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Focus on:
Older women



You are as old as you feel!

*This issue of **The Beacon** focuses on older women with breast cancer.*

Who are these 'older' women? When we called for our readers to submit articles, we heard from women in their 80s and also from women in their early 50s!

As a woman in her late 50s, I certainly would not categorise myself as an older woman. After all, isn't 60 the new 40, or is it the new 50?

The closer I come to 60, the younger that milestone seems. I do, however, recall that when I was a teenager, people of 60 seemed positively ancient!

We've all heard young children, when prompted, describe their new teacher as 'quite old', only to find that she is in fact 34!

It is interesting to note that, in breast cancer terms, the average age of a diagnosis in Australia is 60.

Many of you will be surprised to read this, as so many media stories cover the experiences of young women, such as **Belinda Emmett**, **Jane McGrath** and **Kylie Minogue**. In fact, women under 50 are in the minority as far as breast cancer incidence is concerned.

Apart from being female, the only other clear risk factor for breast cancer is growing older,



Frances Reynolds, now 88, was first diagnosed with breast cancer in 1954. She is pictured here at the Field of Women Live 2005 where she tossed the coin to start the match.

and there's nothing we can do about that.

As you will learn further inside this **Beacon**, the issues and needs of older women with breast cancer are poorly understood.

My mother, at 83, is thankfully active, well connected in her community and fortunate to enjoy good health, in the main, but this is not the case for all older women.

A while ago, when there was a suggestion that my mother may need an operation, I was rather horrified to discover that she had little understanding of the medical reasons for this procedure.

To her it was straightforward; her doctor advised it and she unquestionably trusted his judgement. Not only did she not ask questions, she did not want to ask questions.

My sense is that my mother is not alone in this approach. Even though this was indeed a foreign and even dangerous concept for me, I had to respect her preferences and wishes.

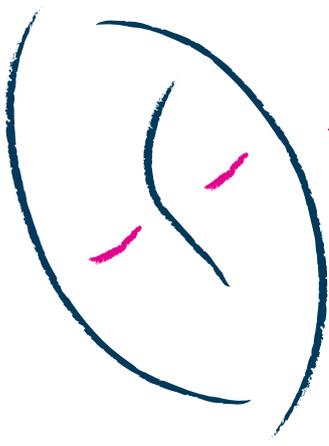
Not all older women will be like my mother, though. My husband's aunt, at 104, asked me to search the web and print off information about a condition for which she'd been diagnosed.

For these women who hunger for information, we should endeavour to make sure this need is addressed, and that their options are presented in a respectful, clear and easily digestible manner.

Just as there is no simple way to categorise 'older women', there should be no standard assumptions made about their needs by those providing individual women with services and care.

*Lyn Swinburne
Chief Executive Officer*





Issue of concern

Treatment-related issues for older women

We know that increasing age is one of the greatest risk factors for developing breast cancer and, in an ageing Australian population, more women will experience breast cancer as part of growing older.

In 2011, we estimate that 5,067 women in Australia aged 65 years and older will be diagnosed with early breast cancer, representing approximately one-third of all breast cancer diagnoses.

While there is evidence to suggest that some older women tend to have less aggressive types of breast cancer, treating older women with breast cancer can be complex and challenging for a number of reasons.

Pre-existing health issues

Women aged 70 years and older may have started to develop other health problems apart from their breast cancer, such as high blood pressure, diabetes or arthritis, which can have an impact on physical health and wellbeing.

Losing bone density is a worry as it is hard to tell whether it is just a part of ageing or connected to the treatment and medication.

– Pamela

Pre-existing health issues can also affect an older woman's ability to endure the stresses of breast cancer and her ability to tolerate certain breast cancer treatments, such as chemotherapy.

Lack of research

In some cases, it can be challenging for doctors to consider the most appropriate treatment for older women. There is a lack of specific clinical research on the risks and benefits of various breast cancer treatments for older women. This is particularly the case for women who also experience other health problems.

Clinical trials tend to exclude older women because of their age alone, or because they may have poor health due to other health issues. Those clinical trials that do include older women tend to include only those who are very fit and healthy.

BCNA believes that older women should be offered the opportunity to participate in clinical research. This will hopefully add to our understanding of issues relating to women as they age.

There is also a real gap in the research about the breast cancer experiences of older women, particularly around the emotional impact of a breast cancer diagnosis and long-term

issues or concerns after breast cancer. BCNA believes that such research is important as it will ultimately improve outcomes for older women.

I expected that after a year or so when the effects of radiation and chemotherapy wore off I would be not much different to how I had been before the surgery. I have been quite tender and sore ever since. I feel that people (including doctors) dismiss this.

– Woman aged 70+
BCNA research

Treatments, side effects and quality of life

In some cases, doctors may be reluctant to offer an older woman certain breast cancer treatments, such as chemotherapy, as they may be concerned about toxic side effects and how that may affect the woman's quality of life. Some research, for example, has shown that chemotherapy side effects such as fatigue and nausea appear more often in older women compared with younger women with breast cancer.

In some cases, oncologists may recommend a lower dose of chemotherapy. Older women often tell us that, when considering whether or not to undergo chemotherapy, they need to be able to understand the side effects and how these may affect their quality of life.

Life expectancy

BCNA believes that a woman's age alone should not exclude her from being offered the full range of breast cancer treatments.

We think that, when considering treatment options, doctors should take into account a range of issues, including health status, life expectancy and, most crucially, personal preferences.

Interestingly, some American research tells us that older women are sometimes willing to select a more risky treatment, such as chemotherapy with major side effects, for a small increase in life expectancy.

BCNA's position when advocating to the medical profession is that every woman is different. Some will want to be given information about all their treatment options so that they can make decisions about the treatment they want. Others we know are simply happy to accept their doctors' advice on the best treatments for them.

It is important that women are offered quality information in order for them to make the decision that is *right for them*. We believe that it is also important to find a medical team that will work both with you and for you.

Ask the Expert

Dr Nicole McCarthy

Dr Nicole McCarthy is a medical oncologist working at the Wesley Medical Centre and Royal Brisbane and Women's Hospital. We asked Dr McCarthy about the treatment and care of older women with breast cancer.

In your experience, are there any differences in treating older women compared to younger women with breast cancer?

Generally speaking, younger women are more able to tolerate breast cancer treatments compared to older women. Older women often experience other medical conditions (such as cardiovascular disease) that may be life-threatening and these can cause more problems than their breast cancer.

Treating women who have been diagnosed with breast cancer at age 70 years and older can be challenging because it requires weighing up the risks and benefits of breast cancer treatments such as chemotherapy. However, age alone is not a reason to deny older women the gold standard for breast cancer treatment.

It can be particularly difficult to determine the risks and benefits of chemotherapy for older women because of the limited amount of clinical trial research information on chemotherapy use by women aged 70 years



Dr Nicole McCarthy

and older. However, some data suggests that side effects of chemotherapy, including mouth ulcers, diarrhoea, fatigue and reduced heart function, can unfortunately occur more frequently in older women (particularly in women aged 75 years and older). The risks of developing these side effects have the potential to cancel out the survival benefits gained through undergoing chemotherapy.

Research has shown that, compared with Tamoxifen, aromatase inhibitors provide a small additional benefit in post-menopausal women with hormone receptor-positive breast cancer (breast cancer that contains oestrogen and/or progesterone receptors).

However, without clinical trial data, we do not yet know whether women aged 70 years and older incur that same additional benefit from taking aromatase inhibitors. In making decisions about which type of hormonal treatment is right for you as an older woman, consider the side effects of both treatments. With aromatase inhibitors, there is a tendency for bone loss; with Tamoxifen there is a small risk of endometrial cancer and blood clots (including stroke).

Decisions about breast cancer treatment ultimately depend on an individual woman's risk of their breast cancer returning, the side effects associated with the treatment, the severity of co-existing medical conditions, and how likely they are to be life-threatening in the near future.

What advice do you have for older women who have recently been diagnosed with breast cancer and who are making choices regarding breast cancer treatment?

Good communication with your oncologist is essential. Your oncologist should be able to provide you with information about your risk of breast cancer recurrence for the next five to 10 years, as well as information about survival benefits and potential side effects associated with the different treatment options.

It also helps to ask lots of questions and to ask your health professional to clarify anything you don't quite understand.

It can also be beneficial to involve your family, support person(s) and your GP in the treatment decision-making process. You may also like to take someone with you to a consultation so that you have another 'set of ears' to help take in all of the information.

Always remember that treatment is a personal choice, and ultimately decisions about treatment belong to you. If you wish to say no to a certain treatment, it's important to understand what you are saying no to.

Many older women go on to lead very active and fulfilling lives after breast cancer.

What advice do you have for older women who are survivors of breast cancer?

I always encourage women to consider themselves as a woman who 'had' breast cancer and who has undergone treatment to reduce the chances of breast cancer returning. It's also a good idea to continue to have regular mammograms.

Helping others to help you

Social support can greatly assist women to adjust and cope with a diagnosis of breast cancer. However, some older women have few support networks available to them, and may feel they are left to cope with breast cancer on their own.

Some American research of older women with breast cancer suggests that those who lack sufficient emotional support may have poorer quality of health and greater difficulty adjusting to their diagnosis.

Loss of friends and family

We know that older age can bring with it the losses of a partner and own-age friends. Some older women with breast cancer may be widowed and living on their own. This can leave them socially isolated and with few people to turn to for help and support.

Often too, younger family members such as adult children are busy with their own lives and may be not available to provide support, or may not even be aware that their loved one is in need of support. Women have told us they are sometimes reluctant to reach out to family members as they don't want to burden them or interrupt their busy lives.



Professor Phyllis Butow, Chair in Psychology, University of Sydney, whose research interests include the impact of support networks on quality of life.

Caring for others

Another complication for older women is that they may already be caring for someone else.

Professor Phyllis Butow, from the University of Sydney, told *The Beacon* that many older women with breast cancer care for others – partners, adult children who may be ill or have a disability, and even elderly parents. As a result, these women have to juggle their own illness while dealing with the demands of caring for someone else.

Professor Butow says that, for these women, accepting support from others to help deal with their breast cancer can provide them with more energy and a greater ability to support the person for whom they are caring.

Difficulty asking for help

It can be hard to ask for help. Many people have difficulty asking for assistance or support and older women with breast cancer are no different.

BCNA believes, however, that many family members and friends are happy to provide support, both emotional and practical – they just don't quite know how to go about it. Asking them for help with specific tasks such as cleaning, cooking, running errands, or providing transport to doctors' appointments and treatments can be a good place to start. BCNA's brochure, *Helping a friend or colleague with breast cancer*, includes lots of suggestions on what is and isn't helpful.

Other types of support

Some American research tells us that few older women use support groups or other types of support networks, although these may be beneficial.

Some older women have told us they found it very helpful to join a breast cancer support group, where they could talk to other women with breast cancer. While it can be daunting initially to join a group and meet new people, most support groups are very good at helping new members to feel comfortable.

My advice to older women is to join a support group or try to talk with someone who's been through breast cancer.

– Peggy, aged 85

There are other ways to get support. BCNA's new online network, for example, provides women with a chance to talk over the internet with other women with breast cancer, and to share their feelings and experiences. Many women appreciate being able to do this in their own home and at a time that suits them.

Some women choose to see a counsellor or psychologist to discuss issues that are worrying them. Others seek help from spiritual and religious institutions.

Professor Butow says it is important that all women with breast cancer feel they have the emotional and practical support they need to help them through their breast cancer journey. More than simply making you feel better and more able to cope, the support of others can help to prevent depression and anxiety, and may even assist in the management of some of the side effects of breast cancer treatments.

A list of resources for older women is available at www.bcna.org.au > News > The Beacon magazine.

The power of information

There is a lack of extensive research about the information needs of older women.

Canadian research suggests that older women with breast cancer have different information needs to their younger counterparts.

In particular, the research suggests older women may want less information about breast cancer treatments and follow-up care than younger women.

This may reflect a view that some older women consider breast cancer a 'bump in the road of ageing' – something to be expected as part of getting older. Or there may be other factors. Undoubtedly, it does not reflect the views of all older women.

BCNA believes that research is necessary in order to know more about the wants and needs of older women, and whether these differ from younger women.

There's not much information out there for us oldies.

– Woman 70+ years
BCNA research

While information needs will vary from woman to woman, we know good-quality information about breast cancer not only assists women in understanding their breast cancer, but also helps them to feel confident about making decisions about treatment and care.

Many women who are actively involved in making decisions find that they adjust better to their breast cancer diagnosis.

Some older women tell us that they are often happy to go along with the treatment that their doctor recommends. However, if you would like to obtain information about other treatments, you are certainly entitled to ask your doctor what else might be available for you.

BCNA also has information on our website that you may find useful, including the following advice and tips from other women:

- speak up if you have any concerns or worries regarding your treatment



BCNA staff member Astrid, showing a woman the My Journey Kit.

- take someone close to you to doctors' appointments to help you keep track of information
- if you're not happy with the information that is being provided to you, or if you feel your questions are not being answered, you can seek a second opinion from another doctor.

If you have recently been diagnosed with breast cancer, you may like to receive a copy of BCNA's free *My Journey Kit*, which has been developed by women with breast cancer and offers support, insights and practical advice. It can also be useful for family and friends. You can order a *My Journey Kit* online at www.bcna.org.au or by phoning 1800 500 258 (Freecall).

BreastScreen for women aged 70+

Women aged 70 and over who have not been diagnosed with breast cancer can access the BreastScreen Australia program for a regular, free screening mammogram. However, many women are surprised that on turning 70, they no longer receive regular reminder letters and correspondence (with the exception of women in Queensland who receive this until the age of 74).

As a result, some women incorrectly assume this means they are no longer at risk of developing breast cancer.

In fact, according to BreastScreen Australia, the main reason women are not being invited to return for breast screening once they turn 70 is that it is not considered to be cost-effective for the program.

They say more lives could be saved by screening and

detecting breast cancer in women aged 50 to 69 years, compared with screening women aged 70 years and over.

A recent evaluation of the BreastScreen program has recommended increasing the age for reminder letters for all its programs to 74, in line with the practice in Queensland. BCNA strongly supports this recommendation but we are disappointed that, to date, it has

not been implemented. We will continue to pursue this issue.

In the meantime, women over 70 who have not had breast cancer can still make an appointment for a free screening mammogram with BreastScreen. They should remain breast aware and see a doctor about any breast changes or concerns.

BreastScreen Australia operates in all states and territories and can be contacted on 13 20 50.

Dedicated cancer care for older people

The Royal Adelaide Hospital has established the first Australian geriatric oncology program. BCNA asked Consultant Medical Oncologist Dr Nimit Singhal and Geriatric Oncology Nurse Janette Prouse from the Royal Adelaide Hospital to tell us more about their program.

We at Royal Adelaide Hospital established the first Australian geriatric oncology program in June 2008, bringing together a multidisciplinary health care team, including a geriatrician, medical oncologist, geriatric oncology nurse, social worker, dietician, pharmacist, occupational therapist and palliative care nurse.

The aim of the program is to optimise the journey for older people with cancer by offering timely and appropriate treatments.

The decision to offer surgery/chemotherapy to older women



Photo courtesy of Royal Adelaide Hospital.

can be particularly difficult as it requires weighing up the benefits and side effects of treatment, as well as considering treatment tolerance. This is where geriatric assessment becomes important.

All patients aged 70 years and over are screened for older age specific issues and their physical, nutritional and emotional

wellbeing is assessed before they receive their cancer treatment. This helps us identify the fit older woman who can be safely treated and at the same time avoid recommending toxic treatments for the less fit woman.

So far more than 500 patients have used this program, of which 15% were women with breast cancer.

Women with breast cancer who have been enrolled in this program have told us that they have appreciated the holistic approach of the multidisciplinary team. Their physical and emotional wellbeing has benefited by having a vast range of support services offered at the time of diagnosis. They also have a key person in the form of a geriatric oncology nurse who often acts as a translator of medical information and navigator to guide them through a difficult and confusing time.

Older women with breast cancer face life-altering adjustments to their lives. This program helps women to optimise their general health and wellbeing by initiating early and ongoing health support.

At present, the Royal Adelaide Hospital is the only one in Australia to offer a dedicated service to older people with cancer, but there is great interest in rolling out a similar program elsewhere in Australia.

More women are surviving breast cancer

More women survive breast cancer in Australia than in other comparable countries, according to a recent international study.

The study tracked 2.4 million patients in six countries (Australia, Canada, Denmark, Norway, Sweden and the UK) and compared the five-year survival rates for the four most prevalent types of cancer – breast, colorectal, lung and ovarian.

Survival rates were highest for all cancers in Australia, Canada and

Sweden, and lowest in the UK and Denmark.

The study found that 88% of Australian women diagnosed with early breast cancer between 2005 and 2007 would survive at least five years, compared with 82% in the UK and Denmark. The researchers suggested that the differences in survival rates may be due in part to British and Danish women being diagnosed at a later stage and to differences in treatment. In

the UK, for example, the study found fewer women had breast cancer surgery, fewer lymph nodes were removed and tested, and fewer women had access to radiotherapy.

Australian survival rates continue to improve every year. In 1999, the five-year survival rate for early breast cancer was 85%; by 2007 it had risen to 88%. Currently the only statistics provided for survival rates are at five years after diagnosis.

We know five years is not long, however, and hope that future studies will look at survival rates of 10 and 15 years.

There is still a lot to be done to continue to further improve survival rates, particularly for those women who do not have easy access to treatments and services. These may include women in rural areas, women from Aboriginal communities and women from non-English speaking backgrounds.

Don't come back!

It is claimed that no one ever died of old age. Yet it is a universal truth that over time the human body will go into decline and we will die of disease which kicks in earlier to a neglected body.

It makes sense that as we are living longer we each take care so we do not become a burden to ourselves, our families, the community and to the health system over an extended period.

Three bouts with cancer in my fifth decade between my husband and me have made us particularly vigilant about body maintenance. So when I turned 70 and was told by my GP I would no longer be officially reminded it was time for my two-yearly Pap smear, my eyebrows went up. 'It's okay,' said the GP, 'you can still come in if you wish, we just won't be notifying you anymore that a smear is due.'

Soon after that revelation I went to see my gastroenterologist to arrange for a five-yearly colonoscopy. The procedure was completed, there were no problems and as I was leaving, my doctor said, 'You don't need to come back again.' 'You mean, ever?' I enquired. 'Yes,' he replied. 'But my father had bowel cancer in his mid-70s, that's why I come in for regular check-ups.' 'Okay,' he said, 'you can come back.'

A few months later I had my annual mammogram, and my consulting specialist of 20 years standing said, 'You're cancer-free after all this time, so you don't need to come back again.'

Having served 10 years as Chair of Breast Cancer Network



Dr Patricia Edgar AM

Australia I am familiar with breast cancer statistics; I know that a woman's risk of breast cancer increases with age, and that if you have had breast cancer before – as I had 23 years ago – your risk is higher. So I pressed my physician to explain what he was talking about.

It evolved that he was retiring and wouldn't be working a year from now. I asked what was he doing with all his records. 'I haven't thought about that,' he said, 'I'll probably put them under the house.' 'What about giving them to your patients?' I suggested. 'I'll think about that,' was the response.

I knew from his lack of interest that my records of more than 20 years, along with countless others, were destined to rot under a house.

A little checking among my peers indicated my experience of turning 70 was not unique. Not all but enough of my 70-year-old friends had been given the same message from doctors that I had received.

Enough for me to conclude the medical system wants to cull the over 70s from those receiving regular expensive procedures because the expenditure is not considered cost-effective.

I put this question to my GP who explained gently that life expectancy statistics do cut in about the time it would take a new cancer to develop – if a person is cancer-free at 70.

He effectively confirmed we are deemed by the medical profession, unofficially at least, to have had our whack and if cancer or anything else catches up after 70, we can't complain too much if we fall off the perch – we've had a good innings as they say.

The Australian breast cancer lobby with its pink banners has demonstrated over a 12-year

period what changes intelligent, informed consumers can make in health policy by getting their message out to the public. The result is earlier detection and more effective care for those diagnosed with breast cancer. Grey advocates now need to bring about change for our compatriots.

Living longer lives is one of the great achievements of the 20th century. The policy aim should be to increase the period of life that is free from disability and disease for all. An enlightened approach to health reform could mean the extended years that medical science is largely responsible for giving us can be put to a useful social and individual purpose.

*Dr Patricia Edgar AM
Founding Chair, BCNA*

Connect via BCNA's online network

I have been waiting for this! I am such a painful user of the Internet but I'm having some training so I was able to register today ... I can't wait to get into it all.

Mary, BCNA Online Network User



It doesn't matter where you live, what time of the day or night it is, or if you're in your pyjamas – you can connect with others who understand what you're going through by joining BCNA's online network. It's easy to join. Simply register at www.bcna.org.au > Network and you'll be off and running.

Once you've registered, you can contribute by adding your own personal story, starting a blog, setting up a contact list, or joining an online interest group. However you decide to participate, you'll have instant access to others with experiences similar to yours.

That crazy year

For weeks before diagnosis, and for the first time in my 68 years, I had experienced major mental health problems and almost daily panic attacks. I had even been admitted for an angiogram, sporting as I must have been, a sizeable breast lump that I was too preoccupied to notice.

The utter emotional exhaustion and drenching tiredness I was experiencing had a major cause.

Six months before and almost immediately after my 94-year-old mother's death after a long illness, my youngest daughter, in her midlife, was diagnosed with paranoid schizophrenia.

Only those who have witnessed a loved one in a psychotic state have any comprehension of the trauma, unpredictability and suffering this wretched illness imposes on the victim and their wider family.

As a result I became *in loco parentis* to a highly traumatised

grandchild. In a state of shock myself, I had to keep her life moving along while simultaneously dealing with my own bewilderment and terror.

One evening after my shower I noticed my oddly shaped boob in the mirror and knew immediately what my next challenge would be.

Having already dealt with skin cancers, a precancerous ovarian cyst and a hip replacement, the fear of both cancer and heavy surgery were hurdles I had already jumped.

With all the treatments, my brain hardly worked and almost every part of my body seemed affected. I kept a diary and towards the end summarised my various bodily parts and recorded their reactions.

Worst was the chronic diarrhoea. The kilos were falling off, and moving onto the simplest diet didn't seem to help that much.

Once, after my evening walk I



An image from our My Journey Kit.

was pulling at some weeds in the garden, thinking to myself that I'd totally had enough of everything.

In horror, I raced to my GP. She insisted I take antidepressants and in a month I was feeling much saner – it really felt as if there might be light at the end of the tunnel both for me and my beleaguered family.

And light, love, fun and laughter have been in my life again, as well as good health. I learnt so much in that horrendous year.

Most of all my compassion goes out to all grandparents who are left to raise their grandchildren after their own children have suffered accidents, ill health or for other reasons. They are entirely unacknowledged and forgotten people in our society yet in so many ways they carry the greatest burden of all.

*Jan
Ipswich, QLD*

Trials and tribulations

In December 2008 at the age of 71 I was diagnosed with breast cancer leading to a left-side mastectomy in January 2009.

I had felt a thickening in the left breast three months before. I had spoken to my GP as I was convinced it was 'just a cyst' as I had suffered with fibrocystic disease in my 40s and 50s.

I decided to stop having mammograms when I turned 70 as I believed it was most unlikely for a woman over 70 to have breast cancer. How wrong can one be?



Sonya with her husband Kevin.

After the shock and the tears my main aim was to fight this enemy in my body.

I am blessed to have a loving, caring husband, wonderful family and supportive friends.

The medical staff and volunteers in the chemo ward became new friends, and as strange as it may seem, I looked forward to spending my day with them every three weeks.

After a difficult 2009, my husband and I decided 2010 would be our year! We celebrated our 50th wedding anniversary in March 2010 in the company of 70 family members and friends followed by a wonderful cruise. Life is good!

*Sonya
Port Macquarie, NSW*

Constant maintenance and repair

I'm 64 and a three-year survivor. A wide lumpectomy and lymph node strip was followed by one round of chemotherapy and six weeks of radiation therapy delivered by the linear accelerators at Wollongong Hospital.

Like many older people, I already had health problems, including an underactive thyroid and high blood pressure. Walking is also more difficult following an ankle break that has led to relayed stress on other joints, particularly my hip. All this means that my older body has lots of 'maintenance repair' jobs constantly in progress.

I opted out of chemotherapy after one round, instead of the six that were prescribed. I did this because it made me feel very unwell and I was told that statistically it would only increase my five-year survival chances by 10%.

Pressure from within medical circles to continue with



Denise

chemotherapy was strong. I believe these pressures would have overwhelmed me, except that, as a graduate ecologist who had sought to demystify complex variables in the plant world, I had a better than average understanding of the statistical probabilities and vagaries facing me.

Three years on, I am quite well and the breast surgery scars are finally healing and softening. I no longer resort to the heat pack after every round of gardening or other arm exercise. Moreover, my energy levels are improving.

I am grateful for the following:

- the many prayers that were said for me, and the Christian healing ministry
- the medical profession's honesty concerning the low statistical chances of chemotherapy being beneficial in my case
- my decision not to continue with chemotherapy, thereby allowing the natural healing processes of my older body to continue without further interruption.

*Denise
Kiama, NSW*

Surviving 38 years of breast cancer

I was diagnosed with breast cancer when I was 50 and had a mastectomy and radiotherapy. In that time I was determined to go back to work and get my super. I left after eight years and decided to do as much travelling as I could afford. I did a lot of travel overseas as well as around Australia.

I now concentrate on seeing Australia, travelling alone in my van. I haven't had to spend much on accommodation as I stay in rest areas and caravan parks.

The reason I have survived so long (I'm now 88!) is that I have focused my mind on doing as



Lorna and her van.

much travelling as possible, which means keeping my licence.

If you see a white van with a little old lady driving somewhere in

Australia just give her a wave and know it is me doing my thing.

*Lorna
Tamworth, NSW*



Pauline

Caring and being cared for

I am almost 74 and was diagnosed last year after I had a mammogram to investigate a 'prickly' sensation in my breast. I had my left breast and lymph nodes removed.

I lived in Queensland in a semi-retirement village. I couldn't get free treatment as it was too far to travel and with a husband suffering from diabetes and Alzheimer's, I found I couldn't manage.

My daughter came from NSW and arranged for me to have treatment in Wollongong Hospital. However, we only had a few days to get there to start treatment. I left my home and long-time friends. I even had to leave our home waiting for a buyer still furnished and with all my food in the pantry.

My daughter and her husband have been so good. We hope to build a flat on to their place.

My husband thinks we are on holidays and keeps asking when we are going home.

Wollongong Hospital has really been helpful – nothing's too much trouble. All the doctors, nurses and staff can't do enough to help. It makes me feel good.

*Pauline
Horsley, NSW*

Looking back

In 1971 at the age of 32 years I had a radical mastectomy with removal of pectoral and other muscles in the axilla (armpit).

I was left with, as one doctor commented, my 'arm hanging by a thread'.

Since then amazing advances and changes have taken place and I am here 40 years later to tell the story. We of that era were trailblazers.

As an older woman, I really appreciate how far we've come. When I started my journey we had:

- radical surgery that took longer to recover from
- no networking – it was years before I met another woman who had breast cancer
- little dialogue and far fewer choices
- no sentinel node biopsies
- interesting prostheses (mine was made up of a cotton pocket shape with one pocket



Heather (centre) with her granddaughters, Darci and Piper.

- holding little metal weights and the other stuffed with natural wool and a sheepskin cover to sit next to the skin)
- little understanding of lymphoedema – I was initially diagnosed and treated for arthritis, then told to keep my arm elevated and prescribed diuretics!

- no government-funded prostheses
- no support service or volunteer visitors
- no easy access to literature for ourselves or our families.

I am thankful that women diagnosed with breast cancer now have access to so much more information, support and

assistance with medical costs.

My 50th birthday was celebrated climbing Uluru and flying in a hot air balloon over the McPherson Range; my 70th with friends who I had known for half a century, who'd shared the highs and lows and who I couldn't have done without.

Now 73 years, I am involved with an organisation called *Zambian Outreach* which aims to support an African community with food, health care and education.

My other interests include patchwork, craft, reading, Bible study and travel, having enjoyed visiting Israel, Tanzania, the UK and a mission trip to Fiji.

As a young mum, my prayer was that I would live to see my children reach 18 years. Now I am blessed with seven grandchildren aged from six to 25 years, and a great-grandchild. I am fortunate and so thankful to be involved with them. We have so much fun!

Heather Beerwah, Qld

Doing my best

I was 72 in 2009 and working part-time when I was diagnosed with breast cancer from a routine screening that I had done.

Although I had reached the age of 70 and would no longer be followed up by BreastScreen, my sister's diagnosis three years earlier at the age of 66 had made me concerned that some form of ongoing screening was necessary.

Despite her diagnosis, mine was still a shock – my family had a history of early heart disease and

I'd had two previous episodes of blocked coronary arteries, so cancer was not on my agenda.

I live in separate accommodation but under the same roof as my daughter and son-in-law and gorgeous granddaughter so I had family close by from the time of my diagnosis, my discharge after surgery, through my chemotherapy and then my radiotherapy.

The hardest thing was asking for help when I was used to being totally independent. I had to train myself to do it.

The things that helped me most were:

- the practical assistance of my family, who lived so close but still gave me lots of privacy
- my McGrath nurse, who was always only as far away as my telephone, for useful assistance from before I left hospital to the end of radiotherapy and beyond
- the breast cancer support group I attended as soon as I had recovered from surgery.

It was incredibly helpful to be with women who knew what

it was like to lose your breasts, your hair and your appetite.

I felt the younger women in the group had far greater disruption of their lives and that it would go on for a longer period for them.

I am back at work, back at the gym and back playing bridge so life feels terrific – and I have kept off the 15 kilos I lost due to the chemotherapy!

Whatever happens, I know I have done my best to survive my breast cancer diagnosis.

Jean Westleigh, NSW

You are not alone

I have to confess I'd never checked my breasts for lumps, but when free mammograms started to be publicised more than 20 years ago I thought I'd go and get checked out. They found a lump and I was in hospital within a week.

In those days they removed the lump then you went home and returned a week later if you needed to.

Just as I was coming around from the anaesthetic the doctor said, 'You have oestrogen-linked infiltrating lobular carcinoma', then left the room. These words will be carved into my brain forever. As she left the room I just wanted to scream.

Fortunately for me, one of the nursing aides came and took me into a little room and we had a chat while she had a cigarette and I felt so much more supported (although I don't



Joan

think the cigarette would be allowed these days).

I've learned from that experience how to speak to people in the right way and to think before you talk. Just by listening you can achieve so much. I would never say, 'I know how you feel'. The fact is everyone is different – so you simply don't. Now that I've travelled the journey myself I feel I have more to offer, but I still say,

'I don't know how you feel but I've got a fair idea.'

Having a strong faith has helped me through some difficult times, and being a keen gardener has also played a great part. If I'm worried or anxious I go into the garden; there's always something to do. I play bowls, and love music and have been going to see the Melbourne Symphony Orchestra for 35 years. But it's perhaps my background as a nurse that has led me to understand that you can derive great satisfaction from helping others.

I joined the Breast Cancer Action Group where I met Lyn Swinburne, then joined the Box Hill Cancer Support Group. My son-in-law asked me to meet a lady who had also been diagnosed with cancer. She was very abrupt and a bit difficult, but at the end of the meeting she said, 'Joan – I am no longer

alone'. It was a tremendous feeling to know that I had done something to help her and it made me realise how much more I wanted to do for women with breast cancer.

One day I bumped into Lyn and she said I could help at BCNA if I wanted to. I told her I couldn't use a computer and would be no help. 'Yes you will,' she said, so once a week I come in and help out.

Not only do I enjoy that I can make a contribution, but it's such a harmonious place to be. I've learned an awful lot about breast cancer itself and also just being able to let people know about the work BCNA does for women with breast cancer. For me it underpins the idea that 'you are not alone'. It's a great reward to be part of an organisation that can do that for women.

Joan
Glen Iris, Vic

Ensuring my quality of life

I do not know at what age one is an 'older woman'. I was 73 when I was recently diagnosed with breast cancer. My doctor, a nice sympathetic lady, told me, 'We won't let you die.'

The surgeon, a pleasant young man, said, 'If you were my mother, I'd recommend we do this', so I went along with his suggestion.

I had a mastectomy, including removal of 12 lymph nodes. The staff at the hospital were efficient and caring and the breast cancer nurse is a great comfort.

I really faced no problems. I received plenty of information

from the BCNA website plus what I could gather elsewhere on the Internet.

The only bothers were the extra demands on my time and the disruption of going to medical appointments three times a week. I tried to make these visits an outing – do some sightseeing, have lunch (and a drink).

Before being diagnosed, I had wondered how I would cope if I ever found out I had cancer, but gradually I have discovered what is important to me. It is not to prolong my life, but to have quality of life for however much time destiny allows.

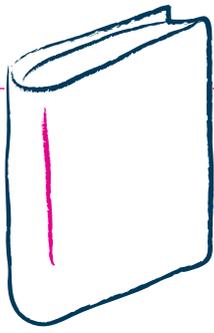


Mireille (right) with her daughter,
granddaughter and great-granddaughter.

I refuse to worry about the 'what ifs'. I don't let those thoughts spoil my daily life ... I just try to

enjoy it. For me, every day is a holiday!

Mireille
Kiama, NSW



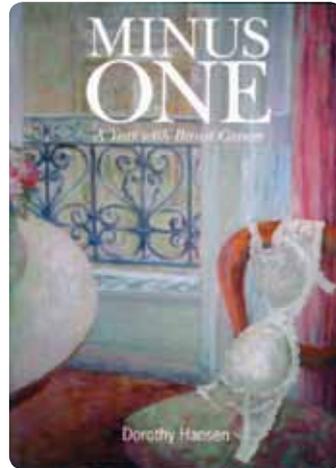
Review

Minus One: A Year with Breast Cancer

by Dorothy Hansen, Ginninderra Press, 2007 (paperback), 165 pages, RRP \$22.

The presentation of *Minus One: A Year with Breast Cancer* is appealing. The colours and artwork of the cover conjure up a lovely sense of calm and the bra draped over the chair provides a confronting element.

As a breast cancer survivor, a BCNA Community Liaison, and a Review and Survey Member, I am always keen to hear about the journey of others. Dorothy Hansen is extremely literate and well-read, and has a great passion for the arts. Her life as a wife and mother has seen her family travel extensively with her husband and children and, it can be said, they have a great



appreciation for the finer things in life. However, confronting cancer and indeed one's own mortality, often brings people back to the basic elements of life. Nature in general, the sound of birds and literally taking time to smell the roses is a positive side of this loathsome disease and Dorothy shares these moments beautifully.

I have heard many people reflect that they would like to write their own autobiography not just for their own benefit, but for the benefit of their family and future generations. In Dorothy's case she has been blessed with the skills to make this thought a reality as she has previously co-authored two biographies.

Dorothy generously shares her story, the wonderful times and the distressing family disharmony which causes her continuing grief. The love she has for her husband and family is abundant. Most people in a family situation face challenges and harmony issues at various times and Dorothy's life is no different to others in this respect. The book is easy reading, and in parts is like a travelogue. For those who have loved visiting galleries around the world they will feel a connection with

Dorothy's travels and passion for art, music and literature.

Dorothy refers to many articles she has read in newspapers concerning studies/surveys and articles of interest to cancer survivors, however, none of these have any scientific data to substantiate them. Most people who have gone through cancer treatment are looking for a bit of magic, definite causes and reasons for their fate. Dorothy is no exception.

I feel that people who enjoy a well written story/biography will enjoy Dorothy's book. I would not recommend it as a book for someone who is seeking practical advice on how to deal with life after a cancer diagnosis, however, it is a poetic, well-written account of one woman's story.

*Christine Mitchell
BCNA Review and
Survey Group Member*

New depression and breast cancer fact sheet

A new version of BCNA's *Depression and Breast Cancer* fact sheet, developed in conjunction with *beyondblue: the national depression initiative*, is now available.

It includes new information about the use of antidepressants and Tamoxifen.

The key messages are that the antidepressant paroxetine (marketed as Aropax) reduces the effectiveness of Tamoxifen and should be avoided by women taking Tamoxifen.

There is a possibility that some other antidepressants may, to a small degree, affect the metabolism of Tamoxifen. However, this has not been proven through research, and not all antidepressants are alike. If you are taking Tamoxifen and an antidepressant, you may like to discuss this with your GP or oncologist.

If you are considering starting, stopping or altering antidepressant medication, it's important that you speak with

your doctor before making any decisions.

Women taking aromatase inhibitors are not affected by this – antidepressants do not reduce the effectiveness of aromatase inhibitors.

To obtain a copy of the new fact sheet, phone BCNA on 1800 500 258 (Freecall), or download a copy from our website at www.bcna.or.au > News > Resources > Fact sheets.



Profiling our Member Groups

Mt Gambier Breast Cancer Support Group, SA

For more than 15 years the Mt Gambier Breast Cancer Support Group has been providing a place for women to come and support each other through their breast cancer journey.

'When I was diagnosed 15 years ago I was welcomed into the group and I've been coming here ever since,' says Chris Parish. 'I had great support when I was diagnosed but it was important to me to feel supported by the outside community too – support from those outside my usual networks of family and friends. I'm not as outgoing as I once was and the group is good for me to get out more and speak to different people.'

Breast Care Nurse Julie Campbell facilitates the group, which meets once a month at the Red Cross rooms in Mt Gambier.

'Julie is really wonderful,' says Chris. 'She sends us a letter in the post about a week before the meeting letting us know what is planned. She has usually organised a speaker but sometimes it's just a chance to catch up for a chat over coffee.'

Ann O'Shannessey, who has been coming to the group since she was diagnosed six years ago, says it's important to her that the group is a positive place to be. 'It's nice to meet people and have a talk, but for some it's daunting coming to a group. That is, until they realise that



The stunning results of an art project that the Mt Gambier Breast Cancer Support Group contributed to in 2010.

our group is very relaxed and positive.'

'We attract people from all walks of life and all ages ... with the one common experience of a breast cancer diagnosis. But that doesn't mean we talk about breast cancer all the time. Julie is dedicated to making the meetings different, which keeps things interesting. We've had all sorts of speakers. Some of the speaker topics have included make-up, lymphoedema, mindfulness, yoga, and even someone who came and shared her experience of walking the Kokoda trail. Last year Julie invited us to be part of an art project run by a local community artist. The result was some beautifully decorated mannequin torsos, which were displayed at our *Mini-Field of Women*, held after the Mt Gambier BCNA forum.

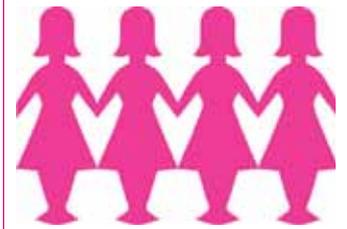
They are still displayed in the Mt Gambier Hospital.'

Some of the members are also involved with other groups in the community.

'I'm also a member of a social breast cancer group called the Booby Bunch who meet socially at a local cafe,' says Ann. 'I like being part of both groups as they give me different kinds of support.'

Both Chris and Ann agreed that what they valued most about being part of the Mt Gambier Breast Cancer Support Group was that it offered them an opportunity to be able to support others.

'We have new members all the time,' says Chris, 'and it helps to know that those of us who have been members of the support group for a while can offer encouragement to those new to this journey.'



Linking together

Over the past 11 years a key part of BCNA's mission has been to **link** Australians personally affected by breast cancer.

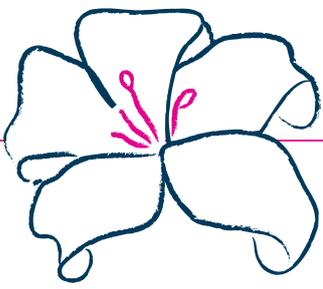
We welcome new Member Groups to our network. They now make a total of 285.

New Member Groups:

- Active Women in the Hills – Pennant Hills, NSW
- Blackwood Hills Breast Cancer Support Group – Blackwood, SA
- Bunbury Breast Cancer Support Group – Bunbury, WA
- Karratha Cancer Support Group – Karratha, WA
- Lithgow Breast Cancer Support Group – Lithgow, NSW
- Young Hope Cancer Support Group – Goulburn, NSW

BCNA also has more than 54,000 individual members across Australia.

Visit our website to find a Member Group, including support groups, in your state or territory at 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 especially like to acknowledge significant contributions recently received from:

- Acoustic Band Night, Sharon Mudge, VIC
- Billie-Jo Reynolds, QLD
- Bus Shopping Tour Geelong Touring Cyclists Group, Heather Christmas, VIC
- Daniel's Shave Off, Daniel McGregor, VIC
- Electrolux Home Products Pty Ltd, Wendy Harrison, NSW
- Greg Northcott, SA
- Katanning Country Club Golf Club, WA
- Kingswood Golf Club, VIC
- Lang Lang Community Centre, VIC
- Legg Mason & Co., LLC, Baltimore, MD, USA
- Lions Club of Victor Harbor & Port Elliot Inc, SA
- Longboard Ride, Nicholas Harris, VIC
- Margaret Browne, NSW
- Movie Fundraising Night, Sarah Verheyen, NSW
- Mt Gambier Breast Cancer Luncheon Group, SA



Congratulations to the Stunners in Runners, our top fundraising team in the 2010 Sussan Women's Fun Run.

- Pam Elliott, TAS
- Pink Breakfast, Leanne Sher, Janice Kirshon, Hyla Bergman and Hilary Herson, VIC
- Players for Pink, Ballarat Clarendon College, VIC
- Quilts in the Barn, Linda Collins, VIC
- RAWR
- Royal Motor Yacht Club, NSW
- Sophie Clarke, VIC
- Woodlands Golf Club Ladies Oaks Day Lunch, Jenny Hagan and Judy Alexander, VIC
- 2010 Sussan Women's Fun Run participants, fundraisers, organisers and supporters

- 2011 Alpine Classic Challenge, Michael Swards and Adam Begg, VIC

And, finally, special thanks to the Manildra Group for its significant support.



Michael and Adam at the finish of the 2011 Alpine Classic Challenge.

Memorials

We pay tribute to the lives of:

- Peter Kevin Blesing
- Bronwyn May Brooks-Wood
- Robert Victor Kindler
- Doris McGrath
- Shirley Paull
- Hazel Sparrow
- Maria Waters

Celebrations

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

- Lara Braithwaite
- Henry Kortt



In February, the 13th Breast Care Nurses conference was held in Melbourne.

Professor **Lesley Fallowfield** from the UK (holding the pink lady, with **Jill Hicks**, BCNA advocate and breast care nurses **Jo Lovelock** and **Rhonda Barnes**) was the keynote speaker and also presented an insightful session called 'The attitudes of healthcare

professionals to elderly women with breast cancer'.

BCNA staff also presented sessions on sexual wellbeing, heart monitoring of women treated with Herceptin, and BCNA's online network. The conference was a great success and an important opportunity for BCNA to catch up with nurses from across Australia.

Pink buns on parade ... soon!

Planning is well under way for the 2011 Pink Bun Campaign. This is a time to celebrate our fantastic relationship with Bakers Delight. During the campaign 100% of the price of each pink bun sold goes to BCNA.

The campaign will run from 28 April until 18 May in all 626 Bakers Delight bakeries around Australia.

The campaign is a great way to:

- raise funds to help us continue our work ensuring women and their families receive the best possible treatment, care and support
- raise awareness of the support that is available in local communities for women affected by breast cancer and their families

I was particularly honoured to have a young man doing his grocery shopping come up to me and introduce himself as a Bakers Delight employee, shake my hand and wish me all the best in my breast cancer journey. I'm already preparing for the 2011 campaign and spoke to some women at the local G.R.A.C.E support group about participating.

– Lyn, BCNA Vic

Join in the campaign's pink festivities by following these six steps:

- visit your local Bakers Delight bakery regularly during the campaign – find one near you by visiting www.bakersdelight.com.au > BakeryLocator

- satisfy your craving for pink buns
- ask all your friends to buy pink buns too
- write a message of support on a Pink Lady silhouette in the bakery
- vote for your local bakery in the 'best dressed awards' on www.pinkbun.org.au
- pop into the bakery at the end of the campaign and thank them.

This is a wonderful opportunity for you to be involved with your local community and Bakers Delight bakery, and help us to raise vital funds and spread the word about how BCNA supports women.

We'll be 'tickled pink' if you can support such an important event on the BCNA calendar.



Treat yourself, support BCNA

In celebration of its four-year partnership with BCNA, Sussan has designed and produced a series of funky bead bracelets.

These expandable bracelets come in a range of new season colours and each one in the range features a different charm. Wear a few of them together to make a statement, or coordinate them with other bracelets for the new must-have look.

Sussan has supported us in many ways through the years, from individual staff members giving their time to volunteer, to raising money and organising one of the most popular fun runs in Australia.

Sussan will donate to BCNA the profits from every bracelet to help us continue to provide our services free of charge to all Australians.

A perfect gift (even for yourself!) the bracelets are exclusive to Sussan and available in stores from April. They cost \$9.95 each.

We'd love you to visit your local Sussan store to buy a bracelet and while you are there please take the opportunity to say thanks to the Sussan staff, who are proud supporters of BCNA.



Margaret Carroll, BCNA Community Liaison, and the team from Bakers Delight's Diamond Creek bakery during the 2010 Pink Bun Campaign.



BCNA gratefully acknowledges our partnership with Bakers Delight.





Dates for your diary

24 March: Free BCNA Wagga Wagga Forum, Charles Sturt University. For more information or to register, visit www.bcna.org.au or 1800 500 258 (Freecall). Partners and carers welcome.

2 April: Free BCNA Sydney Forum, The University of Sydney. For more information or to register, visit www.bcna.org.au or 1800 500 258 (Freecall). Partners and carers welcome.

April: Free BCNA Sunshine Coast Forum. Register an expression of interest on 1800 500 258 (Freecall). Partners and carers welcome.

28 April – 18 May: Pink Bun campaign. Visit your local Bakers Delight store to show your support. For more information visit www.bcna.org.au.

5 May: BreaCan presents a free workshop on 'Advanced Breast Cancer and Bones', 10.30 am – 12 pm, Ground Floor, 210 Lonsdale Street, Melbourne. Dr Richard De Boer, medical oncologist, will speak about new treatments and highlight current thinking and preventative strategies. Registration is essential. For more information or bookings phone 1300 781 500.

8 May: Pink Footy/Netball Day Mother's Day Weekend. Local football and netball clubs will turn pink on the Mother's Day weekend to support BCNA. Clubs participating will be playing with a specially designed pink footy or netball. For more information and to find out if there is a game in your local area, visit www.pinkfootynetballday.org.au

14 May: Annual Bakers Delight Pink Lady Family Race Day at Kembla Grange Racecourse, Illawarra, NSW. For more information phone Mick Fuller, Bakers Delight, on 0419 299 348 or email him at mickandpatty@westnet.com.au.

15 May: The 20th *Sydney Morning Herald* Half Marathon presented by Colonial First State. BCNA is again the lead charity for this event. To register for the 21km race and raise funds for BCNA, visit <http://halfmarathon.smh.com.au>. Don't forget to wear a touch of pink on the day to show your support for BCNA.

June: Free BCNA Brisbane and Bundaberg Forums. Register an expression of interest on 1800 500 258 (Freecall). Partners and carers welcome.

1 July: Raelene Boyle's 60th birthday celebration. Crown Palladium Ballroom, Southbank, Melbourne. For more information visit www.bcna.org.au > Events.

16 July: Hunter Breast Cancer Education and Support Committee and BCNA Public Forum, Western Suburbs (Newcastle) Leagues Club. Register an expression of interest on 1800 500 258 (Freecall).

July: Free BCNA Cairns Forum. Register an expression of interest on 1800 500 258 (Freecall). Partners and carers welcome.

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

Seeking stories

We are seeking stories for the Spring 2011 issue of *The Beacon* about the **financial impact** of your diagnosis and treatment. Did cost influence your choice of treatment? How did you manage with the medical costs and

out-of-pocket expenses? Were you aware upfront of the likely costs? Did you experience loss of income? Were you offered any financial support services? Do you have any tips to share with other women?

Please email articles of 200–300 words (about half a page) to beacon@bcna.org.au by the end of June 2011.

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.

The Rural Health Education Foundation hosted *Moving Forward: Surviving Breast Cancer* on 22 February. It featured Professor **John Boyages**, director Westmead Breast Cancer Institute, and a panel of experts discussing health and wellbeing after treatment for breast cancer. To view the broadcast visit www.rhef.com.au.

Join our mailing list

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BCNA

293 Camberwell Road,
Camberwell, Victoria 3124
1800 500 258 (Freecall),
(03) 9805 2500
beacon@bcna.org.au or
www.bcna.org.au

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