmoil of juggling work and domestic commitments.

A survey carried out last year by the National Breast Cancer Centre (NBCC) found that men do not have the same network of friends and family that women can turn to. They tend to rely on their partners for emotional

support, so there is often nobody to turn to when the partner is diagnosed.

Finding strategies to support the partners of women with breast cancer was a challenge for the NBCC, as little research has been done into their needs.

To help partners understand their feelings and find ways to cope, the NBCC has produced two audio tapes – one for men whose partners have early breast cancer and one for those whose partners have advanced disease.

On the tapes, men talk about the

strategies they used to cope and explore their feelings.

Brisbane Broncos player, **Kevin Walters**, who lost his wife Kim to breast cancer, shares his experiences.

The tapes were developed by the NBCC, in partnership with women, health professionals, cancer organisations and governments, to improve breast cancer outcomes for women.

These excellent tapes are available from the NBCC for \$10 each. Orders can be placed on (02) 9334 1882.

I couldn't sleep comfortably, as I could not lie on my right side. I couldn't sit up easily, as my waist line was somewhat expanded, and I had little-or-no use of my right arm. I had a cut from my breastbone to my armpit, complete with drainage tubes. And I had three children who wanted to climb on my hospital bed and cuddle me.

I left hospital four days after my operation, complete with a fibre-filled bra – my first prosthesis – and arrived home to the cleanest house I can remember, thanks to two friends.

This was one of my most emotional times. I was scared for my babies, and I had needed much reassurance from the anesthetist that it would be okay. The first heartbeats I heard on the fetal heart monitor after coming out of the anesthetic were the most wonderful sounds I can remember.

A community nurse visited the day after I came home with some discouraging news – two of the removed lymph nodes had been affected by the cancer cells. I needed to meet the oncologist!

Four weeks later and without any fuss, the oncologist laid the facts on the line for my husband, Tom, and myself.

The positives: The tumor was comparatively small and had been detected fairly early.

The negatives: I was pregnant, with twins, I couldn't undergo routine bone scans or chest x-rays, and chemotherapy couldn't safely be delayed.

Tom and I discussed the doctor's recommendation. Should I proceed with the treatment as advised or should I wait until our babies were safely born and take the risks of delaying chemotherapy?

After much thought, prayer and support from two women who had been through similar experiences, we decided that I needed to stick around for the three beautiful children who were at home depending on me.

I also knew I couldn't leave Tom to cope with five children. I wasn't ready to die yet! I had so much to live for.

A week later, Tom and I arrived back at the hospital. I cried my way through my first treatment at the thought of being injected with this poison, and was then instructed to go home and drink

three litres of water each day for the next few days.

Anyone who has had two little people sitting on their bladder can imagine the pain of drinking all that fluid.

The following weeks saw a combination of dramas. Drastically low white blood cell counts had me back in hospital in isolation. My hair began to fall out, so Tom and the kids took great delight in giving Mum a No.1!

The twins were to be induced just before my third chemotherapy treatment and I was ready to meet them. I was becoming uncomfortable, teary and scared. The mirror revealed a very pregnant, bald and lopsided image.

At 34 weeks, I was admitted for an induction. The twins arrived bottom first without the planned epidural! When Katie, the first born, cried, Tom cried and I have never known such feelings of relief, joy and overwhelming love.

An hour later, with a little bit of pushing, our darling Damian appeared. They were here, they were healthy and they were proof that miracles do happen.

Since then life has had its challenges!

When the twins were eight weeks old, a change in my chemotherapy treatment landed me back in hospital, seriously ill. My aunt moved in to help Tom, while Mum and Dad came each day to look after everybody.

I underwent several blood transfusions, platelet transfusions and, to top it off, I was suffering pneumonia. I came close to giving up. I was tired of fighting and didn't have the energy anymore.

Eventually, Tom stayed with me at the hospital. The support, love and motivation to get better that he provided was the magic I needed. I came home, weak and tired, but ready to go on.

I have finished my treatment, a new year has begun and life is looking up. Katie and Damian continue to thrive, and are living definitions of perfection.

However, life with twins is never dull. Yesterday, I took Damian to the hospital to have a full plaster cast put on his fractured leg.

In this drought, the worst since 1982, I can say that, in our house at least, it never rains ... it pours!

– Kerry Glover, Nicholls, ACT

Reflections

While undergoing chemotherapy for breast cancer, **Wendy Coates** decided to put together a resource booklet of practical advice based on her own and other patients' experiences.

She consulted the medical professions to make sure that all the suggestions were medically and ethically approved, and found **John Howcroft** to illustrate her book with his gentle, humorous drawings.

The result is a little book which offers practical experience from people who have 'been there' and know which simple measures might make things a little easier for someone following them through breast cancer treatment.

'Reflections' is available direct from Wendy Coates at PO Box 114, North Melbourne, Victoria 3051. Cheques or money orders should be made payable to Cancer Resource Booklet.

Raffle proceeds to benefit the Network

A large convention for doll enthusiasts has generously chosen us to receive the proceeds of its annual raffle.

The South Eastern Doll Show and Fair, being held in Dingley, Victoria, in November will feature a Shirley Temple Convention.

With stalls featuring Shirley Temple displays, antique and reproduction dolls, as well as bears, this fair is likely to attract many people.

Shirley Temple-Black is a long-term breast cancer survivor.

For more details, phone Graeme Horne (03) 9795 5644.

If you would like to share your story with others, send it to Lyn Swinburne, who will have it included with our other women's stories on the Internet (If you like, there is no need to include your surname). The Internet address is <http://www.users.bigpond.com/bcan>

New Resources

Young Women's Network

At our conference in October, many young women identified the need for an Australia-wide network for younger women.

That month, the Queensland Cancer Fund (QCF) launched its Young Women's Network (YWN), a support and information program for younger women with breast cancer.

Suzanne Steginga wrote to tell us about their network.

"Younger women with breast cancer now have the opportunity to attend monthly meetings in Brisbane with guest speakers, and have contact with other women by mail and telephone throughout the state," she says.

"The 1999 topics for discussion chosen by group members include hormone replacement therapy and menopause, dealing with young children following a diagnosis, sexuality and self-image, relationships, lymphoedema and breast reconstruction. At each meeting there is opportunity for women to talk and support each other.

"In the first meeting of the group, the women present decided not to have an age limit for the group. Instead, it was decided that common issues and life stage would be a guide, so women could decide if the group was for them."

Jayne Poynts, one of the founding members of the YWN and a Breast



Jayne Poynts, one of the founders of Queensland's Young Women's Network, and her family.

Cancer Support Service Volunteer for the Queensland Cancer Fund, is delighted her request for such a service has come to fruition.

"Nothing like this existed when I was diagnosed at 33. I hadn't even heard of women my age getting breast cancer. I would have loved to speak to someone else my age at that time," she says.

"I was visited by a woman more than 10 years older than me. Unlike now, there wasn't a BCSS volunteer close to my age.

"Younger women are now being seen by volunteers their own age and have the opportunity to have on-going support and contact with women in a similar situation in the YWN."

For further information about the YWN phone the QCF's Cancer Information Line on 1300 361 366 or (07) 3258 2264, or write to conference attendee Leonie Young, c/- PO Box 53, Aspley, Qld 4034.

Network mentioned in Parliament

Our idea for a register of breast cancer trials was introduced into the federal Parliament in February by Jane Gerick, the Member for Canning in WA.

During a Private Members' Business debate in the House of Representatives, three other members also spoke about issues relating to breast cancer.

Albert Schultz (Hume, NSW) called for more government money to be put into breast cancer research, particularly to fund of clinical trials.

Tanya Plibersek (Sydney) pointed out that the challenge is not only to provide more money for research, but to make sure the money is well spent.

More collaboration is needed, she said, between scientists and researchers, to make sure work is not duplicated or crucial areas of research overlooked. She also mentioned the NBCC's suggestion of developing a National Action Plan for Breast Cancer Research to ensure high levels of co-ordination.

Judi Moylan (Pearce, WA) spoke in support of women with breast cancer and added her voice to the call for more research funding.

We applaud these politicians for raising these issues on our behalf.

She's Got What?

Often when there is a problem to be explained to children, we turn to books and a story to help them understand. But books about cancer, particularly breast cancer, suitable for children have been difficult to find.

Two first-time Australian writers, **Carrie Lethborg** and **Angela Kirsner**, have produced a book – 'She's Got What?' – which is going to help many young children whose mothers have

been diagnosed with breast cancer.

The story is told from Harriet's perspective. Harriet's orderly life is turned upside down when her mother is admitted to hospital.

We glimpse the anxiety of the grown-ups, but it is Harriet's thoughts and imaginings that we follow throughout her mother's treatment. Will her mum be okay? Was it her fault that she got sick?

Harriet is terrified her mother will die of

cancer, like her grandmother, a few years earlier.

This is a difficult topic, sensitively and expertly handled. While the story squarely faces the seriousness of any cancer diagnosis and the fact that sometimes people do not get better, Harriet's story is still a positive one.

'She's Got What?' is available for a short time from the BCNA for \$9.95, including postage.

Our Family Has Cancer, Too!

From Christine Clifford, the author of 'Not Now, I'm Having a No Hair Day', 'Our Family Has Cancer, Too!' is a little paperback explores the issues facing families when a mother has breast cancer.

Christine has two boys and one of them, Tim, has helped write this book.

Illustrated with the same delightful types of line drawings as the first book, it finds humour in the everyday efforts of a family to cope with this disease, and to give love and support to one of its members.

BCNA has a limited number of copies available for \$15, including postage.

High-dose chemotherapy

In April, the American Society of Clinical Oncology, released its report on the effect of high-dose chemotherapy.

It was hoped that the new data would provide guidance on whether women should undergo the potentially risky, high-dose chemotherapy requiring bone-marrow transplants, or the conventional, lower-dose therapy.

Unfortunately, the results, while inconclusive, show disappointing signs.

Four of the five studies showed that survival rates for women treated with the high-dose chemotherapy were similar to those who opted for the standard

treatment. The fifth indicated that the high-dose chemotherapy might work better, but the study was a small one.

Where does that leave us?

These are only the preliminary findings of studies that were each quite different, so definite conclusions cannot be drawn.

The results highlight the need for proper clinical trials. Unless women have this expensive and debilitating treatment in strictly controlled trials, we will never know if there are real benefits.

For more information, visit <http://www.cnn.com/HEALTH/9904/15/breast.cancer.01/>

Breast cancer and inherited risk

A great worry for women with breast cancer is whether their daughters and other female relatives are also at risk of developing the disease.

According to **Dr John Hopper**, director of the Australian Breast Cancer Family Study at the University of Melbourne, two in every three women with breast cancer have no close relatives with the disease.

Their female relatives usually have a small increased risk, but 90% will not develop breast cancer.

In some families, the risk is greater, and research has been under way in Australia for the past two years into the genetic history of some families where breast cancer is prevalent.

The Australian Breast Cancer Family Study has produced a newsletter which outlines the project, its aims and progress, and provides information about family history, genetic testing and breast cancer.

Copies are available by phoning (03) 9344 6459.

The Climb of My Life

A friend gave me **Laura Evans'** 'The Climb of My Life' when I was looking for a break from books about breast cancer.

Laura Evans loved climbing mountains, but after treatment for breast cancer, she wondered whether she'd make it around the corner, let alone up a mountain.

But a desire to resume the activity she loved fuelled her quest to regain a

semblance of normality in her life.

Laura's experiences climbing peaks in North America, Nepal, Africa and Russia saw her form 'Expedition Inspiration' and lead 16 breast cancer survivors up 23,000 feet of Mount Aconcagua in the Argentinean Andes.

Inspirational stuff. Enjoy the climb!

— Judy Burley, Bendigo, Victoria

Call for dragon boat members

Tanya Wilson from Victoria and **Michelle Hanton** from the Northern Territory are forming a Breast Cancer Dragon Boat Team to represent Australia in April 2000 at the Sydney International Dragon Boat Festival.

Canada, the US and New Zealand will also be sending teams, so it will be a great opportunity to raise awareness and form new contacts with other breast cancer women.

There is no age limit or experience required to join us, but you do need to be able to swim 50m in a t-shirt and shorts, and be able to train in your state once a week or fortnightly, starting at the end of this year.

You will also need to be willing to get together with the rest of us in Sydney for about four days in April 2000.

For more information, phone Tanya on (03) 9330 2785.

PS: Breast Cancer Network Australia is looking for a company to sponsor our team. Any ideas?

New advanced cancer group in Brisbane

A new group for women with advanced breast cancer has started in Brisbane.

It is organised and conducted by two experienced consultants, Dr Bronwen Beacham, a psychiatrist and psychotherapist, and Mary O'Brien, a psychotherapist.

The groups are modelled on the work of Dr David Spiegel of Stanford University, the author of 'Living Beyond Limits: New help and hope for facing life threatening illness', and Dr David Kissane and others at the University of Melbourne, who have been running supportive and expressive groups for women with early and advanced breast cancer since 1994.

For more details, phone Dr Beacham on (07) 3843 2706, or Mary O'Brien on (07) 3844 5855.

COMING EVENTS

June 26: Breast Cancer Action Group Victorian meeting, 2.30-5pm, Auburn Primary School. Sarah Tyson from the Royal Australasian College of Surgeons will explain the audit process which breast surgeons are using to help improve their performance and how consumers can assist with this.

Contact: Sue Lockwood (03) 9878 0736.

June 27: Breast Cancer Action Group NSW meetings (Support Issues), 3pm, Sydney YWCA.

Contact: Sally Crossing, BCAG NSW, (02) 9436 1755.

July: Encore in South Australia. This eight-week program of gentle exercise and support program for women recovering from breast cancer will be held at Northcare Centre, 192 Park Terrace, Salisbury.

Contact: Bev Edwards or Heather Hewitt (08) 8255 1353.

July 4-9: Nourishing the Body, Mind & Spirit of Woman, a five-day residential program at Killarney in Bundanoon, NSW, with Petrea King.

Contact: Quest for Life (02) 4883 6599.

July 13-16: 'Cancer: We Care', The Australian Cancer Society's Conference, Australian Jockey Club, Randwick Racecourse, Sydney. Issues to be covered include survivorship/living with cancer, treatment advances, recognising the carer, advocacy and communication skills.

Contact: Emma Mesaros (02) 9380 9022 or e-mail acsपो@cancer.org.au

July 15: National meeting of Breast Cancer Network Australia, 11.30am – 12.30pm, Randwick Racecourse, Sydney (as part of the Cancer: We Care conference). All readers of *The Beacon* welcome!

August 29: Breast Cancer Action Group NSW meetings (Statistics and Me!), 3pm, Sydney YWCA.

Contact: Sally Crossing, BCAG NSW, (02) 9436 1755.

September 17-19: Spirited Women, a weekend program for women who have/had cancer or other life-threatening or serious illness at Killarney in Bundanoon, NSW, with Petrea King.

Contact: Quest for Life (02) 4883 6599.

October 17: Field of Women ceremonies in all capital cities. Major field in Melbourne.

October 23: 5th Annual Breast Cancer Information Day, Royal North Shore Hospital, St Leonards, NSW. \$25.00 all inclusive – bookings essential.

Contact: Di Montague (02) 9926 7246 or Louise Kippist (02) 9926 6584.

October 25: Australia's Breast Cancer Day.

• To include events in *The Beacon's* spring issue (September, October, November), please submit brief notices before the end of August.

YOU'RE NOT YET ON OUR MAILING LIST?

Contact: Lyn Swinburne or Jenny James, phone (03) 9660 6865, fax (03) 9662 3881, e-mail bcan@bigpond.com or fill in this coupon and send it to: Breast Cancer Network Australia, PO Box 4082, Auburn South, Victoria 3122

Name:

Address:

.....

State: Postcode: Phone: ()

Have you had a diagnosis of breast cancer? Yes No

THE BEACON

The Beacon is the newsletter of the Breast Cancer Network Australia.

We are currently seeking sponsorship for *The Beacon*.

Editor: Lyn Swinburne

Design: Liz Grant, (03) 9898 8834

Layout: Substitution,
(03) 9329 3535

Your comments and items for the next newsletter are welcome. Send them to PO Box 4082, Auburn South, Victoria 3122.



Seeking Shelter

We welcome the following groups, which are linking up under the Breast Cancer Network Australia's umbrella:

- Murray Mallee Breast Cancer Support Group, Pinnaroo, SA
- Riverland Breast Cancer Support Group, SA – 'Breast Friends'
- The Young Women's Network, Queensland

Please discuss the Network with your group and let us know if we can create another link. Remember – there is strength in numbers!

Contact: Lyn Swinburne, PO Box 4082, Auburn South, Victoria 3122 or phone (03) 9660 6865.

YOUR SAY

We will be introducing a new section in *The Beacon* – Letters to the Editor.

If you have something to say, please send your letter to Lyn Swinburne, PO Box 4082, Auburn South, Victoria 3122 or e-mail bcan@bigpond.com

In the next issue ...

- Reconstruction?
- Send us your thoughts!