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Focus on:  
Communication



## Communication counts

When I found out I had breast cancer it was really hard to tell people. It is not exactly a conversation starter! I sent an email to one particular group of good friends, to avoid having to tell each of them the same news. I rang other friends and close family and spoke to them directly. Responses ranged from 'you'll be fine' to 'that sucks!' to 'I am coming over right now!' As many of you know it is not a simple story to tell, as there are so many types of breast cancer, and breast cancer treatments and many unknowns.

Going to the shops or walking my dog, the first thing people ask by way of greeting is 'how are you?' Not everyone wants an honest or detailed response. I nearly always replied 'good thanks' rather than 'not too bad, but I have been diagnosed with breast cancer'. On one occasion, I regretted being honest, as a neighbour responded with a long and detailed story of her own cancer experience many years ago and never asked me anything about how I was going. You have to laugh!

Good communication is vital for feeling in control and confident in managing your treatment and care. This is especially so in dealing with health professionals

and your treatments that you understand. While at the Cancer Council of Victoria, I worked on a research project looking at the supportive care needs of newly diagnosed patients. I was concerned to find that some did not understand they had cancer. Sometimes this was because of the language used. For example, their doctor may have told them they had removed a 'tumour', rather than saying they had removed a cancer or a cancerous lesion. The doctor may have wanted to soften the news by avoiding the word cancer, or perhaps they were using clinical language that is not broadly understood. Or perhaps some people didn't want to hear they have cancer or family members

Communication provides essential knowledge, and I truly believe that knowledge empowers you. Research has shown that having an active role in your treatment contributes to improved quality of life after breast cancer. Being informed and able to communicate your wishes are essential. The goal is to have an equal relationship with your doctor. If you don't have a good relationship with your treating doctor, you don't have to put up with it. I know that changing doctors is more easily said than done. It also may be a challenge if you are living in an area with limited choice.

Your doctor should provide information about your cancer



*Good communication can help ensure you receive the support you need*

may have wanted to protect them from confronting news.

This is a great example of why BCNA's work with Melbourne University medical students is so important. Our members speak to students to help them understand the importance of the doctor-patient relationship and the need for effective communication.

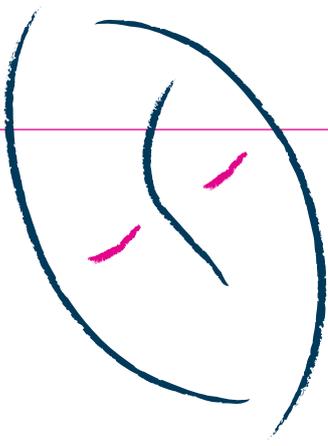
I encourage you to attend our national conference in Sydney in October. It is a wonderful opportunity for you to learn, share and connect. The program covers a broad range of issues, with the opportunity to hear from experts around the world. This is a communication experience not to be missed! See page 5 for more information.

I am sure you will get a lot out of the contributions on communication in this issue of *The Beacon*.

*Maxine Morand  
Chief Executive Officer*

Breast  
Cancer  
Network  
Australia





# Issue of concern

## Starting the conversation

*Being diagnosed with breast cancer often comes as a great shock – not only to you, but also to those around you. Good communication can help to ensure that you get the support you need, but it may be up to you to start the conversations so that family and friends know how best to help you.*

The Beacon spoke to Dr Annabel Pollard, Head of Clinical Psychology at Peter MacCallum Cancer Centre in Melbourne.

### **Why is good communication important?**

Communication is about being able to:

- express your emotional concerns
- share information
- exchange ideas
- assist with processing information, making plans and ensuring that everyone knows what to expect
- getting and receiving support
- maintaining intimacy.

All of these things are very relevant when a woman is diagnosed with breast cancer.

### **How can women start difficult conversations with family and friends?**

It's important that women and their close family and friends acknowledge what is happening, and that starting such a conversation can be daunting.

Acknowledging fear, distress or anxiety is important. You could start by saying 'This is what is happening. I understand there is some uncertainty – this is fearful for me and it may be fearful for you too'. Talking things through can help clarify issues and reduce anxiety.

My sense is that to encourage others to feel comfortable when talking about difficult issues, women need to give those around them 'permission' to talk. One way you can do that is by raising the issues yourself. Acknowledge that your diagnosis is a difficult subject; that you understand that people don't know what to say or do, and that that is okay.

I hear often from partners and close friends that they are afraid to raise the issue of the woman's diagnosis because they don't want to upset her. Upsetting someone is usually equated with crying and unpleasant emotions, but crying can be an important and therapeutic emotional release. We often feel better after a good cry and a good conversation about what's worrying us.

Conversely, no-one wants to talk about difficult issues all the time. Set aside some time to talk about what is happening, but also have some time to not talk about it – to talk about regular everyday things.

### **How can women help themselves to get the support they need from family and friends?**

We all know that some people are better at some things than others. I often say to women recently diagnosed that they need to become a 'general manager' of their health care. Part of organising your care is to allocate jobs to people who are going to do them well. If you have a friend who will be really good at dropping off a casserole once a week but hopeless at chatting in a sympathetic way, get them to bring the casserole! If you have empathetic friends who can help you work through your emotions, then open up to them.

Be aware that your partner often can't provide all the support you need all the time. It is important to have other family or friends who can help support you.

Sometimes women tell me they are disappointed in the response they received from someone close to them, or that someone they didn't know so well was able to provide better support. I think this can be because those closest to you are as frightened of what is happening as you are.

In new situations, like a breast cancer diagnosis, no-one really

knows what to say or do, so sometimes family or friends say and do nothing because that is the neutral response. They think 'If I do nothing and say nothing, then I can't upset her. I won't feel bad and I won't have to deal with my own feelings about this'. This can be misinterpreted as not caring, when in fact that person is busy trying to protect themselves, and you, from scary feelings.

### **How can women encourage their partner to talk?**

I suggest you sit down with your partner and together write down three things you could do to improve how you communicate about this new and scary situation. It's about trust, taking a risk, acknowledging each other's distress and fear, and finding a way to both talk openly about your concerns.

Confronting and dealing with challenging issues in life often brings a sense of relief. Many people say that the experience of a serious life event, such as cancer, can be transformative because it challenges us to 'dig deep' and to think more closely about what is meaningful and important in life and relationships.

# Ask the Expert

## Fran Boyle

*Fran Boyle is a medical oncologist at the Mater Hospital in North Sydney and Associate Professor at Sydney Medical School. She is involved in breast cancer research through the Australia New Zealand Breast Cancer Trials Group, and is a BCNA Board Member. For many years she has facilitated workshops to help doctors improve their communication skills through her work with the Pam McLean Centre.*

### **What do your communications skills workshops involve?**

A small group of doctors works with an actor, who plays the role of the patient, and a facilitator, whose job is to get the doctor working well with the 'patient'. We cover conversations that doctors and patients tell us are difficult: prognosis, complex treatment decisions, clinical trials, high-cost drugs and what to do when you have run out of treatment options. We also look at what to do when something has gone wrong – how do you say sorry and rebuild the relationship with the patient when everybody is feeling angry and scared.

### **Do different communication styles suit different women?**

We know that women respond to life's challenges in different ways. Some women want to do an internet search and go through all the data before making a decision. Some women just need time to think through their options. Others will be very

happy to accept advice if they have built up trust in the doctor's expertise. What is important is that you find a doctor who can respond flexibly to what you need.

### **Why is good communication between a woman and her doctor so important?**

Good communication is primarily about safety and quality of care. A doctor can't make good decisions about a woman's needs if they don't know what is going on. If the doctor is not listening to important things the woman is telling them, or if the woman is withholding information because she is scared of what the doctor might think, poor choices can be made.

We also know that having a satisfactory relationship with their doctor helps women to cope better. A warm two-way interactive process ensures that women and their families feel supported and helps to improve quality of life.

Doctors also cope better with the demands of dealing with serious illness day after day if they have good relationships with their patients and work in a team that communicates well.

### **What can women do if they are not happy with the way their doctor communicates with them?**

The biggest constraint in doctor-patient communications is time. If you are not happy



Fran Boyle

with how things are going, think about scheduling a double appointment, go in the afternoon rather than the morning, and try not to have an in-depth conversation in the chemotherapy hallway! Flag with your doctor that you have a number of things you want to discuss. Before you go to your consultation, prioritise your list. Work out the top three issues you want discussed and start with them. If you are not sure what is important, show your list to the doctor. They will be able to see if there are any important safety issues that need to be addressed first.

If you want a second opinion, it is very important that you get that opinion from someone who knows a lot about breast cancer. The best person to ask for a referral will be your oncologist, because they will know who will be a good person for you to see, particularly if there are clinical trials that are not available in your hospital. They can facilitate the referral for you.

If another oncologist rings me and says they have a patient they would like me to see, I am going to put that patient higher up my priority list when a space comes up, expecting that they will come with all the necessary documentation for an informed opinion and will have had time to get their questions organised.

Often you can return to your usual care relationships with a bit more of the 'big picture' and reassurance that nothing important has been missed. And maybe even a few ideas for making the communication work better for you.

# Seeking a second opinion

If you've ever thought about seeking a second medical opinion, you may have wondered 'How do I go about doing that?'

Women seek second opinions on aspects of their breast cancer treatment for many different reasons. There could be communication difficulties between a woman and her specialist, or she may not be able to access a particular treatment option that she feels would benefit her.

There are a number of options available to you in seeking a second opinion. You can ask your current specialist for a referral to another specialist. You can ask the health professional who gave you the original referral to your current specialist for a referral to another specialist. Or, if this was not your GP, you can also talk to your GP.

If you are seeking a second opinion because you are unhappy with your current specialist, a frank and honest discussion with your GP about

your concerns will help to ensure they are able to refer you to a specialist who can better meet your needs. Your GP may also use the feedback you have provided when considering referring other women to a breast cancer specialist.

Your GP will write a referral letter to the second specialist, and will include with it your test results and medical history. If you feel the second specialist better suits your needs, the new specialist may contact your

original specialist to ask for any test results, scans or other information not included in your GP's referral. Alternatively, you can request a copy of your record from your first specialist.

Remember, if you have any concerns about your breast cancer treatment, you can discuss these issues with your GP. If you do decide to seek a second opinion, these candid discussions will help your GP to refer you to someone who will best suit your needs.

## A health record that moves with you

You may recall in the last issue of *The Beacon* we let you know about the new eHealth system which will be introduced from July this year.

Your eHealth record is expected to eventually allow a comprehensive summary of your medical history, including referrals, test results, scans, prescriptions, and hospital discharge summaries, to be stored electronically in a way that will enable you and your doctors to easily access it. However, it will take some time for all parts of the new system to become available.

From 1 July this year you will be able to register for your own personal eHealth record by phoning Medicare or visiting one of their offices.

Once you have registered, you will be able to access your record

online and begin to add some basic information such as your emergency contact details, medications you are taking and medications to which you may be allergic.

Whether or not you choose to use eHealth is entirely up to you – you will only have a personal eHealth record if you 'opt in' and register for it. Health professionals also have the choice to use eHealth or not, so it may be that, initially at least, not all of your doctors will use the system.

This may result in some gaps in your eHealth record. If you would like all of your health information to be available via eHealth, you may need to encourage your doctors to register if they have not already done so.

If your GP has registered to participate in eHealth, your

health information can be added to your eHealth record during a consultation. It is important to note, however, that you can only get a Medicare rebate for this service if it is combined with a medical consultation. You may like to ask before the appointment if there will be any additional out-of-pocket

costs, as some GPs may charge extra to transfer your medical information to your eHealth record.

For more information, visit [www.bcna.org.au](http://www.bcna.org.au) > Living with breast cancer > Practical issues > eHealth.

*Twenty years from now you will be more disappointed by the things that you didn't do than by the ones you did do. So throw off the bowlines. Sail away from the safe harbor. Catch the trade winds in your sails. Explore. Dream. Discover.*

– Mark Twain

# BCNA national conference



Registrations are now open for Strength to Strength: Breast Cancer Network Australia National Conference in Sydney on 25 and 26 October.

The conference is part of the Sydney International Breast Cancer Congress and will be held at the Sydney Exhibition and Convention Centre in Darling Harbour. A broad range of topics will be covered to ensure women affected by breast cancer, from those currently going through treatment to those many years out from their diagnosis, will find the conference interesting and informative.

It is a wonderful opportunity for women to:

- listen to international, world-leading authorities speak about the latest breast cancer issues
- learn more about breast cancer treatment and care and ask questions of leading authorities
- connect and network with more than 600 women from across the country

*I would like to hear world leading experts talk about breast cancer, breast cancer care and current research. It is fabulous to have experts present these topics virtually on our doorstep. As a BCNA Consumer Representative, I like to remain current with my knowledge and I also like to talk with and learn from other breast cancer survivors from around the country! – Petrina, WA*



Petrina

- feel empowered to make informed decisions about treatment, care and lifestyle choices
- find support in a warm and positive setting

- come together as a united voice.

Health professionals will also benefit by gaining valuable insight into the experiences and needs of the women they care for.

*I'm looking forward to attending BCNA's national conference and broadening my knowledge and awareness of what is happening in breast cancer. I've had three breast cancer diagnoses so I'm particularly interested in finding out about advancements in treatments. And I'm always keen to meet other women with breast cancer and hear their stories of survival. – Pauline, Tas*



Pauline

The fantastic two-day program covers topics including:

- new directions in breast cancer treatment
- managing relationships with partners, family and friends
- dealing with menopausal symptoms
- sexual wellbeing
- managing fear and anxiety.

We will also be hosting a *Mini-Field of Women* and a cocktail party.

**Please let women in your community know about the conference so they have the opportunity to register for the early bird price of \$200 which closes on 23 August 2012.**

We hope to see many of our members there! For more information and to register, visit [www.bcna.org.au](http://www.bcna.org.au) > Events > BCNA Conferences > National conference 2012. Or phone 1800 500 258 (Freecall).



## Airport body scanners

From July this year, new high-technology body scanners will be introduced into international security checkpoints at all Australian international airports.

The new body scanners are being introduced to enhance airport security. They are designed to detect threats that current scanning technology is unable to pick up.

The Australian Government has advised that the scanners will produce only a generic outline of a person's body and will not display details that would, for example, indicate a person's gender. However, if a woman is wearing an external breast prosthesis, this will be detected by the scanner. Breast implants will not be detected.

The Government has assured us that women wearing prostheses will be treated sensitively and their privacy will be protected. They should not be asked to remove their breast prostheses or raise their clothing to show any prosthesis they are wearing.

If you are travelling overseas and are wearing a breast prosthesis, or carrying one in your hand luggage, you may like to let the security staff know before you are scanned so that they can be sure to treat you discreetly. You can ask to speak privately with a female staff member if you wish. It may also be wise to carry a letter from your doctor explaining the prosthesis.

For more information, including how to make a complaint if you feel you are treated insensitively, visit [www.bcna.org.au](http://www.bcna.org.au) > New diagnosis > Treatment > Breast prostheses.

# Stay in touch with BCNA

Don't want to wait for your *Beacon* to arrive to hear the latest news from BCNA? You can keep up-to-date on the latest news, events and fundraising campaigns by connecting with BCNA on Facebook and Twitter.

More than 9,000 BCNA supporters across Australia 'like' our Facebook page, while BCNA's Twitter feed – @BCNAPinkLady – has just taken off and followers are growing daily.

Social media isn't for everyone but for those who like their news hot-off-the press you can join BCNA on Facebook or Twitter to be informed immediately about the latest happenings at BCNA.

Facebook and Twitter don't replace *The Beacon*, our website or Online Network, but instead provide you with an easy way to stay connected with us, our supporters and each other.

Our Online Network is designed especially for women affected by breast cancer to share their experiences with each other, while our website is still our best source of information on breast cancer.

Social media complements rather than replaces our communication with you. It

allows not only our members to stay up-to-date, but is an easy way for friends, family and other supporters to connect with BCNA.

Encourage your own networks to connect with BCNA through Facebook and Twitter, too.

We look forward to connecting with you!

## Like us on Facebook and follow us on Twitter

*The easiest way to connect with BCNA on Facebook and Twitter is from the BCNA website home page. Simply scroll down to the bottom of any page and look for the logos which will take you directly to BCNA's Facebook and Twitter pages. Remember, it's 'follow' on Twitter and 'like' on Facebook.*

*Or search for 'Breast Cancer Network Australia' on Facebook and @BCNAPinkLady on Twitter.*

## Generic aromatase inhibitors now available

If you take Femara or Arimidex, you may now be offered generic brand name alternatives to these drugs when you get your script filled.

Femara and Arimidex are brand names for the drugs letrozole and anastrozole (known as aromatase inhibitors), respectively. The patents on these drugs have expired and therefore generic versions of letrozole and anastrozole will now be available. They will have the same active ingredients as Femara and Arimidex, but will have different brand names and are manufactured by other companies.

BCNA has been advised that Arimidex and Femara will not cost any more than the generic versions, so you can keep taking your usual brand if you wish.

If you take Femara and participate in the Novartis bisphosphonate access program, switching to a generic version will mean you will not be able to continue to access free bisphosphonates. If this affects you, your doctor should ensure that your prescription is for Femara only, not a generic brand.

Women who take Aromasin may have noticed there are already

generic versions available to them, such as Exaccord. Aromasin is the brand name for exemestane, another form of aromatase inhibitor. BCNA has confirmed that Aromasin will not cost more than generic alternatives.

If you have concerns about your prescription or feel you've been overcharged for your medication, speak to your pharmacist or doctor about the issue. If you have any general queries, you can email BCNA at [beacon@bcna.org.au](mailto:beacon@bcna.org.au) or call us on 1800 500 258 (Freecall).

# The importance of communication

I have always been aware of the importance of communication, but never more so than in the six months between my diagnosis of breast cancer and now.

In late July I told my daughter and son-in-law that I needed to consult a doctor because of my concerns. We communicated openly about my fears and immediately I was referred for mammography and ultrasound. The family were calm, supportive – but shocked. I was an 82-year-old who appeared to be in perfect health.

My surgeon was a patient and caring man. I brought a list of questions. On one occasion he remarked that he had only answered nine out of ten! I asked what would happen if, because of my age, I took no action.

He didn't seem surprised and answered my question. During my hospital stay, he saw me regularly, always with a kind word.

I had a radical mastectomy followed by radiotherapy. Now I'm active and feel remarkably fit.

I would like to emphasise how important it is that the patient should communicate. Your oncologist and other members of your medical team need to know of your feelings and concerns. The patient who builds up a relationship with them will be surprised at what help and advice is available. They have a difficult job, and appreciation from a patient may make their job a little easier. A thank you, a card or just a smile may brighten their day.



*Edith*

Many cancer survivors have spoken to me, having heard of my diagnosis. There seems to be a bond between women with breast cancer. Even strangers will often relate their experiences.

Most wish to express gratitude to family, friends and medical personnel, feeling this has been a life-changing experience.

*Edith, NSW*

## Seize the day

Don't leave your communication until it's too late.

I always thought of myself as a good communicator. Friends would describe me as a communicative person who had good people skills, but it was not till after the early death of my mother that I realised I had never really communicated to the most important person in my life – her.

Every day we use verbal and non-verbal forms of communication but often find it hard to truly open ourselves to meaningful communion with others, especially those who mean the most to us. It can sometimes take an illness or



*Amanda*

tragedy to break down the wall of reserve to allow us to really reach out.

Many years later when I was facing the possibility of my own death with breast cancer I realised the great need to reach

out and communicate to those I loved as time seemed so fleeting and precious. The fears and insecurities that had previously held me back from saying what I felt were no longer a barrier. During that time I wrote a letter to my mother telling her I had always loved her and although it was too late for her to read it, the words I expressed are still as true today as when she was alive.

Now 12 years later I am still standing strong and not afraid to face life head-on with the help and support of those loved ones around me. Just open up and let them in.

*Amanda, ACT*

*Believe in the power of your spirit.*

*Believe in inspiring people with who you are.*

*When you can tell your story from a place of passion, people cannot fail but be moved.*

*– Chris, from A Pocketful of Sequins, 2006*

## If you don't ask ...



Ruth

I found the easiest way to communicate with doctors was to ask questions.

Talking to friends and family as well as strangers was healing for me and made it easier for them to approach me. The saddest thing that was said to me was that I was 'getting as big as a house' while I was going through chemotherapy. I burst into tears, and thankfully was comforted by friends. At the moment I have

lost 12 kilos by watching what I eat and walking daily.

Unknowing people ask me if my health is okay. I try to reassure them by telling them that I am deliberately losing weight for the sake of my health. When I finished my treatment, some of my friends said initially they didn't know what to say to me. They told me that because I talked about my experience they

were made to feel comfortable to talk about it.

I had very caring and approachable medical specialists and doctors and a great support group where I was encouraged to share my feelings. This was very important as I was still grieving for my mother who had lost her life to breast cancer seven months before I was diagnosed with it.

Ruth, QLD

## Faith in doctors

In October 2009 I was diagnosed with breast cancer in my left breast. I underwent a mastectomy by a surgeon who was recommended by my GP. At the same time I had a reconstruction, however, I was unhappy with the way my new breast looked and the shape was quite odd. I decided to get another opinion from another plastic surgeon who confirmed the breast shape was quite wrong. I went back to the surgeon who did the operation

and she was quite rude and angry that I had sought a second opinion and did not offer to fix the problem.

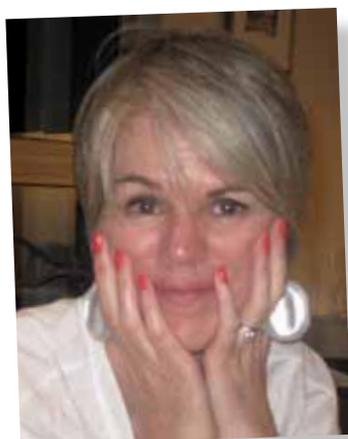
I went back to the second surgeon and I could not believe the difference between the two doctors. He told me he was sorry about the way I had been treated and wanted to help me. Having known how much out of pocket my husband and I were with the previous operations, he said he wanted to restore my faith in surgeons and would do the

operation for whatever we could afford to pay. I had both breasts removed as I had intended all along. He was so warm and approachable every time I saw him. He has even hugged both myself and my husband when we have been overcome with tears on this very emotional journey. We have come to know him not just as a good surgeon but as a very kind man – he certainly has restored my faith in doctors.



Julie

Julie, VIC



Raine

## Communication breakdown

Four years after my breast cancer diagnosis and subsequent treatment I still have a giggle over one communication breakdown whenever I think about it.

I had decided to treat myself to a manicure at the nail bar as my fingernails were the worse for wear after six months of

chemotherapy, three surgeries, and so on.

Wishing to clear the air in case my manicurist mistook the ridges and discolouration of my nails for some weird fungus, I explained quietly to the somewhat English-limited Asian lass that I had just finished chemotherapy.

'Oh', she exclaimed, 'that must have been very nice for you.'

I laughed out loud; delighted by the young nail therapist whose interpretation was clearly that anything ending in 'therapy' must be a wonderfully pleasant experience.

Raine, NSW

# Sharing the Spirit

Following mastectomies in 2010, my sister Alice took the advice of her breast care nurse, Gillian, and joined the Encore Program at the Cook and Phillip Aquatic Centre in Sydney.

It was November and too late in the season to find a good post-mastectomy swimsuit so Alice just wore her old speedos.

We met at the pool in the dead of winter. Having always been a keen swimmer, Alice was uncertain how freely and comfortably her arms would stretch, how she would lie in the water and how her buoyancy may be affected. And, what if a prosthesis came out! Would it float or sink? Who would dive for it?

There were many more challenges than the average swimmer imagines even before

dipping her toe in the pool. And, although she swam better with the prostheses, she wondered if the white bra underneath her black speedos looked okay.

She ended up tracking down a new costume but it wasn't the solution. It dragged in the water and the prostheses had to be repositioned at the end of each lap. It was a bit low at the front and was probably meant for poolside lounging.

We decided she needed to ditch the white bra and have her original costume modified so the prostheses were secure and she would feel confident. Later we turned our costumes inside out and wondered how a savvy seamstress might make the necessary modifications.

We decided to contact the manufacturer. I emailed Speedo

in Sydney and communicated our problem. They invited us in and listened to all we had to say.

A week later, Alice was given two different styles to trial over the summer. In these swimsuits Alice has swam miles along the black line at the pool and at her favourite local Bronte pool. She has dived and tumbled through the surf and swum beyond the breakers, recently completing the Cole Classic and the Dee Why Surf Swim.

From her feedback, amendments were made, and the 'Spirit' evolved.

But, the best feedback followed a dip at Bronte pool. Standing with a towel tucked around her waist and holding her cap and

goggles, she was asked by a passing man, 'What was it like out there?'

Then she knew she looked just like any other swimmer. She looked the part.

We are so thrilled that this can be the experience of every woman after breast surgery. The 'Spirit' will be launched for Summer 2012 and is thanks to our wonderful collaboration with Speedo and breast care nurse Gillian Neil from the Royal Hospital for Women, at Randwick, Sydney.

*Helen, NSW*



*A photo shoot of the 'Spirit' at Speedo, with Helen, her sister Alice and breast care nurse, Gillian*

*Dare to question.  
Cause chaos  
wherever it is  
needed.*

*Do something to  
make the journey  
for others a little  
easier.*

*– Robyn, from a  
Pocketful of Sequins,  
2006*

## Invaluable care and support

After I received my breast cancer diagnosis I was referred to my local breast care nurse Rachel. I was in a state of shock and emotionally distressed but she gave me lots of information and talked me through what was going to happen in the operation. She also told me to contact BCNA for the *My Journey Kit*. Once I had seen Rachel I felt like I was back in control.

Rachel's support has been invaluable. A couple of years later she helped me to form a local breast cancer support group. At our first meeting I spoke about experiences and how lucky I was to have access to a breast care nurse and how important her support was.

Since that time all patients who attend our local hospitals are referred to Rachel, which is a welcome advance in communicating with women who have been diagnosed with breast cancer.

*Heather, NSW*



*Heather, second from right, with members of her breast cancer support group*

## Easing my anxiety

I joined BCNA's online network about 18 months ago. Having finished chemotherapy, I was waiting for my bald head to sprout some hair but by 10 weeks there was no sign of it. Feeling quite distraught, I blogged about my 'lack of hair' woes on the online network and immediately received support and reassurance from women who were ahead of me in this breast cancer journey. This eased my anxiety and I was so grateful to the women who shared their stories and to BCNA for providing this wonderful network. It really is a great place to come no matter what stage of breast cancer you are at. The BCNA network



*Tonya*

provides a platform for women to express their feelings, vent their frustrations and fears, and share information and personal experiences. As supportive as family and friends are, our

'pink' sisters truly understand because we've all trodden a similar path. Women who have a breast cancer diagnosis (or an association with) can join the BCNA online network from

almost anywhere in Australia and not feel so alone. I have made several friendships since joining the network and, in fact, I attend weekly art therapy with one of those friends. I would not have known about these classes had it not been for her.

It is such an invaluable service. Although I am currently two years on from my diagnosis (nine years if you count my first!), I continue to blog to help and comfort others going through similar treatments. I would encourage all women around Australia with breast cancer to use this wonderful service.

*Tonya, NSW*

## A real wag!

When I was first told I had breast cancer I was so frightened about having to go to hospital and the prospect of being there for four to five days. Home was four hours away and it was difficult and expensive for my partner Glenn to make the trip.

I went there with my tail between my legs but what a relief when I found myself in a ward of lovely ladies who cracked me up!

The lady in the bed opposite me, Liz, had had a full mastectomy. I was only there for a lumpectomy and as soon as I came round I could hear laughter and soon I was laughing

myself with Liz who was a real wag. Even the nurses all wanted to come to our ward! Liz was always making fun of herself. She would say things like 'I thought my boobs were gone but they've put them on my back' (that was all the fluid), and play tricks on me like hiding my breakfast and saying they never got me any.

I loved it; it made me feel so much more comfortable and she assured me everything would be okay to go home with the drain bag on. Two years on I am cancer-free and Liz, if you're out there, thank you from the bottom of my heart.

*Debbie, NSW*



*Glenn and Debbie*

## Care and communication

I was diagnosed with breast cancer at 72. I was fortunate to have a daughter living in Brisbane, only a stone's throw away from the hospital where I had surgery, chemotherapy and radiation. Home was 1,100 km away.

The communication between the breast clinic, the surgeon, the oncologist, the breast care nurse in my home town, the chemotherapy team of nurses, the radiation oncologist, the radiation team and me was nothing short of outstanding. I was in hospital for three days after surgery and commenced chemotherapy three weeks later. The oncologist had a keen sense of humour and the morning chemo was due to commence, he bounded into the ward remarking, 'You've got rubbish veins, all that time you have

spent in the sun and that harsh climate you live in are to blame. You'll need a portacath.' He explained this in detail, but was upset that the treatment would be delayed by another day.

Following the third chemo treatment, each three weeks apart, the oncologist advised us to return home (by plane) and return for a couple of days for each of the remaining three treatments. This worked brilliantly and the staff at the local airport went out of their way to make us comfortable on each trip.

In mid-June I commenced radiation and at the end of July, I was cleared to return home. The whole journey was an exercise in communication between all parties – brilliant!

*Elaine, QLD*

## The healing power of words

Having worked as a social worker and counsellor for 30 years, communication is my business, so I knew I had breast cancer even before the pathology tests confirmed it.

I could read the truth via the care and sympathy in the eyes and voices of all the medical staff as I had an ultrasound, mammogram and biopsy. My heart sank and my mind panicked but another part of me held hope. My GP continued to allow me that hope, but

efficiently and empathetically referred me to a surgeon.

Despite my feelings of devastation, my surgeon communicated his expertise to me, not just verbally but with his reassuring eyes and beautiful, steady, life affirming hands. He generated faith and a sense of security. He conveyed the important message to rely only on the *My Journey Kit* and BCNA for my information and not to be waylaid by wacky ideas from other sources.

Random acts of kindness popped up everywhere just when I needed it most.

For example, a random handsome medical student told me how well I looked the morning after my third surgery. Did he know how healing that felt? And long-term survivors told me their stories and filled me with hope and inspiration.

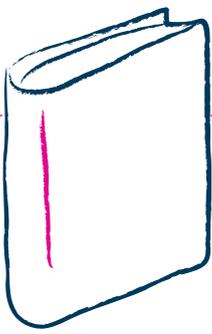
Where would I have been without my family, my friends and my journal? I communicated



*Alexandra*

the whole journey to them, and that helped purge me of the fear, sadness, rage and negativity.

*Alexandra, NSW*



# Reviews

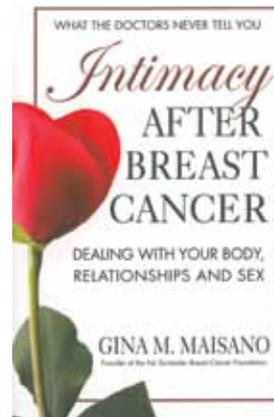
## Intimacy After Breast Cancer: dealing with your body, relationships and sex

by Gina M Maisano  
Brumby Books, 2010  
paperback, 224 pages  
RRP \$23.95

*Intimacy After Breast Cancer* is a positive, frank and detailed discussion of the problems that can confront a woman if her breast cancer treatment included surgery, chemotherapy and/or radiation. This book deals with sensitive topics openly and with a touch of humour – chapter titles include ‘Getting to Know the New Girls’; ‘Sex and The Single

Survivor’; and ‘The Moment of Truth’. The author is a young woman who has been diagnosed with breast cancer twice and has confronted her own issues concerning fear of recurrence, loss of dreams, her own sexuality, and relationship confidence. However, her book is aimed at all age groups and situations.

Some of the topics can be a bit confronting – such as the ‘toy chest’ (no, you have to read the book to know what this is!) and vaginal atrophy – and the ‘Resources’ chapter is aimed at the American reader. The author discusses reconstruction options, as well as post-treatment diet, exercise, skin and hair care. I related to the frilly underwear



section (in my case, the lack thereof!), dropped the book and raced to the shops and bought three pretty bras and matching lacy knickers. Wearing them and losing the ‘mom jeans’ really DOES help your self-esteem!

The book is written in a ‘you go girl’ style – its underlying message being to live life to the full, enjoy each day and live in the present. As Gina states: ‘The point of all this is that when you are actively working toward looking the best you can, you start to reclaim control over your life. With that control, you start to feel empowered. And with that empowerment, comes a sense of newfound sexuality.’ I would recommend this book to any woman experiencing self-doubt in the face of sexual intimacy after cancer treatment.

Amanda Hingston  
BCNA Review & Survey Group member

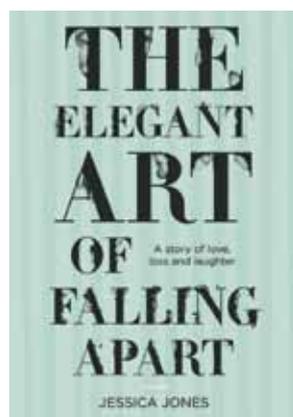
You may also be interested in BCNA’s free *Breast Cancer and Sexual Wellbeing* booklet. You can download it or order a copy by visiting [www.bcna.org.au](http://www.bcna.org.au) > Resources, or by calling 1800 500 258 (Freecall).

## The Elegant Art of Falling Apart

by Jessica Jones  
Hachette Australia 2011  
paperback, 343 pages  
RRP \$32.95

*The Elegant Art of Falling Apart* is an accessible and well-written memoir by Jessica Jones in which she chronicles a year in her life following a diagnosis of early breast cancer, with London and Sydney as the backdrop. She writes with humour, candour and self-deprecation.

Jessica admits her life has been complicated; she spent 30 years away from home, travelling, battling addiction and experiencing the highs and lows of dysfunctional relationships whilst trying to build a successful



career. We get to know her family, friendships, her relationships, her sense of place and how she thinks she fits into all of this. The morning she is told she has breast cancer her life *changes completely and forever* and the reader has the privilege of travelling alongside her as she navigates her way through this extraordinary experience and,

at times, harrowing sequence of events.

Jessica is disparaging of self-help books that try to tell us there is one way to approach a diagnosis of breast cancer. At no time does she claim to have answers but she cleverly inserts very insightful and practical passages called *Things I wish I knew before* which reflect her experience. I found these very helpful as they resonated with my experience and gave me a lot to think about. For example, how to break bad news; the capacity of friendships; how to prepare for a week in hospital; dealing with medicos; how to evaluate an anti-cancer diet or alternative therapies and how to manage stress.

One aspect of the book I found troubling though was the feeling that Jessica was totally absolved

of all other responsibilities in life. It felt like a one-way street.

I think most women’s reality with a breast cancer diagnosis is they have to deal with the illness, the treatment and the aftermath whilst concurrently managing the aspects of their life such as children, partners, relationships and work.

But I enjoyed this book and would recommend it to readers who enjoy the ‘chick-lit’ genre and are perhaps newly or recently diagnosed. It would also appeal to younger readers. Themes such as courage, capacity, reflection, loss, friendship, resilience and appreciating the ‘now’ emerge and are excellent food for thought.

Kate Reynolds  
BCNA Review & Survey Group member



# Profiling our Member Groups

## Lower Murray Breast Cancer Survivors Group

*Rosie Scott from the Lower Murray Breast Cancer Survivors Group shares how the group collaborates with others to provide a unique and informative day they have named 'Living Well with Breast Cancer'.*

Our support group, which started in 1995, includes members of the original group and women who have been recently diagnosed. We now have more than 40 women on our mailing list and our regular monthly meetings usually attract between 10 and 15 attendees. We have strong connections with two other BCNA Member Groups: Breast of Friends – Victor Harbor and the Mallee Breast Cancer Support Group members from Pinnaroo, Lameroo and Karoonda.

For the past 10 years or so with the Mallee group, and more recently the Victor Harbor group, we have gathered biannually in a central location to catch up socially and to hear what each group has been doing. In December 2011 we added further value to our meeting, turning it into a forum we called 'Living Well with Breast Cancer'. It was the highlight of our activities for the year.

The day was planned with the help of local breast cancer survivors, the integral support and knowledge of Yvonne Thomson, Breast Care Nurse and Women's Health Nurse from Murray Mallee Community Health, and McGrath Breast Care nurses Cheryl Baxter from

Victor Harbor and Kylie Campbell from the Adelaide Hills. We took over the Wellington Hotel on the Murray River for the day, turning it pink! The staff were most obliging, efficiently serving lunch for the 90 women who attended.

Funding through Country Arts SA for skill development enabled us to engage the Willunga Playback theatre group and it was fantastic! Women told their stories and then the group 'played back' the story using performance and music. The interpretations by the skilled actors enthralled the audience and there was lots of laughter between the many poignant moments.

We had guest speakers on various topics, including mindfulness and what it means to be a 'survivor'. The YWCA Encore program, representatives from the Look Good Feel Better program and the local Amoena mobile prosthesis fitting specialists attended, giving women a chance to learn about these services firsthand.

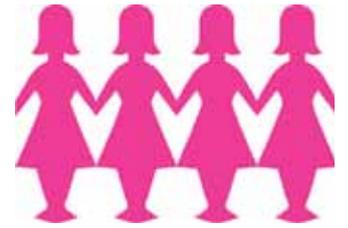
The Pink Victory River Dragons, an all-women group that grew out of our Lower Murray Breast Cancer Support Group in 2010 (through a Polo Ralph Lauren grant submission by Yvonne Thomson) demonstrated their techniques on a park bench by the water's edge. The dragon boaters are becoming an incorporated body and their own dragon boat, donated by the Royal Australian Navy, is being lovingly restored. The paddlers are all cancer survivors – the majority of them breast cancer. The forum was an opportunity for the women to recruit new members for the team, and to show to all those present that life is for living and living well!

The day was informative, lively and fun, and women who have shared similar stories were able to connect with each other. We plan to do it again this year, and build on the success of 2011.

If you would like any more information about our event please find us on BCNA's website: [www.bcna.org.au](http://www.bcna.org.au) > Sharing & support > Search for groups.



*Pink Victory River Dragon team show their style*



## Linking together

Over the past 13 years a key part of BCNA's mission has been to **link** Australians personally affected by breast cancer.

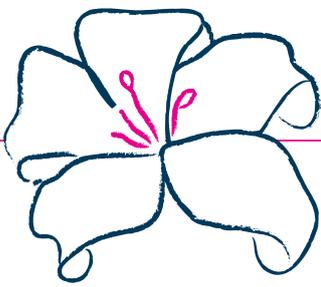
We welcome new Member Groups to our network. They now total 312.

BCNA also has more than 70,000 individual members across Australia.

New Member Groups:

- Adelaide Breast Cancer Friendship Group – Adelaide, SA
- Ocean Grove/Barwon Heads Breast Cancer Support Group – Ocean Grove, Vic
- South East and Bayside Social Group – Seaford, Vic
- Supporting Blokes (for male partners of women diagnosed with breast cancer) – Melbourne, Vic
- Warwick Breast Cancer Coffee Club – Warwick, Qld

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



# Thank you

Thousands of generous supporters across Australia donate their time and money to support BCNA. We would like to especially acknowledge significant contributions recently received from:

- Andrea Townley, WA
- Fantastic Pets, VIC
- Girls Night Out committee, VIC
- Heather McAlpine, NSW
- Horsham Golf Club, Julie Obst, VIC

- Iris Potter, ACT
- Jackie Paris, NSW
- Maureen Chan, ACT
- Michelle Gibson, NSW
- Nick Bracks, VIC
- Redlands Modern Country Music Club, QLD
- Roslyn Mitchell, NSW
- Sophie Clark, VIC
- Southern Italian Tours, VIC
- Sue Knight, VIC

## Memorials

We pay tribute to the lives of:

- Inge Imberger
- Irene Halmans
- Jennifer Fiume
- Joy Spears
- Margaret Mary McKean
- Patricia Mae Davies
- Renate Metraux
- Yvonne Esmæe Waddington

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

## Celebrations

Thank you to those who celebrated a special occasion and asked for donations to BCNA in lieu of gifts:

- Annie Roberts
- Daniela De Nichilo
- Jane Garvey

## Nissan and BCNA: finding footy's Hidden Heroes

In 2011, Nissan launched a promotion to recognise the hidden hero behind local footy clubs (both rugby and Australian rules). Many local clubs have women who, working behind the scenes, provide valued support. This was a wonderful way to expand our relationship with Nissan which began when Nissan's Pink Navarra led the way for Shane Crawford's run from Adelaide to Melbourne for BCNA. We are delighted to let you know that Nissan is on the lookout for Footy's Hidden Heroes again this year and we need your help.

If you are involved with a football club you can nominate a woman to be recognised – there are always women who go above and beyond and we know that without many of you, some teams would never get out on the oval!

The women who are nominated do not need to be breast cancer survivors, but for every vote the women receive Nissan will donate \$1 to BCNA. There are rewards for the women and great prizes for the clubs to help cover their costs.

We are looking forward to continuing our relationship with Nissan and hope that it will be a long and rewarding partnership. This campaign will also give us the opportunity to strengthen existing relationships and build some new ones with football clubs around the country for future *Pink Footy & Netball Days*. Nominations for Footy's Hidden Heroes will open soon.

For more information visit [www.bcna.org.au](http://www.bcna.org.au)



*ARL legend Luke Ricketson surrounded by some of the hidden heroes of football*

## Get ready for October!

October is Breast Cancer Month when communities host events that pay tribute to those affected by breast cancer and help to raise awareness and funds. If you'd like to get your community involved, BCNA is here to help!

## Mini-Fields of Women

Host a *Mini-Field of Women* to show support for women and their families affected by breast cancer. Simply set the date and venue, register at [www.bcna.org.au](http://www.bcna.org.au) > Events, and we'll send you a free pack including Pink Lady silhouettes, tribute tags and everything pink you will need.

## Pink Lady fundraising event

For an easy and fun way to raise some money to support BCNA's work, organise a Pink Lady event. From a simple afternoon tea to a fancy cocktail party, you can choose the size and scope of the event.

For help with ideas or plans, please contact Marita on 1800 500 258 (Freecall).

# A delightful success

Our annual Pink Bun campaign has once again turned Bakers Delight bakeries across Australia into a sea of pink – from balloons, streamers and paper Pink Ladies, to shelves of the sweet buns that give the campaign its name.

The Pink Bun campaign highlights the generous and enduring support Bakers Delight provides to women affected by breast cancer and their families and BCNA.

*Of all the campaigns we do throughout the year, the BCNA Pink Bun campaign is the staff favourite. – Sue, NSW*

The funds raised from this year's fantastic efforts will contribute to the development of a new booklet to inform women

with breast cancer about the importance of staying active.

Sporting legend and breast cancer survivor Raelene Boyle has experienced the benefits of exercise after a breast cancer diagnosis: 'Exercise has made

such an amazing difference to me in managing many of the emotional and physical side effects that came with a diagnosis of breast cancer.'

We would like to thank all of the BCNA members and Member

Groups who joined in the Pink Bun festivities – your support and enthusiasm is a great way to strengthen our connection with local communities and help promote a very special partnership. We hope you enjoyed your time in the bakeries!

*It is a pleasure to be able to say thank you to all the hard-working bakery staff who support us with Pink Bun. – Sharyn, Vic*

As this issue of *The Beacon* goes to print, we are still counting the funds raised. Keep your eye on the website for our final fundraising total, and check out the photos at [www.bcna.org.au](http://www.bcna.org.au). Congratulations on a great team effort and thank you for supporting us again this year.



*Raelene Boyle with Michaela Gallagher from Bakers Delight, Mt Waverley*

## And the crowd went PINK!

This Mother's Day weekend (12–13 May 2012) saw more than 900 football and netballs clubs from around Australia participate in BCNA's annual *Pink Footy & Netball Day*.

In this, its fourth year, *Pink Footy & Netball Day* went national for the first time, attracting more than double the number of clubs involved in 2011.

Clubs across every state and territory seized the chance to turn their matches pink – from ovals, courts and canteens to

clubhouses and even whole towns, pink was the theme for the weekend!

Jeremy from Eagles Football Club in Rockingham WA enjoyed his first year participating in *Pink Footy & Netball Day*.

*Our community is very close and it meant a lot to us to be able to stop and remember the women and their families who have been affected by breast cancer. We invited a survivor to toss the coin, organised a sausage sizzle and asked for gold coin donations*

*upon entry to the field. The 'best-dressed-in-pink' spectator on the day even won our match football! Everyone enjoyed the day, learnt more about BCNA, and we will definitely add it to our fixture for next year! – Jeremy*

A very big thank you to everyone who participated in this year's *Pink Footy & Netball Day*. It was wonderful to see our members get involved and help spread the word about our work to support Australians affected by breast cancer.



BCNA gratefully acknowledges our partnership with Bakers Delight.





## Dates for your diary

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

**7 July – 8 September** Trip around Australia. Jacques Stap, in conjunction with the Ulysses Club, is riding around Australia to promote BCNA in remembrance of his wife, and to support all those affected by breast cancer. For further information visit [www.triparoundaustralia.com](http://www.triparoundaustralia.com)

**Wednesday 18 July** BreaCan presents a free session on the psychological aspects of managing unexpected long-term side effects which arise as a consequence of cancer treatment such as lymphoedema, peripheral neuropathy, bone and joint problems, fatigue, and menopausal symptoms. 12 – 1.30 pm Queen Victoria Women's Centre, 210 Lonsdale Street, Melbourne. Bookings are essential. Phone 1300 781 500 or email [breacan@breacan.org.au](mailto:breacan@breacan.org.au)

**Thursday 19 July** Living with Cancer Education program. Royal Melbourne Hospital. 9.45 am – 4 pm BMDI Rotary House, 14 Blackwood Street, North Melbourne. Call Naomi Sprigg on 9342 3174 or the Cancer Council Helpline on 13 11 20 for details.

**August/September** Free BCNA Alice Springs information forum. Keep an eye on BCNA's website for more information.

**Sunday 16 September** Blackmores Sydney Running Festival. BCNA is one of the official supporter charities for this festival. Register to participate in one of four events: Blackmores Sydney Marathon, Blackmores Half Marathon, *The Sunday Telegraph* body + soul 9 km Bridge Run, or *The Sunday Telegraph* 4 km Family Fun Run. To participate in the event and to fundraise for BCNA, visit [www.sydneyrunningfestival.com.au](http://www.sydneyrunningfestival.com.au).

**25–26 October 2012** Strength to Strength: BCNA National Conference 2012. Sydney Exhibition and Convention Centre, Darling Harbour, Sydney. Early bird registration (\$200) closes 23 August; full registration (\$250) closes 22 October. Places are limited so register early to avoid disappointment. For more information visit [www.bcna.org.au](http://www.bcna.org.au) > Events > BCNA conferences > National Conference 2012 or phone 1800 500 258 (Freecall).

Visit our website [www.bcna.org.au](http://www.bcna.org.au) > Events for more information about recent and coming events held by or for BCNA in your state or territory.

## Seeking stories – keeping active

We are seeking stories for the Summer issue of *The Beacon* about **keeping active**. Did your diagnosis lead you to make changes in your lifestyle? This may be some form of exercise, or pursuing an activity you are passionate about such as

gardening. Do you try to stay active and, if so, how? If you're not active, what stops you? Please email articles of 200–300 words (about half a page) to [beacon@bcna.org.au](mailto:beacon@bcna.org.au) by the end of September 2012.

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

## Join our mailing list

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



the BEACON

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If you wish to unsubscribe to *The Beacon* or *The Inside Story* please contact BCNA.

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