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Focus on:

Breast cancer at any age

Breast cancer at any age

To echo the women who generously share their stories in this edition – there's never a good time to get breast cancer. Facing the challenges that breast cancer brings is never easy, no matter what age you are. Women of all ages face issues related to body image, relationship concerns and an uncertain future.

We also know that a woman's age often influences her breast cancer journey. For this issue of *The Beacon* we asked readers what it was like to be diagnosed at their age.

We know that younger women can face the challenge of being taken seriously at the diagnosis stage. A doctor may dismiss a young woman's concerns regarding breast changes or lumps because she does not represent the typical breast cancer patient.

It's worth noting that this is an experience shared by many men (of all ages). Like breast cancer in young women, male breast cancer is rare, so some doctors may not immediately suspect or investigate breast cancer in a man.

But how young is young? The breast cancer world generally refers to pre-menopausal women as 'young', as the treatment options can



Christine Nolan (third from right) at the 2017 GiveEasy Innovation Index awards, where BCNA was ranked in the top five.

be different according to menopausal status. This means that, once diagnosed, young women often face issues relating to early menopause.

How challenging it must be to have plans for motherhood thrown into chaos. How tough it must be for those who have to explain their diagnosis to young children. How difficult it must be without the financial fall back of a house or superannuation.

However, as the stories we share in this edition show, the challenges that may more often be linked to young women can be experienced by women of all ages. This can include being single and facing dating after a diagnosis, reviewing or changing careers, and changes to sexual wellbeing.

In Australia, the average age

of the first diagnosis of breast cancer in women is 61. This may be surprising to the general public, as many media stories cover the experiences of young women, such as Kylie Minogue.

Perhaps due to such media coverage, many people think that there has been an increase in the number of young women diagnosed with breast cancer. However, over the past few decades the rate in Australia has stayed relatively stable.

Apart from being female, the main factor that influences breast cancer risk is getting older. It's no surprise then that 78 per cent of new cases of breast cancer in women are diagnosed over the age of 50.

As readers of *The Beacon* will know, BCNA is celebrating 20 years in 2018.

One of the ways we will recognise our anniversary is with a new-look *Beacon*. We know how much this magazine has meant to its readers over the years, so we hope you will be pleased with the refreshed design.

Some of our members have been part of the network since its beginning in 1998, and others will remember when we celebrated our 10th and 15th anniversaries. We'd love to hear suggestions from any of our members and supporters about how we should mark 20 years of BCNA. Email your suggestions to beacon@bcna.org.au.

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Issue of Concern

The financial impact of breast cancer

If someone had said to me 'When you get cancer it costs money, it wouldn't have occurred to me what that meant until now.'

– Farrah

A diagnosis of breast cancer is a major trauma in your life. Fears and anxieties around treatment and health, both immediate and in the future ('Will I survive this?') are common and understandable. However, there is another element of trauma that is not often considered – the financial trauma of breast cancer.

Over our nearly 20 years, we have often heard from our members about the impact a breast cancer diagnosis and treatment has on their financial situation. Unlike some other cancers, active treatment for early breast cancer (surgery, chemotherapy and/or radiotherapy) can continue for 12 months and daily hormone therapy treatment may continue for up to 10 years beyond that. Some women find that the financial impact of breast cancer over such a long time puts a huge strain on both their budget and their relationships. Some women are pushed into poverty, forced to rely on government benefits, support from charities or emergency help from family, friends and community to get by.



Farrah

To learn more about how breast cancer impacts women's finances BCNA commissioned Deloitte Access Economics to conduct an online survey of our membership. Almost 2,000 women completed the survey, indicating how important this issue is to many of you. BCNA also interviewed 16 women extensively, to better understand the financial impacts of breast cancer on them.

The survey and interviews found that many women with breast cancer worry about their finances as much as they worry about their health. Some of the factors that contribute to financial worries include:

- using private health insurance and having to pay 'gap' fees
- having a breast reconstruction
- living in a rural or regional area

- paying for tests not covered by Medicare, such as MRI scans and Oncotype DX gene testing
- work-related issues such as needing to reduce work hours or stop working altogether during treatment.

Our survey found that most women pay some out-of-pocket costs, with only 12 per cent reporting no out-of-pocket costs for their breast cancer treatment and care. The out-of-pocket costs for the remaining 88 per cent of women typically ranged between \$1,500 and \$17,200, with women usually paying around \$4,800. Some women paid significantly more, into the tens of thousands of dollars. Having breast reconstruction in the private health system is usually associated with these very high costs.

We used our redraw facility from our mortgage because we had to pay \$24,000 for the plastic surgeon up front. We had to pay \$6,000 for the anaesthetist up front. We did get some of it back, but I think all up we're probably \$13,000 out of pocket just on the surgery. – Susan

Women with private health insurance pay over 10 times as much as women without private health insurance on their direct medical costs, typically around \$3,700 for women with private health cover compared to around \$350 for women

without private health cover. The amount spent on non-medical items, such as wigs, transport and post-mastectomy bras, was very similar for women who have private health cover and women who do not, at around \$3,300 for both groups. This tells us that the big difference in costs comes down to treatment in the private hospital system and paying large 'gap' payments for medical treatment.

Having radiotherapy in the private system is also associated with high out-of-pocket costs. Radiotherapy is not covered by private health funds as it is an outpatient procedure. Some women may not be aware that they have the option of having some of their treatment – such as surgery and chemotherapy – as a private patient in a private hospital and other treatments – such as radiotherapy – as a public patient. This can help keep costs down.

The survey looked at costs for the first two years after diagnosis, but we know that many women will have costs that continue for many years. These may include paying for ongoing lymphoedema treatment, hormone therapy drugs such as tamoxifen, letrozole and anastrozole, and counselling. BCNA will release the full report later this year and will continue to advocate to reduce the financial burden for Australians affected by breast cancer.

Ask the Expert:

What's new in breast cancer research

Dr Nicholas Zdenkowski is a medical oncologist and Clinical Research Fellow at the Calvary Mater Hospital Newcastle and Hunter New England Local Health District. The Beacon spoke with Nick about the latest breast cancer research presented at the American Society of Clinical Oncology (ASCO) Annual Meeting held in Chicago in June.



Dr Nicholas Zdenkowski

What are some of the standout findings from the research presented at ASCO?

One highly publicised result this year was from the OlympiAD study, a clinical trial comparing the drug olaparib (a PARP inhibitor) to standard chemotherapy for women with a BRCA gene mutation who have developed metastatic HER2-negative breast cancer. These women, who are in great need of new treatment options, lived on average three months longer without a worsening of their cancer, and they had better quality of life despite having had multiple prior chemotherapy treatments. Olaparib is available in Australia for women with advanced ovarian cancer and a BRCA gene mutation, but is not yet available for women with metastatic breast cancer.

The SOLE study, which included 370 Australian and New Zealand women, found that after five years of hormone therapy women with higher risk early breast cancer who had a three-month break from letrozole each

year had the same risk of a breast cancer recurrence as those who took letrozole continuously. Importantly, those who had a break had fewer side effects and it was safe to do so. This opens up a new treatment option for some women on extended hormone therapy.

For women with HER2-positive early breast cancer, the Short-HER study found that 12 months of trastuzumab (Herceptin) remains ideal, compared with nine weeks of treatment. Women who had the shorter nine-week treatment still did well, which is reassuring for those who need to stop early due to side effects or for other reasons.

What other research presented may be of interest to women in Australia?

One issue many young women grapple with after a diagnosis of breast cancer is whether pregnancy is safe. A study reported at ASCO showed that pre-menopausal women who became pregnant after a

diagnosis of early breast cancer did just as well as those who did not become pregnant, irrespective of the hormone receptor status of their cancer.

Fear of cancer recurrence impacts on the lives of many breast cancer survivors.

Australian researchers presented the results of a study showing that a psychological treatment program, called Conquer Fear, reduces the severity of fear of cancer recurrence compared with relaxation training. More work needs to be done to make this sort of program available to all who might benefit.

The MONARCH2 study showed that the CDK4/6 inhibitor abemaciclib is effective for women with metastatic hormone receptor positive breast cancer. The study is discussed in more detail on page 5. There are now three drugs in this class at advanced stages of development, including palbociclib and ribociclib. This introduces healthy competition in making these drugs available to Australians.

A randomised study found that yoga helped reduce cancer-related fatigue and improved sleep quality in a group of cancer patients, most of whom were breast cancer survivors. This is a practice that can be taken up immediately and that can also help with fitness, strength and flexibility. An Australian researcher presented encouraging findings suggesting that exercise starting six weeks

post surgery for early breast cancer may help prevent breast cancer recurrence and death. This is consistent with larger, observational studies showing that women who exercise have lower rates of breast cancer and overall mortality.

Who can women talk to about whether the findings are relevant to them?

You can discuss these findings with your cancer specialist, being mindful that new treatments need to be assessed and approved by regulatory and funding bodies such as the Therapeutic Goods Administration (TGA) before they are available to Australian patients.

How can women find out more about clinical trials that might be relevant to them?

Clinical trials are a very important part of improving outcomes for people diagnosed with breast cancer but, for one reason or another, many women are not able to participate in a trial. Ask your cancer specialist about trial opportunities, and look at websites such as clinicaltrials.gov, anzctr.org.au and clintrial.org.au.

Is there anything else you think would be valuable for women to know?

Improvements in breast cancer outcomes from individual studies might seem modest, apart from the occasional major breakthrough. However, over the last 30 years better detection and treatment have improved survival by a significant 30 per cent.

Your experiences making a powerful statement

Our State of the Nation project continues to gather momentum. Through this project we are identifying gaps in treatment and care for people with breast cancer right across the country. Thank you to all those who completed our Member Survey – more than 10,000 of you! These responses have given us a good understanding of the unmet needs we need to explore through consultations around the country.

We have now had more than 3,000 face-to-face meetings with our members and will have covered every state and territory by the end of September.

It will not surprise many of you that we are hearing about gaps in services and supports for those who have finished their active treatment (surgery, chemotherapy and/or radiotherapy).

This is a time when all the contact you have been having with your treating team suddenly ends and you, your family and friends may expect things to return to 'normal'. However, we know this is not the case for many people.

As we have travelled around the country, we have also been alerted to local issues. Some of these have been fixed with a simple conversation. Others have required the power of our collective voices, knowledge of the healthcare system and state lobbying to reach a good

outcome. One example is our ongoing efforts on behalf of the women of Far North Queensland, who told us they have been waiting more than seven years for a breast reconstruction. See our website, bcna.org.au, for more information.

Another important aspect of the State of the Nation project has been to acknowledge the services that have been providing good care for those affected by breast cancer – from local hairdressers to health professionals and large public hospitals. We want to let these services and people know they are doing a good job and thank them for their hard work.

Advocacy has always been the foundation of BCNA, and the State of the Nation project



State of the Nation consultation in Alice Springs

brings into sharp focus all that we have achieved over 20 years. However, it sadly highlights how much is still to be done.

The State of the Nation report will be released in early 2018. It will provide practical and workable solutions to ensure

that there is a better journey for you and those who follow you.

If you have an issue you would like to discuss with us, please email policy@bcna.org.au or call our Helpline on 1800 500 258.



Port Lincoln information forum and State of the Nation consultation

Latest research: CDK inhibitors

In recent issues of The Beacon and The Inside Story, we have provided you with information about a class of drugs called CDK inhibitors and the work BCNA has been doing to advocate for a subsidy for the CDK inhibitors palbociclib and ribociclib through the Pharmaceutical Benefits Scheme (PBS).

CDK inhibitors are oral treatments used to treat hormone receptor positive, HER2-negative metastatic breast cancer. The drugs work by blocking the function of enzymes involved in the pathway that helps control how cells grow and divide. The CDK4/6 pathway is commonly overactive in breast cancer cells, resulting in loss of control over cell growth.

The PALOMA-2 clinical trial tested the benefits of the CDK inhibitor palbociclib for women who had not previously received treatment for metastatic breast cancer. It showed that treatment with palbociclib in combination with the hormone therapy drug

letrozole improved progression-free survival (the length of time before the cancer grows or spreads) to 24.8 months compared to 14.5 months for women treated with letrozole only. The study also found that palbociclib was generally well tolerated and women experienced low rates of the side effects common to cancer treatments, such as nausea, diarrhoea and hair loss.

After learning my breast cancer had returned after eight years and had spread to my bones, I was offered a lifeline in the form of taking part in a clinical trial for palbociclib. Since taking the drugs last July, my initial symptoms of nausea, lack of appetite and fatigue have diminished to the point where they do not figure in my consciousness and I look and feel well. Regular monthly tests have returned positive results and have also revealed that my cancer markers continue to fall.
– Jane

Researchers are now also investigating the potential for palbociclib as a treatment option for early breast cancer in the PALLAS study, which is recruiting patients at some Australian institutions.

The MONALEESA-2 clinical trial, also for women who had received no previous treatment for metastatic breast cancer, showed that the CDK inhibitor ribociclib in combination with letrozole improved progression-free survival to 25.3 months compared to 16 months for people treated with letrozole and a placebo. Ribociclib was also found to be generally well tolerated.

At the American Society of Clinical Oncology (ASCO) Annual Meeting in June, findings from another clinical trial were presented that looked at the effectiveness of a third CDK inhibitor, abemaciclib. The MONARCH 2 clinical trial compared abemaciclib plus fulvestrant (Faslodex) to fulvestrant plus placebo in women whose cancer

had progressed on previous hormone therapy. The study found that treatment with abemaciclib in combination with fulvestrant resulted in 16.4 months of progression-free survival compared to 9.3 months for women who received fulvestrant only.

BCNA has been advocating to the Australian Government to have at least one of the CDK inhibitors added to the Pharmaceutical Benefits Scheme (PBS) so that these new treatments are available equally and affordably to all Australians who can benefit from them. We will keep you updated about developments through *The Beacon* and our website. You can also read our submissions to the Pharmaceutical Benefits Advisory Committee (PBAC) in support of listing palbociclib and ribociclib on the PBS on our website.

If you have metastatic breast cancer and would like to know more about accessing CDK inhibitors in Australia, read the article in the current issue of The Inside Story or visit our website.

October is Breast Cancer Awareness Month

October is Breast Cancer Awareness Month. It is an important time to come together and recognise the impact that breast cancer has on our families, friends, work colleagues and communities.

This October, BCNA will recognise the experiences of men diagnosed with breast

cancer as we launch Australia's first Male Breast Cancer Awareness Day on 20 October. This will be an opportunity for men affected by breast cancer and those around them to share their stories and experiences and raise awareness that men get breast cancer too. This day will coincide with male breast cancer

awareness days recognised in some states in the USA.

We will continue to acknowledge the experiences of women and men affected by metastatic breast cancer, with international Metastatic Breast Cancer Awareness Day taking place on 13 October. This day is an important way

of raising awareness of the particular needs and challenges experienced by people with metastatic breast cancer.

No matter where you are in your breast cancer journey, the month of October is a reminder that you are not alone and that there is a strong community of support behind you.

Expanding our reach

Speaking to you, our members, helps us to understand your experiences and identify gaps in information and support.

Following research and consultation with people diagnosed with breast cancer, their carers and health professionals, BCNA has developed a range of new information resources.

The new resources include information for:

- people with a disability or low English literacy
- people from Chinese-speaking backgrounds
- carers of people diagnosed with breast cancer.

Information for people with a disability or low English literacy

We know that people living with a disability can face a range of additional challenges when

diagnosed with breast cancer. People with disabilities and their supporters have told us that they need more inclusive information and support in a range of formats.

Our new resources for people with a disability or with low English literacy aim to empower and help them overcome the challenges they face in accessing breast cancer information and support.

The Easy English fact sheets and audio recordings are adapted from existing BCNA resources and focus on survivorship issues.

Our new videos aim to help reduce stigma, assist health professionals to understand some of the issues faced, and provide further information and support for carers.

Information in Chinese

Hearing unrealistic or unhelpful advice from friends and family

about what you should or shouldn't be eating after your breast cancer diagnosis can be frustrating or even distressing.

Without access to reliable information, it can be difficult to identify myths and misconceptions.

BCNA's new healthy eating resources provide culturally appropriate information on healthy eating after a breast cancer diagnosis for women who prefer to receive information in Chinese. Based on BCNA's existing *Healthy eating and breast cancer* booklet, the new resources include a booklet in Traditional Chinese and audio CDs in Cantonese and Mandarin.

Information for carers

Many people diagnosed with breast cancer will have a partner, family member or friend caring for them, both during and after treatment.

Caring can mean many things, from being a good listener, to doing housework, to attending medical appointments with the diagnosed person.

Many people who support someone with breast cancer don't see themselves as a carer, so don't know that there is help available.

BCNA's new video series for people caring for someone diagnosed with breast cancer shares the experiences of carers.

The videos provide information to help carers to support someone diagnosed with breast cancer, while also looking after themselves.

To view, download or order any of the new resources, visit bcna.org.au or call 1800 500 258.

Switching to generic medicines

You may have missed it, but in this year's budget the Australian Government announced plans to change the prescribing software used by doctors to write scripts so that the default script is for the active ingredient, or generic term, of a drug rather than the brand name.

The aim is to increase the use of generic drugs in Australia. Currently only 19.5 per cent of scripts written by GPs use the generic term, compared with 83 per cent in the UK. Increasing the use of generic drugs will

provide significant savings to the Pharmaceutical Benefits Scheme (PBS) budget. Minister for Health Greg Hunt has said that savings to the PBS would be reinvested in the health budget.

There are a number of commonly used breast cancer drugs that are available as generics, including hormone therapy drugs. This may mean your doctor talks to you about using a generic version of these drugs – for example 'tamoxifen' instead of 'Nolvadex', 'anastrozole' instead of 'Arimidex'

or 'letrozole' instead of 'Femara'. The doctor can still write a script for the brand name if preferred. If you are happy to use generic drugs, you may like to consider supporting the For Benefit Medicines (FBM) model.

FBM is Australia's first not-for-profit pharmaceutical company. It distributes 100 per cent of its profits to patient support and medical research in Australia, rather than to shareholders. FBM distributes two breast cancer drugs – Anastrozole FBM

and Letrozole FBM. Under an agreement between BCNA and FBM, 50 per cent of all profits from the sale of these two drugs is donated to BCNA. The remaining 50 per cent is donated to Breast Cancer Institute of Australia to fund research into breast cancer treatments and a cure.

If you are interested in supporting this model, you can talk to your doctor or pharmacist. More information is available at bcna.org.au.

Culture is healing

Aboriginal and Torres Strait Islander women diagnosed with breast cancer tell us that connecting to culture is an important part of healing and survivorship.

BCNA recently led two locally based cultural healing projects to allow Aboriginal and Torres Strait Islander people diagnosed with cancer to connect and support each other in culturally safe spaces.

In Victoria, prominent artist Vicki Couzens and Baraparapa Elder Aunty Esther led the making of a possum skin cloak. The cloak is now available to all Aboriginal and Torres Strait Islander patients



The completed possum skin cloak

undergoing cancer treatment at Peter MacCallum Cancer Centre.

The use of a possum skin cloak is of cultural significance to

communities throughout Victoria.

In Queensland, Stradbroke Island Aboriginal weaver Sonja

Carmichael facilitated a weaving workshop with Aboriginal and Torres Strait Islander breast cancer survivors. The final art installation will be framed and gifted to the oncology ward of the local hospital most frequently used by Aboriginal and Torres Strait Islander women.

Our online network now has a private group for Aboriginal and Torres Strait Islander peoples affected by breast cancer.

These projects are part of BCNA's ongoing commitment to better support Aboriginal and Torres Strait Islander women diagnosed with breast cancer.

Comfort at a time of chaos

In May 2013, at age 38, I was diagnosed with locally advanced breast cancer, which had spread to the lymph nodes.

The weeks to follow were surreal. I felt like life was carrying on around me, yet I was no longer a part of it. I was fortunate to be referred to a wonderful multidisciplinary team of doctors and other health professionals who (cautiously) gave me hope. I was told that as the tumour was large, surgery was not an option unless they could reduce the size. While this was terrifying, the general attitude of the doctors was one of optimism.

One of the best things they did for me was to encourage me to think positively. I underwent six months of chemotherapy, followed by a mastectomy with full axillary clearance, radiation and Herceptin therapy.

I was lucky to be surrounded by a wonderful community who rallied behind me and my family (at the time my children were 6 and 3). There was a meal roster set up, the teachers at my son's school made his lunches while I was having treatment, I had friends come to chemo sessions with me and someone even offered to clean my house for me!

The support of my friends, family and general community was such an enormous comfort.

It has been two and a half years since my treatment finished and I feel so grateful to be in remission.

There are times that I am anxious about recurrence, but for the best part I do my best to remember how fortunate I am and focus on getting back into life.

Lisa, NSW



Lisa with her mum and son

Would anyone be attracted to me again?

Twenty-nine. Single. No kids. Certainly not the stage of my life where I ever expected to be diagnosed with any kind of serious illness, and especially not breast cancer, which I naively viewed as an 'older lady' disease. One of the many struggles I faced as a young, single woman was wondering how on earth I would tackle dating post treatment. The additional challenge of knowing when to mention my breast cancer diagnosis and all that comes with it was overwhelming. Would anyone be attracted to someone who has lost a breast? I might never have kids; would my future partner be okay with that? Something that I tried to continually do through my treatment was to not think too

much about the things I couldn't control. It helped to keep me positive and allowed me to focus on the things I needed to.

Someone else's thoughts and opinions of me are one of those things I have no control over. If I am true to myself, and share what I feel comfortable sharing, when I feel comfortable sharing it, the result won't matter.

I'm so grateful to my friends and family, and especially my brother for putting this in perspective for me. He told me, 'Boobs are not the most important things to guys. If someone has an issue with the stuff you've been through, then that says a lot about their character doesn't it?'

A diagnosis like this, at any age, certainly puts life in perspective,

and helps you to realise that worrying about little things is a waste of your time. Be grateful

for what you have, stay positive and spread that joy wherever you go.

Katrina, NSW



Katrina

Lessons I learnt for my second time around

I was first diagnosed with ER+ breast cancer in 2009 at age 50 – a devastating diagnosis for an active, healthy, divorced mother of two.

I had one daughter completing her HSC and another at uni. I was determined to maintain a brave face throughout my surgery and treatment. I put my wig and makeup on, drove myself to chemo and radiotherapy and kept up with all my social engagements.

I then returned to work in a wig when it was all over. Many people didn't even know I was having treatment or had been sick. Others just thought I was coping extremely well.

The hardest thing for me was getting out of bed in the morning and driving my daughter to school. Often I would just put on a turban and a sloppy joe over my pyjamas and hope I would not have an accident or a breakdown on the way.

The saddest part was then climbing back into bed and having no one to make me a cup of tea and toast. I would often cry myself to sleep at night wishing I had a partner to cuddle into and tell me it was going to be all right.

The second time I was diagnosed was in 2011. It was triple negative breast cancer. My

daughters were both adults now, so I decided that I would not only accept all offers of help, but I would also share my tears and fears. I wasn't afraid to show off my bald head either, and I gratefully accepted meals and lifts to chemotherapy.

I joined different support groups and I contributed to BCNA's online network.

My newly reconstructed breasts are still there for the world to see! I celebrate every October, as that's the month my final treatment ended.



Diane

Diane, NSW

Listening to my own advice



Karen

I was diagnosed at the end of January 2017, not many months after I had turned 48 years old. There is no 'good time' to get cancer, but this just felt like it must be some sort of mistake.

I already had a lot going on in my life – working two jobs, which I knew were ending in May, doing PhD research with lymphoma cancer survivors, and being a single mother to two teenagers.

I did not have time for cancer and I definitely couldn't afford to have cancer financially,

emotionally or physically. Thinking I had a secure job and wanting to reduce some travel time to work and school, we had recently moved, and that meant a huge mortgage.

I was realising a dream to get my PhD in something I am passionate about – cancer survivorship – but I wasn't letting it take all my time. My children still depended on a fully functioning mother. Life was challenging, but it had felt manageable (most days).

I have been a cancer nurse my whole career, so I know age is no barrier, but suddenly I felt I was too young – I hadn't had

a chance to do all the things I wanted to do. I felt too old to contemplate trying to get through all the treatments and start living a 'new normal'.

I am always telling people that cancer does change you, and life after treatment will be different. So now I have to start living the suggestions I make to my patients: take it easy on yourself and don't feel guilty for putting yourself first. Acknowledge side effects like fatigue and cognitive impairment are ongoing. And regardless of your age, hope for a long and fulfilled future.

Karen, WA

Making the right decisions for me

In February 2015, at the age of 80, I was diagnosed with a small (stage 1) early breast cancer. I had surgery in March 2015 and then had radiotherapy.

My breast cancer was hormone positive so I was prescribed Arimidex tablets and told to take one daily. Unfortunately, this tablet did not agree with me – I was having chest pains and was told to stop straight away.

My husband of 62 years was now in shock more than I. He took me for a six-week holiday overseas to Malta.

I saw a lot of my school friends over there. A few of them had breast cancer and were taking tamoxifen with no side effects. When I returned from my trip, I went to see my oncologist and I mentioned tamoxifen and was put on that.

This tablet also did not agree with me. This time I ended up at the Royal Melbourne Hospital with blood clots in my left foot, and I was told it was coming from the tamoxifen. I mentioned it to my oncologist and was put on the last tablet that he could prescribe, which was Femara.

This Femara tablet, which I persisted with for a few months, was making me depressed. My hair was getting thinner, I had pain and sometimes I felt vibrations in my body. I was feeling miserable.

I did not have much support and I still had to look after my 86-year-old husband. I started gambling and attended a lot of bingo sessions.

It was suggested to me that at my age, I should think about my quality of life.



Margaret

In June 2016, I decided to stop taking any medication. My quality of life improved dramatically.

I consider myself a young 82 and started enjoying the things I love doing again – sewing,

crocheting, reading, etc. I am still driving and try to carry on as though the cancer did not occur. I encourage others at the club I attend to see the bright side and enjoy each day as it comes.

Margaret, VIC

Small acts of kindness kept us afloat

In 2010, I was feeling tired. That was hardly surprising, as that year I clocked up some serious miles.

I was juggling a teenager in college, a teenager in high school, a primary schooler and a pre-schooler. I was working part-time and there was the normal round of sports, play dates, school commitments and appointments.

I was used to being busy and I would head into military mode to make the days work. I was counting down the days until 2011, but all was good because I knew exactly why I was tired.

With a simple visit to the GP to check my vitamin D levels, my world tilted on its axis.

Over the following Christmas holidays, I turned 41, we moved



Cate

house, celebrated Christmas and two birthdays, and I had a mastectomy.

The kids started back for the new school year and I dragged myself to the classroom and gingerly hugged my youngest as he started kindergarten, hiding the drainage bag in my oversized handbag.

Then, I went home and started preparing for a few months of chemo. Cancer changed the world as we knew it. I missed my daughter's first swimming carnival, didn't do reading in the kindy class like I had for the others, skipped parent-teacher interviews, much to the delight of my older boys, and just managed to stop my daughter from taking my prosthesis in for show and tell.

The freezer was always overflowing, as were the biscuit and cake tins. In fact, my kids probably never ate so well.

Just as much difference was made by the people who happily dropped the kids home after school so my husband wasn't constantly rushing home from

work. Friends took me out for walks and movies and wanted to chat honestly about cancer and shared what was happening in the real world. People who helped out with getting kids to sports and training so some routine could be maintained. Play dates and sleepovers all still happened so their worlds weren't all about my cancer.

People always wanted to do more, never realising that it was the combination of small actions of our community that kept us afloat.

It was this that stopped us from imploding. It gave us the foundation from which we could rebuild our family life.

Cate, ACT

The isolation of youth

'You have breast cancer.' The words you never want to hear, at any age. I was only 27. Sitting next to my boyfriend, I was terrified. Life just stopped. At that moment I knew I didn't want it to beat me and vowed to fight whatever was thrown at me.

I felt guilty when I broke the news to my mum, dad and grandma. I saw their hearts break and their tears, and knew it was my fault. My mum gave up work to come and stay with me during treatment because I lived alone and couldn't look after myself.

It was so isolating being diagnosed at such a young age. My friends' lives all carried on around me. While they worried

about bad hair days and the latest trend, I fought to keep my hair with an ice cap during chemotherapy and dealt with weight gain and menopausal side effects.

My friends just didn't understand how I felt. I found myself putting on a smile or a brave face for visitors because if I cried they couldn't handle it. I had to be strong to help them get through it.

Everyone in the treatment room was so much older, and I longed for support, but just got sympathetic nods and smiles. I was so grateful for all the care and attention from the medical teams.

That was five years ago. I lost some friends along the way,

but made some incredible new friends for life. They supported me through the darkest of days and laughed at all the odd things cancer throws your way.

Life changed forever. I am a better person for going through the battle. I am stronger and appreciate the smaller things in life. I smile, listen to the waves and notice life around me.

I am now married to my gorgeous husband, we immigrated to Australia and set up a new life. Earlier this year I jumped out of a plane to raise \$2,194 for Brave for BCNA.

I don't know what the future



Rebecca at Brave for BCNA

holds, but I live for today. I am happy and healthy and I am here.

Rebecca, VIC

How to tell my six children

'Your mommy has cancer.' When I was 45 years old, these were words I had to tell my six children, who ranged in age from 5 to 18. They were words I was still struggling to comprehend myself, and once I spoke them aloud our entire family was plunged into this seemingly irreversible world of cancer.

Being diagnosed at any age is difficult and poses its own unique challenges. For me, driving the kids to soccer practice or music lessons, or even getting a meal on the table or the house cleaned were, some days, simply unachievable. I was so blessed to have the support



Helena and her husband Andrew

of my family and church community, who time and again came to the rescue.

Finding ways of explaining cancer to my children that accounted for their different ages and characters was difficult and took considerable thought. For my three young boys, I used the example of having 'bad Lego

blocks' in my body that the doctor had to take out.

Later, I described chemotherapy to them as destroying any remaining nasty Lego blocks that my doctor couldn't remove.

My oldest son needed reassurance that only some cases of breast cancer were terminal. Being a cricket fan, he could only think of Jane McGrath, and that was hard for him.

One of my daughters, who is interested in medicine, wanted to know specific details, while my other daughter desperately needed reassurance that her world as she knew it would not change.

But our family did change. Looking back, the three and a half years that contained operations, surgeries, a recurrence and chemotherapy/radiation treatments refined and redefined who we were.

Yes, it was hard, even painful at times, especially when watching your children struggling because of a disease that you have and seeing your husband having to do so many things you usually did. But God used cancer to strengthen our family's bond and gave us a deep appreciation for what we meant to each other and how precious each day together was.

Helena, WA

I don't have time for breast cancer

We ponder the 'Why me?' no matter how old we are. Cancer is crap!

My story started when I turned 40, I found a lump in my breast. I had a mammogram and there was no concern. Phew!

Then nine months later I discovered that the same lump had grown and there was also a lump in my armpit. I had a mammogram and ultrasound again. Nothing of concern showed up, but to just double-check, the doctor suggested to catch up with a surgeon.

My cancer didn't show up on the mammograms and ultrasounds, but we could feel it. By the time I had a MRI the cancer was about 6 cm long and I had two lumps in lymph nodes – my cancer was sneaky.

I didn't have time for this. My youngest son had just started school, I had just gone back to study and was thinking about me again and it was so nice. I didn't have time for it.

Now, a year and four months after my diagnosis, I am a stronger person in so many ways. I am proud of the person I have become and how I dealt with my roller-coaster cancer journey.

I only focused on the positive. Chemotherapy treatment days were changed to 'treat' days and 28 new tubes of watercolour paint followed my 28 days of radiation. Too exciting!

Every night before I went to bed I would think about something exciting I was going to do the next day. Most of the time it was simple things like painting

a picture, but it allowed me to think of the good and most importantly to sleep with happy thoughts, rather than dwelling over what was really happening in my and our family's life.

Going through such a significant life change, you really filter out what and who are not important in your life. I now only surround myself with people that make me feel good. I only do what makes me happy, and the simplest things in life are of greater importance.

I really have reflected on myself, who

I am and what I want to do. And I have learnt to be kinder to myself; as we don't have to do everything yesterday as thankfully there is always tomorrow.

Katie, VIC



Katie with her sons Ben, Jack and Max

Two breast cancers, 19 years apart

I was 39 when diagnosed with breast cancer in December 1997. My youngest child was 8 years old. I remember standing at his bedroom door watching him sleep, thinking about my diagnosis and crying at the thought of what was going to happen to me and to my family. My husband and I had four children and had just signed a contract to build a new family home.

As my cancer was all through the milk ducts, a mastectomy was the only choice. This was followed by taking tamoxifen for five years. At 39 to have a breast removed was devastating for me. Reconstruction wasn't an option at that stage, as I just wasn't ready for it and wanted to make sure that the cancer wasn't going to come back in my right breast. My husband was beyond amazing and incredibly supportive, and I had an extended network of family and friends who gave me such positive support.

Thirteen years passed and finally I had the courage to undergo

reconstructive surgery using a muscle from my abdomen and my own tissue. The operation was successful and the results were amazing. I was extremely happy to be 'whole' again.

In November 2016, I went for a routine check-up. Every year for the previous 19 years I had been going for routine check-ups and every time I became nervous regarding the results. However, this time I was working and had appointments to attend in the afternoon. I was hoping that they were not running behind. It didn't enter my head that there could be a problem.

They called me in and I had the

mammogram. Then I was called back into the room for a second mammogram. Something was seriously wrong – I could see the X-ray up on the screen and it wasn't good. I was then taken in for an ultrasound and was told that I needed a biopsy there and then.

The news was devastating – I had invasive early breast cancer in my right breast. I was numb. I left the doctor's rooms in total shock. How was I going to tell my husband and my family? How could I protect them from this news?

I had a mastectomy of my right breast. They found that the

cancer had spread to the nodes under my arm. I was taken in for a second round of surgery to remove further nodes.

I am currently having six months of chemotherapy treatment and will have radiotherapy once the chemotherapy is over. As my cancer has tested positive for hormones, I will also be taking tamoxifen or something similar for at least five years after all my other treatment is over.

My husband and family continue to be as supportive as ever, and I will be forever grateful to them for the love and support that they have given to me throughout this time in my life.

Family is everything to me and I intend to be there to watch my grandchildren grow up. I also have been very fortunate to have a caring and compassionate employer who has allowed me to take this time out to receive treatment. My job will be there when I wish to return, but for now I will take time out to recover. It's the mental battle that is the hardest.

Elaine, SA



Elaine and her husband Jeff

Thank you David

In the last issue of The Beacon we included a story from David in Queensland, who shared his perspective of his wife's diagnosis. We received a number of calls and emails in response to his story, including this email from Donna.

Please pass my thanks to David for his empathetic partner's story. Such a realistic letter has

helped me to know I'm not the only person out there trying to explain joint pain to my partner. My partner is truly caring and we try to pace our walks and holidays to fit around my changed physical state due (I'm sure) to the follow-up medication. I fully encourage my partner to continue with his

own longer walks and bike rides. Pacing is the key to our walks and excursions together.

We mix walking round the city with train rides instead of walking the whole way. Not overdoing it leaves me with less inflammation and more to give on the next day.

I also appreciate the frank comments about sex. Even nearing 70, sex is still an important part of a loving relationship. I find many

researchers and writers in breast cancer literature try to brush over the problem with platitudes.

Yes, we are grateful to still be alive, but strongly support research into ways of offsetting the side effects of follow-up medication and also finding new medications that preserve our sexual function.

I will show my partner David's helpful letter.

Donna, NSW



Checking in with our Member Groups

This year BCNA is embarking on a review of our wonderful Member Group program. The motivation behind this is to 'check in' with as many of the almost 300 groups operating across Australia as possible to see how each is travelling.

During these consultations with the primary and secondary contacts, it is our aim to learn about the group, hear what BCNA is doing well and what we need to improve on. We will also discuss training, look at group numbers and the general ages of group members, and learn about the individual focus of each group and anything else that comes up.

As many of you would know, Member Groups can take on many roles, including:

- social support through regular informal gatherings
- providing educational opportunities involving health professionals such as breast care nurses or specialists
- providing practical support and opportunities for members to take part in a variety of activities
- informing group members of BCNA's free resources and services via regular emails and newsletters.

At BCNA, we see Member Groups as a critical and very necessary

part of supporting Australians diagnosed with breast cancer.

As an organisation, we need to make sure we are equipping all current and future Member Groups with the right information and support, particularly as we progress forward with a greater digital focus.

If you are the primary contact for your group, would like to participate and you have not already been contacted, please email communityprograms@bcna.org.au with your best contact details.

Thank you in advance for helping us improve this important area of our organisation.



Connecting people

A key part of BCNA's mission is to connect Australians personally affected by breast cancer.

We welcome new Member Groups to our network. They now total 288.

To find a support group in your state or territory, visit bcna.org.au.

If you can't find a face-to-face support group in your area, consider joining our online network. Connect with hundreds of others talking about:

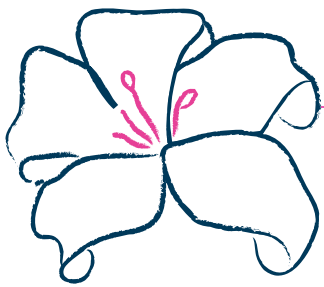
- what it's like to be newly diagnosed
- undergoing treatment
- breast reconstruction options
- living with metastatic breast cancer
- getting active and well again.

The online network now has an Aboriginal and Torres Strait Islander peoples group. You will need to be a member of the online network and request to join the group.

For more information, visit bcna.org.au, or phone 1800 500 258.



Wagga Wagga Breast Cancer Group in 2012



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:

- AAA Security
- Australasian Hellenic Educational Progressive Association (AHEPA) Daughters of Penelope, NSW
- Corryong IGA – Robyn McGowan, VIC
- Elwood Primary School – Amanda Booth, VIC
- Flo Espresso – Tony Hager, WA
- Jeanette Murray, QLD
- Jennifer Ebbage, VIC
- Karen Whittock and Deborah Walsh, WA
- Mister Minit – Sandra Flocas, VIC
- Moo Gourmet Burgers, NSW

- National Council of Jewish Women of Australia – NSW
- Redlands Modern Country Music Club – Wendy King, QLD
- Sons of the Southern Cross social motorcycle club – Duane Monckton, VIC
- Teresa Hooper, QLD
- Tschirn's Mechanical – Janice Tschirn, SA
- Veljohn Pty Ltd, NSW

BCNA Great Aussie Outback Trek team

- Adele McDonough
- Anne Hall
- Ann-Marie Pistikakis
- Bronwyn Pressland
- Claire Norman
- Deb Wilson
- Debbie Carey
- Donna Kelly
- Donna Noye

- Donna Pampa
- Emily-Kate Garvey
- Fiona Thompson
- Gina Highet
- Glenda Woodall
- Heidi Jones
- Jane Andrews
- Jane Garvey
- Jane Pool
- Janine Mercer
- Joanna Reaby
- Julie Carter
- Kate McLoughlin
- Kate Pollock
- Leanne Elliss
- Lisa Considine
- Lisa Griffiths
- Lynda Pollock
- Lyndell Farmer-Smith
- Meg Cox
- Rebecca Venton
- Resh Padilla
- Susan Fraser

- Suzanne Conder
- Vicki Spanring

Celebrations

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

- Ildi Tyler, VIC
- John and Judy Wills, VIC
- Lila Wenzel, QLD
- Lucia Araujo, VIC

Memorials

We pay tribute to the lives of:

- Agnes Atkins, NSW
- Despina Argyropoulos, VIC
- Dorothy McKenzie, QLD
- Jean Chamberlain, VIC
- Leesa Christensen, QLD
- Suzanne Hopgood, VIC

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

PINK UP FOR Breast Cancer Awareness Month THIS OCTOBER



Pink Lady Pin

\$5

Pink Lady Survivor's Pin

\$15

Special price for Breast Cancer Awareness Month
RRP \$20



A symbol of survival

BCNA's Pink Lady first came to life at the inaugural Field of Women in 1998, when 10,000 Pink Lady silhouettes were planted outside Parliament House. A vibrant hot pink was chosen to reflect the strength of women. Since then she has come to represent BCNA.

While many breast cancer organisations are represented by a pink ribbon, our Pink Lady is symbolic of our focus on the people affected by breast cancer, not just the disease.

After creating the first Pink Lady pin in 1999, we were inundated with requests. Many breast cancer survivors told us how they wore their pins with pride. Since then, many others have wanted to wear the Pink Lady pin to show their support for BCNA and people diagnosed with breast cancer.

To mark our 10th anniversary, in 2008 we produced a sparkling Survivor's Pin, designed especially for breast cancer survivors.

For more items visit bcnashop.org.au or call 1300 020 650

DINE *Pink*

this October

We were delighted when Brisbane's South Bank precinct got behind our Dine Pink campaign in October last year. The week-long event involved more than 20 restaurants, with pink tables and specially themed menus.

In 2017, Dine Pink is back and bigger than ever.

We're asking restaurants, cafés and bars nationwide to show their support for their patrons affected by breast cancer by joining our Dine Pink campaign.

Venues can have a dedicated Dine Pink table, create a special Dine Pink dish or drink, or host a Dine Pink night.

The Dine Pink campaign was inspired by one of our wonderful Community Liaisons, Donna Falconer. Donna asked restaurants in her home town Dubbo to show their support for her and others in their community affected by breast cancer by having a dedicated Pink Lady table, with proceeds donated to BCNA.

You can support the campaign by dining at a participating restaurant this October.

To find a participating venue near you, visit dinepink.com.au.

New from Berlei

We are delighted to announce that Berlei has just released a new bra for women who have had breast cancer surgery.

The Post Surgery Deluxe Bra was developed with input from members of BCNA's Review & Survey Group. It aims to give women a fashionable and flattering option to wear following a mastectomy.

The bra features softly lined reinforced straps for comfort and additional support, and cotton-lined cups that are breathable and soft against the skin.

Its cotton stretch inner pockets accommodate a prosthesis and its double-layered back gore and padded hook and eye minimise discomfort.

Berlei is committed to supporting women diagnosed with breast cancer with pioneering products, and ongoing research and development into new fabrics and technologies.

The bra costs \$64.95. It is available at David Jones, independent retailers and berlei.com.au. Breast form inserts are sold separately.



The new Post Surgery Deluxe Bra



Margaret Blee

A lasting legacy

We would like to acknowledge one of our members, Margaret Blee, who nominated BCNA as a beneficiary of her estate.

Margaret grew up in the inner-southern suburbs of Adelaide. She entered the South Australian Police force in a secretarial role and later became one of the first uniformed female police officers in South Australia.

Margaret was awarded a

Certificate of Commendation for outstanding commitment and performance in an investigation and trial relating to a double homicide.

In her retirement, Margaret took great pride in maintaining her home and garden, and doted on her dogs. She was diagnosed with breast cancer in 2015.

Margaret is remembered by friends as a very private and

independent person, yet loyal and generous of spirit.

We are very grateful to Margaret for her gift. Her generosity will help ensure our work can continue into the future.

If you are considering leaving a gift to BCNA in your will, or would like more information, phone Abby Cormack on (03) 9805 2580 or email acormack@bcna.org.au.

Breaking a Pink Bun record

We are very pleased to announce that the 2017 Pink Bun campaign has raised more than \$1.8 million. Thank you to Bakers Delight and all BCNA members who contributed to the record-breaking campaign.



In May, Pink Buns made their way to Parliament House. Minister for Health Greg Hunt MP, Minister for Foreign Affairs Julie Bishop MP, Prime Minister Malcolm Turnbull MP and Minister for the Environment and Energy Josh Frydenberg MP joined BCNA's Rozalee Erceg (second from left), Megan James (second from right) and Community Liaison Lan Crowley (centre) to show their support for the Pink Bun campaign. We used this opportunity to raise with the ministers key issues facing Australians diagnosed with breast cancer.

Introducing a breakthrough in bread

Bakers Delight's brand new wholegrain low-FODMAP loaf is certified as low in FODMAPs. Made using a delicious mix of grains and seeds including oat bran, sesame seeds, poppy seeds, linseed and kibbled sorghum, the new loaf is packed with goodness. This deliciously fluffy healthy bread is also high in protein, which supports healthy bones, tissue repair and building muscle mass.* If you suffer from bread sensitivities, you don't need to miss out on bread anymore. ^ Try the new Lo-Fo Loaf at your local Bakers Delight bakery.

* Health claim is in the context of a balanced diet. ^ This product is not suitable for those with coeliac disease.

Seeking stories – the network turns 20

For the Autumn 2018 issue of *The Beacon*, we want to hear about the impact BCNA has had over the past 20 years.

What does the network mean to you?

What does the Pink Lady mean to you?

Stories should be about half a page long (200–300 words) and can be posted to BCNA, 293 Camberwell Rd, Camberwell

VIC 3124 or emailed to beacon@bcna.org.au by the end of November 2017.

Please also include a high-resolution photo.

BCNA Partners

Foundation Partner



Major Partners



Join our mailing list

Would you like to be on the mailing list for *The Beacon* or *The Inside Story* (a supplement for people with metastatic breast cancer)? To subscribe, telephone 1800 500 258, email beacon@bcna.org.au or visit bcna.org.au.



the BEACON

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Layout: SUBStitution



The printing of *The Beacon* is kindly supported by Reflex and Australian Paper.



Printed on Australian-made REVIVE 100% recycled paper

