Getting off the couch

Getting off the couch is harder than it sounds. We all want to be healthier, and know we will feel better if we are active and eat a healthy diet. However, doing this while undergoing or recovering from the physical and emotional challenges of breast cancer treatment can be really hard. For many it is the last thing you feel like finding time to do. Yet as our stories this issue show, it can be the best thing you can do. Exercise is so good for you, whatever your age and whatever your size, and some exercise is always better than none!

Providing information is a fundamental part of what BCNA does. So I am really pleased that we have just translated our new easy English booklets into five languages – Italian, Greek, Chinese, Vietnamese and Arabic. These represent the five communities we identified have the greatest need for information about breast cancer in their own language. Next year, we will have a new website that will also have information in these five languages in audio format. Our staff will work with the relevant communities now to offer support and ensure our resources reach women in these communities.

During Breast Cancer Awareness Month many of you will have seen the promotion of Secondary Breast Cancer Awareness Day on 13 October. It is really important that we understand the challenges of living with an incurable disease. As part of our awareness campaign, we released the findings from our recent survey about the needs of women with secondary breast cancer. One of the key findings of the survey was financial difficulty from out-of-pocket cost and loss of income. Our next steps are to explore these costs and to work with relevant bodies to address these issues.

Finally, this is my last contribution to The Beacon as CEO. I am sad to be leaving BCNA, as I have greatly enjoyed my three years in the role. The good news is I am very well and looking forward to pursuing some of my other interests. The organisation is in great shape and it continues to go from strength to strength with a team of wonderful staff and volunteers. The heart of BCNA remains you – our members and supporters – and all Australians affected by breast cancer who we aim to assist. As The Beacon goes to print the Board is well underway in recruiting a new CEO to steer this great organisation into the future.

I will always be a Pink Lady!

Maxine Morand
Chief Executive Officer

Kerrie Skene, Lyn Swinburne, Maxine Morand, Rebecca Herman and Donna Rullo
at BCNA’s Pink Lady luncheon in Melbourne in October
Many women diagnosed with breast cancer experience fatigue at some point after their diagnosis. Fatigue is often described as extreme tiredness, lack of energy or physical and mental exhaustion.

We know that fatigue can be distressing and frustrating, making it hard to do day-to-day tasks, participate in work and other activities, and feel up to socialising with family and friends. Some women may feel fatigued for several weeks or months, while others can experience fatigue for a year or more, even after their treatment for breast cancer has ended.

Research suggests that cancer-related fatigue is not always lessened by sleep or rest. However, if you are experiencing fatigue, there are a number of things you can try that may help to manage it.

What causes fatigue?

Fatigue can be a side effect of the cancer itself, and of breast cancer treatments including chemotherapy, radiotherapy, hormone therapy (e.g. tamoxifen or the aromatase inhibitors) and targeted therapy (e.g. Herceptin).

Medications used with breast cancer treatments to help manage pain and nausea can also cause fatigue.

Anemia, or low levels of red blood cells, can also cause fatigue. Some breast cancer treatments reduce red blood cells in the body, leading to anaemia.

What can help reduce fatigue?

If you are experiencing ongoing fatigue, you may like to speak to your medical oncologist, GP or another member of your treating team to address underlying health issues, such as anaemia, and for advice about managing fatigue.

There are a number of things you might also like to try.

Research has shown that doing some daily physical activity can help reduce fatigue. BCNA's booklet *Exercise and breast cancer* includes information about the recommended amount of exercise, and tips to help you exercise when feeling fatigued. If you haven’t exercised much before, you may like to start slowly, perhaps with a 10-minute walk around your neighbourhood at the time of day when you feel the least tired.

Eating a healthy, balanced diet that includes a variety of foods, as well as drinking enough water, can also help manage fatigue. BCNA's new booklet *Healthy eating and breast cancer* provides tips for eating well during and after treatment, as well as information about how to eat well when fatigued. For instance, it can help to sit down when preparing meals, cook at a time you feel the most energetic, use pre-prepared ingredients, and keep some pre-cooked meals in your freezer for when you don’t feel up to cooking.

You may also like to organise to have some practical help around the house, such as help with housework, cooking or caring for children.

Giving yourself time to rest during the day and allowing your body time to recover can also be helpful. Try to limit daytime naps so that you are still able to sleep at night.

Some women also find relaxation techniques and activities such as meditation or yoga helpful. Other women have found it useful to talk about their feelings with a support group, counsellor or psychologist.

To order any of BCNA’s booklets or to find a support group, visit www.bcna.org.au or phone us on 1800 500 258.

I notice that a walk really makes me feel better in the week after my chemotherapy. I was surprised at how it not only lifted my mood . . . but I physically felt better and lighter in spirit.

– Sarah
Ask the Expert: anxiety and depression

Professor Jane Turner

Jane Turner is Associate Professor in Psychiatry at the University of Queensland and has been caring for people with cancer for 25 years. Jane spoke with The Beacon about anxiety and depression, which affect up to half of women diagnosed with breast cancer.

Are women with breast cancer at risk of anxiety and/or depression?
Many women juggle multiple roles and responsibilities throughout their life. When the challenge of breast cancer is added to that mix, it can be the ‘straw that breaks the camel’s back’.
It’s not just the emotional impact of breast cancer that can contribute to anxiety and depression. Side effects (such as lymphoedema, pain and fatigue), the financial burden of treatment, and isolation from friends and family can all contribute.

What are the symptoms of anxiety and depression?
There are physical and emotional symptoms. For women having breast cancer treatment, some of the physical symptoms may mirror side effects of their treatment. For example, loss of appetite is a symptom of depression and a side effect of chemotherapy, so it’s important to discuss any symptoms you are having with your doctor to determine its cause.

A woman may be depressed if she has felt sad or down most of the time for two weeks and lost interest in her usual activities and pleasures. Other symptoms of depression may include:
- poor sleep
- lack of energy and motivation
- feelings of hopelessness, helplessness and guilt
- negative thoughts about yourself, your environment and the future.

Anxiety is a feeling of being ‘on edge’. You may feel jumpy or easily startled. Some women with anxiety report:
- feeling worried most of the time
- thinking the worst about situations
- poor sleep
- feeling exhausted.

Some women may even have episodes of severe panic. These panic attacks can be very scary and can interfere with your ability to live your normal life.

What should women do if they think they may have anxiety or depression?
Don’t suffer in silence – get help. If you feel down and it isn’t going away, you may need professional help.
A GP is usually the best option. If you are diagnosed with depression or anxiety, your GP can write a GP Mental Health Care Plan that will give you access to a psychologist for treatment.
Treatment usually involves talking. Often, a therapy called Cognitive Behavioural Therapy will be very effective, as it teaches women to identify and challenge unhelpful patterns of thinking.
Some women will need medication. Antidepressants are very effective and are not addictive.

What should friends and family do if they think someone they love may have anxiety or depression?
Tell her that you love her. Let her know you are concerned and want her to feel as well as possible. You may like to offer to go with her to see her GP.

Care Plan that will give you access to a psychologist for treatment.
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Researchers at the University of Melbourne are undertaking a study of twins to better understand how genetic, environmental and lifestyle factors may increase women’s risk of developing breast cancer. This study is investigating the roles of childhood and adolescence in the development of breast cancer. The researchers are investigating whether development in early life (e.g., age at first period and age at which a young woman’s breasts develop) play a role in determining a woman’s risk of breast cancer later in life. The study is also investigating the concept of ‘epigenetics’ – how the environment influences the way genes work. This phenomenon in part explains why genetically identical twins do not necessarily develop the same diseases. Studying women who are twins, where one or both of the women have developed breast cancer, provides a powerful way of understanding the effect of epigenetic factors on women’s risk of developing breast cancer because the twins are matched for genes (100 per cent for identical twins and 50 per cent for non-identical twins).

The researchers are looking for women throughout Australia to participate in the study. You may be able to participate if you are a twin (either identical or non-identical), over 18 years old and one or both of you have had a diagnosis of breast cancer. As part of the study you will be asked about your medical history, lifestyle and environmental risk factors and your personal and family history of cancer. You may also be asked to provide a blood sample and results from genetic testing you may have had. If you have had breast cancer, the researchers would also like your permission to obtain samples of your tumour specimen from your pathologist.

If you would like more information about this study, please contact the researchers on 1800 090 990.

A study of breast cancer in twins

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My Journey Kit continues to help women

The My Journey Kit is extensive and covers a lot more than I needed, but that isn’t a bad thing. Overall I found it very helpful. You don’t know beforehand what areas you need information on, so it’s good to have it all there to choose from. – My Journey Kit survey respondent

Most women reading The Beacon will have received BCNA’s My Journey Kit. Our records show that more than 80 per cent of women newly diagnosed with breast cancer from right across Australia receive the kit each year. We receive wonderful feedback about it from women and health professionals, and we know it is helpful for many women starting their breast cancer journey.

It is important that we keep My Journey Kit up to date and relevant, so we regularly review it. The first edition of My Journey Kit was released in 2004, with a second edition released in 2010. This year we have conducted another review to make sure that women continue to receive high quality, helpful information at the time of their diagnosis.

The review has been guided by a reference group made up of BCNA Consumer Representatives and health professionals such as breast care nurses, representatives of the Medical Oncology Group Australia, Clinical Oncology Society of Australia, Breast Surgeons of Australia and New Zealand, McGrath Foundation, a General Practitioner and an oncology social worker.

We also conducted a survey with women who have received My Journey Kit recently to hear their opinions about the format and content.

The key findings of the review were that My Journey Kit meets the needs of most of those who receive it, with 93 per cent of those who completed the survey saying they were either ‘very satisfied’ or ‘satisfied’ with the amount of information in My Journey Kit.

Some of the areas where women asked us to provide more information were side effects of treatment, lymphoedema, relaxation techniques, breast reconstruction and life after treatment.

The third edition of My Journey Kit will be available in early 2015. Next year we will also investigate technology options that might complement My Journey Kit and make it easier for women to find information through their smart phone or tablet. This can be especially useful when you are away from home, or at appointments and don’t want to carry the My Journey Kit with you.

Seeking Victorian women about to start tamoxifen

Tamoxifen is a drug commonly prescribed for women with hormone receptor positive (ER+) breast cancer to help reduce the risk of the breast cancer returning.

While it is very effective, like all drugs it can have side effects. While you may know about the hot flushes, other side effects may include weight gain, increased abdominal fat, lowered sensitivity to insulin, and changes to the lining of the uterus.

Melbourne-based researchers are conducting a study looking at whether a diabetes drug called metformin can help to prevent weight gain and changes to the uterus. Metformin is also being studied overseas to see if it reduces breast cancer recurrence.

The researchers are looking for women who are under 75 years old, about to start tamoxifen for the first time, and are not on any medication for diabetes. You will need to be able to attend their clinic at Monash University in Melbourne three times over 12 months.

If you choose to participate, you will be required to have a vaginal ultrasound before starting tamoxifen to examine the lining of your uterus. You will then be randomly assigned to either the group of women being given metformin or the group being given a placebo (a substance that looks like metformin, but does not contain the medication). After 12 months, you will be required to have another ultrasound and a biopsy of the lining of your uterus.

If you would like more information on this study, please contact Jenny on (03) 9903 0833 or Corallee on (03) 9903 0836 at Monash University, or email the research team at med-pecam@monash.edu.
BCNA resources in other languages

BCNA is committed to providing accessible and appropriate information and support to all women with breast cancer. With assistance from our Supporting Sponsor Sussan, we are helping women from diverse cultural backgrounds. We are excited to announce that a series of resources in languages other than English will be available later this year.

Through research and consultation with health professionals and other cancer organisations, we identified gaps in information available about breast cancer in languages other than English. We found a great need for this information in Italian, Greek, Chinese, Vietnamese and Arabic communities.

Like all BCNA resources, we received input from women affected by breast cancer, health professionals and, in this case, the multicultural sector. The result is four booklets in each language covering the following topics:

- About breast cancer
- Breast cancer treatments
- Support that may help
- Messages of hope and support.

Each booklet is written in simple, easy-to-read language and includes English to ensure health professionals and English-speaking family members can also refer to the information.

Our plans for the translated resources

The booklets will be available later this year for women and health professionals to order in addition to the My Journey Kit. These resources are a supplement, not a replacement, to the My Journey Kit.

Women have told us that they like to receive information in different ways. The resources will be available to download from BCNA’s website, with a dedicated page for each language. Next year, we will also include an audio file of a woman reading the booklets in each language.

What’s next?

BCNA continues to work with women from diverse cultural backgrounds and with the organisations that support and represent them. In November 2014, BCNA will be partnering with Greek community organisations to deliver the first ever breast cancer information forum in Greek. The forum will be held in Melbourne and will provide Greek-speaking women with information on the latest treatments, care and support available.

In 2015, we plan to develop additional resources to further support women from Italian, Greek, Chinese, Vietnamese and Arabic communities.

BCNA’s website gets a makeover

Early next year, we are launching a refreshed website in response to the evolving information needs of our members and supporters.

The new website aims to provide you with:

- a better overall user experience, especially when you visit the website from your portable device such as a mobile phone or tablet
- more information about topics our members have asked us to include on the website, such as the financial impact of breast cancer, reducing your risk, and the benefits of exercise
- clear steps for joining the online network
- an easy way to share your personal story.

We’d love to hear your feedback on the new website. Please email bcnaonline@bcna.org.au or phone us on 1800 500 258.
Following my new passion

I never have really been much of a one for sitting on the couch, but recovering from my breast cancer operation in 2000 made me realise I needed to spend more time on 'me', and this meant increasing my walks along the beautiful Swan River in Perth. Walking has always been a joy and allows me time to think away from kids, emails and work.

Over the years since then I have done a couple of fabulous walking holidays. However, my feet became a problem in recent years, so I switched to cycling. At first a 20 kilometre ride was an effort but as I grew fitter I realised what a marvellous way it is to see the world.

I started to dream of exotic rides overseas but my sensible husband said we had to do one in Australia first, just to make sure we didn’t make complete fools of ourselves. So I booked our first proper cycling holiday – a six-day, 300 kilometre trip in Victoria.

So, just when you think things are going well don’t they always have a habit of going awry! A week before the trip I had a second diagnosis of breast cancer. I literally couldn’t believe it.

My surgeon recommended a mastectomy this time. She also asked if I had any plans to travel in the near future, but said it would be absolutely fine for me to go on the cycling trip and that it would actually be really good for me.

It was a great adventure and although some days were a real challenge I enjoyed every minute. Apart from one wet and windy day, I rode with a big smile on my face every day, but on the last day I just lost it. Thinking of the events to come I spent the whole day crying in the saddle but made it to the end and then to the pub with our newfound friends.

Once home I was soon into hospital for surgery. Everything went well, and I was home and back on my bike three days later. I know without doubt that my high fitness level has helped me survive and recover quickly. I have now had one heart operation, two breast cancers removed and both feet operated on. I feel bullet-proof!

Lesley, WA

A worthwhile change

Earlier this year my surgeon rang me on a Friday evening to tell me I had breast cancer in my other breast, and that as this was my second breast cancer the treatment was to remove both breasts.

I was a little shocked but not upset, as I had sensed that something was not right. What did upset me was my husband saying that we ought to not move to the retirement village that we had made a formal hold on. I was so upset by this that I told him that either he could come with me or I would go by myself. We went and it has been the best thing we have done – and my husband agrees.

We had to delay the move until I was over my surgery, but we have been in our new unit three weeks now and I have been going to the hydro pool to keep my muscles strong. We also go to happy hour twice a week. We have made some new friends and they are all very interested in my journey and want to know how I am getting on.

This has been a big step, but a worthwhile one that I would recommend.

Chris, VIC
A little bit of exercise is better than none

For most of my life, pre-breast cancer, exercise was a dirty word. I was known to drive rather than walk even the shortest distance. I wasn’t interested in any sport. My weight rarely fluctuated one kilogram, and then only at Christmas.

At the beginning of 2011, I knew that I would have to start looking for a new position as a carer, and the last time I had done that I ended up with a sore back. So I joined a gym at the hospital where I was working and started a program of weights. I also met a most marvellous man who enjoyed sports and took plenty of exercise for his own health issues.

In May, a routine mammogram set the cancer journey in progress. I had to quit my work as a carer and start treatment. Throughout this time I tried to exercise, but, honestly, sometimes it was all I could do to walk to the letterbox. After the treatment finished I thought I would feel much better but it was a very long haul. My fabulously supportive partner encouraged me to participate in our normal exercise routine at a rate I could handle. Walks were taken slowly sometimes, and I would sit out the odd track or two at aerobics. Three years later, our weekly routine still includes aerobics, gym and walks, and I have taken up karate. Like any cancer survivor I am concerned about a recurrence. I read that regular exercise, post cancer, will help prevent that. I am aided by my partner because this is our normal lifestyle now. I have also put on about eight kilos and would prefer not to put on any more.

Any advice I would give to others struggling to return to normality is not to be too hard on yourself. Do what you can, and don’t expect an instant return to health. Get an exercise partner and realise that a little exercise is better than none. I am so grateful for all the treatment I have and continue to receive, and for the support of family members – legends, all of them.

Judy, QLD

Out and about in the fresh air with friends

These two women, both breast cancer survivors, recently played off in the final for the Malua Bay Bowling Club Major Singles Championship. The match was an emotional day for both Gay and Joan and other club members (including myself) who are also breast cancer survivors. We are all very proud of them. It was a close game with a great display of their ability, the winner, Gay, being decided by a very close margin.

Lawn bowls is a great game and can be managed by just about anyone young or old. The friendship and support within the club is wonderful. I would encourage all to play. It’s great exercise and good fun as well as being out in the fresh air with friends.

Yvonne, NSW

Gay and Joan

take a chance.
step outside your comfort zone.
give it a try
don’t wonder ‘what if?’
– Jenny, 43 from A Pocketful of Sequins
A slimmer, fitter and happier version

It would be a stretch to say that my breast cancer diagnosis was one of the best things to have happened in my life, but not much. That diagnosis four years ago caused me to assess my life and options. I made a list of activities which were positive and those which were negative and resolved to maximise the former and minimise the latter.

The biggest negative in my life at that time was my work as a professional. The work was stressful and not too rewarding so I decided to remove that stress and retire. That decision took about 18 months to implement and I have not had any sickness at all since then.

The next decision was to assess my health and fitness situation. I was a little overweight and lacking in fitness. The solution to that problem was handed to me when I was included in a clinical trial to determine the relationship between exercise and bone density. I haven’t looked back and continue with the gym.

My final decision was to make time in my life for those things I enjoy and maintain contact with those people on my Christmas list I had not seen for some time. What a pleasure it has been to catch up with people who have added something positive to my life over the years. I am still working through the Christmas card list. I love reading and patchwork and make sure I include both activities in my life daily.

So, as a result of my breast cancer diagnosis I am slimmer, fitter and happier. What’s not to like about that?

Laurie, VIC

Tips for getting off the couch

I was diagnosed with breast cancer in 2011. It took much of 2012 to physically recover. In 2013 I had a scare – suspected secondaries in the liver. Four months of agonising uncertainty followed before I was pronounced clear.

There is a lot of focus on physical recovery but once treatment is over, the mental effects become apparent. Life has changed; fatigue, chemo brain, weight gain, adjusting to a prosthesis, depression. The couch can become a welcome and comfortable friend.

Persuading myself to get off the couch was not easy, but I realised that life is too short and might be even shorter! Did I want to spend the rest of my life like this?

So, here are my tips for getting off the couch:

- Make the decision to recover. Physical recovery from cancer treatment will occur gradually but inevitably. The mental recovery – from depression, anxiety, fear of recurrence – is not so easy.
- Ask for help – see a counsellor. Talking about the cancer, its impact on your life and the fears it arouses, will definitely help. See your GP. Maybe anti-depressants are the answer, even if only for a short time. Ask a friend or family member to assist with any daunting chores.
- Train your brain. Try it. There are programs on the computer and I swear it wakes up the brain.
- Take that walk. Exercise cheers you up!
- Whatever you weigh, accept it. Buy some new clothes. You’ll look and feel better.
- There are a range of prostheses, some lighter than others. A properly fitted bra helps.
- Make yourself go to bed at a regular time (before midnight); take a sleeping pill if it helps.
- Get out and see people, keep appointments, do chores. This becomes easier once you start to feel better about yourself. The sense of achievement in getting things done helps.
- Above all, be kind to yourself. You’ve had a trauma. You could have died. Small steps are better than none.

Laurie, VIC
Don’t take your Saturdays for granted

It is dark. It is cold. It is 6 am on a winter’s Saturday morning and my life has changed. After being diagnosed with breast cancer I quickly realised how precious and short my life was. I am 48. I have been addicted to exercise for about eight years now. This alone has made my recovery and mindset positive after surgery. I could not wait for the six-week recovery period to be over so I could get back to running and my outdoor exercise group with my trainer Mick – a life changer, that man.

As soon as I was home from hospital, I was walking every day and Mick adapted my bike so I could ride on my verandah during those first few weeks. At the six-week mark I ran a couple of kilometres, then a four kilometre run. I needed the challenge and the sweat and the pain; it helped me forget the cancer, it helped me feel alive and it made me positive about the future. A lot of the group I exercise with had started a Saturday morning running group called the Dungog Misfits. I valued my Saturday morning sleep in after a week at work so rarely went except when I was training for my half marathon. Now I am one of the first there, even after a long week at work and the sleepless nights brought on by Zoladex.

This group laugh, support me and they are my friends. They get me off the couch and back into the world. I spend a lot of my run catching precious moments of this world with my camera. I was lucky and am cancer free but will never take my Saturdays for granted again and waste them by staying in bed and missing the love of the Misfits.

Robyn, NSW

Believe you can and you’re half way there
– Theodore Roosevelt

A few speed bumps along the way

I was diagnosed in 2012, after finding a lump in my left breast. The waiting for the results was one of the hardest things I have ever had to endure, but once the results were in, as my surgeon said, ‘You have to put your blinkers on and focus, don’t think about the what ifs – this is the situation and you just have to deal with it.’ I had six treatments of chemotherapy. Some of the side effects were not pleasant, but only lasted for about a week. Hair loss didn’t worry me. I had a gorgeous wig.

I had fantastic support from family and friends, and I feel I am so fortunate to have ‘almost breezed through it’ with no lasting side effects. It is now 21 months since diagnosis, and I am feeling great. So far, so good. I read everything I could get my hands on in the beginning, and found the booklets put out by BCNA were great, along with information from Cancer Australia. As they say, knowledge is power. Being a practical person, I have found that just getting on with it, (which I appreciate, is not always easy for some) has helped me to cope with the diagnosis and subsequent treatment.

It seems like a cliché, but once you’ve had cancer, things that you may have worried about before are no longer an issue. I used to hear people say, ‘Don’t sweat the small stuff’, and now I know what that really means! Life’s good, in spite of the speed bumps along the way!

Denise, QLD
Regaining my fitness and a positive outlook

Running. I love to run. I also love swimming. So I took up triathlons. I would train five to six days a week and on weekends race at my local club. In 2010, I ran 21 km, in 2012 I ran 42 km and in September 2013, my first Half Ironman. I was super fit and loving life.

In December 2013, I was diagnosed with breast cancer. On New Year’s Eve, I had a double mastectomy followed by six rounds of chemo and 25 sessions of radiation.

As much as breast cancer is a shock, it has been a positive experience for me. It has brought my family together and strengthened friendships, has made me a stronger, deeper and more empathetic person. I feel at peace.

I’ve always been a positive person. I was determined to get my fitness back and took the time to do it. As much as our bodies need the time to recover and heal, it’s important not to fall into a heap.

Don’t let negative thoughts come creeping in. Be positive and proactive. Try to take a positive look on life.

Yes, I had cancer, but I have life. I don’t have breasts, but I have working arms and legs. Yes, chemo makes you sick but it’s not forever. Radiation made my skin peel and burn, but now I have fresh skin there. Never doubt yourself. You can do this, and you will. There are obstacles in the path but none of them is ever too high for you to get over.

Every day get up with a smile, walk as much as you can, be it five metres or five kilometres. Congratulate yourself for having a go. Do it again and continue to smile and remain positive. Be grateful for life.

Some people lose friends when diagnosed, but you can make new friends through support groups and treatments. There will always be a positive. If you can’t see one now, there is bound to be one on the way.

Although I was very fit, by the time I had been through my treatments I had to start from scratch. It’s taken a while but I’m nearly back to normal and loving it.

Ang, NSW

Motivated to move for my wellbeing

In 2012 I was diagnosed with breast cancer. It felt like I had been hit by a freight train, but after listening to my surgeon tell me that survival rates increased if you engaged in moderate exercise regularly, I became motivated to move for my health and overall wellbeing!

My problem was finding something that was sustainable, affordable and that I enjoyed. That’s when I discovered running.

I had a school mum friend who ran, so I asked her for advice on how to get started and she said slowly, with a decent pair of shoes, and build up from there. I asked her if she would run with me, she agreed and I set myself a goal after active treatment had finished to do the Colour Run, which was five kilometres. I was scared as I had never done anything like it before but when I crossed the finish line I knew I was hooked!

Since then I have done Mother’s Day Classic, City to Bay, Adelaide half marathon and the City of Onkaparinga Community Cup.

The thing about running is you don’t have to be the fastest; just having the courage to start is what matters and I figured I’d overcome cancer so I could do anything I set my mind to.

My advice to anyone wanting to exercise is to speak to your specialists, find something you love to do and nourish your body with good food, and things will fall into place.

Kate, SA
Book review

Drink the wild air: An accidental awakening
by Fiona Evans
Wild Air Publishing 2013
paperback, 294 pages

A quick glance at the website for this book (drinkthewildair.com.au) was enough to convince me that I wanted to read Fiona’s story. She sounded young, vibrant, real, and I loved the title. When the book arrived, I admired the cover with her beautiful imperfect breasts proudly displayed.

I then promptly put the book face down on the kitchen bench. I stopped and thought, am I ready? I hadn’t read a cancer book since my own journey two years ago. I wasn’t sure that I wanted to be reminded of my experience or be sad for yet another woman. I wondered if I had appropriately thought through my commitment to review this book. Was it too soon?

Later that evening I picked up the book and started to read. Now or never, I thought, and I am so glad I did. Fiona’s story is not about cancer. It is a raw story of a woman discovering herself and working out what is meaningful in her life. Her breast cancer is a part of the story but most definitely not the focus. The honesty and directness with which she writes makes her book a very refreshing quick read (I finished it in three nights).

At no point did I feel that she wrote the book for sympathy. This isn’t a ‘poor me’ story. It also isn’t a book of extraordinary triumph or achievement. While some women do amazing things like run marathons after cancer, others, like myself, and to some extent Fiona, use our energy to just keep fit, be healthy, wiser and kinder to ourselves and our battered bodies.

Her book highlights some of the many issues women struggle with including depression, and her story shows professional assistance can help. For health professionals she nicely explains how a compassionate attitude makes a patient feel like a person and that words spoken without thought can have a huge negative impact.

At the end of the book, Fiona felt like a friend. I do recommend this book and I am donating it to my local library in the hope that a range of women (not just those with a cancer journey) and perhaps a few blokes will read and enjoy her book.

Tonia Woodberry,
Review & Survey Group member

DCIS of the breast: Taking control
by Professor John Boyages, MD, PhD; BoyCare Pty Ltd 2014
paperback, 300 pages

From the ‘Dedication’ of the book to the last page, this book captured and held my attention. Professor John Boyages has written a must-have read for all women diagnosed with ductal carcinoma in situ (DCIS). The easy manner in which information is discussed gave me a sense of being in a consultation with Professor Boyages during my journey.

The book is divided into three parts – ‘Shock control: Taking control immediately after diagnosis,’ ‘Gaining control: Taking control before your surgery’ and ‘Maintaining control: Taking control after your surgery.’ The author takes the reader through the DCIS journey one step at a time describing in detail each new issue. Throughout the text, Professor Boyages stresses the options, positive outcomes and possible problems. He encourages and urges the reader to take control of their diagnosis and treatment options.

The book includes an extensive list of suggested important questions that you may wish to ask your treatment team, from your first visit of your journey to your final visit. Professor Boyages suggests that you take a pen and paper to each visit to write notes, have your questions written down in advance and not to be afraid to ask questions. He recommends you always ask for your reports, to keep them in order by date and to take someone with you to your appointments.

Reading this book took me back to my early journey. The information at that time was limited for consumers though my surgeon always answered my questions and kept me informed. During and after reading this book, my choices concerning my treatments have been endorsed and I would still make the same decisions as I have made. I feel that I have taken control.

At the end of the book there is a list of useful websites, if you need them.

Whether you are newly diagnosed or quite a way along your journey, consider this book as your tool to help you take control and navigate your pathway.

Thelma Fulton,
Review & Survey Group member
Volunteer co-facilitator, Tracy Taggart, shares some of the ways the group helps women in the community.

Hot flushes, fertility, weight gain and surgical reconstructive options are just some of the lively topics of discussion at the monthly meetings of the Young Women’s Support Group in Perth, Western Australia. The group is aimed at women with early breast cancer under 40, or those with school-aged children.

Other regular topics of discussion include exercise, side effects of treatment, and the impact of breast cancer on sexuality.

Our group is one of many coordinated by Breast Cancer Care Western Australia (BCCWA*), an amazing non-profit organisation that was established in Western Australia in 2000 by Ros Worthington OAM. BCCWA provides emotional, practical and financial support to people affected by breast cancer. We’re fortunate that every meeting is attended by a counsellor, something that’s particularly valuable for members attending their first meeting and still grappling with their diagnosis, and also for women who have experienced the trauma of a secondary diagnosis.

I think the other members would agree that the greatest post-treatment challenge is managing anxiety, and our group offers a safe and caring space in which to process those feelings, as well as practical suggestions on how to cope.

We meet at a community centre in Leederville every second Monday of the month. Ours is a noon meeting, and we all bring a small plate of food to share. Often our discussions are so intense that we all forget to eat!

Every second or third month we invite a guest speaker to address a topic of interest to our members. Past speakers have included an exercise physiologist, physiotherapist, meditation teacher, an expert in managing menopause symptoms, and the owner of a female-friendly sex shop. The founder of BCCWA, Ros Worthington, has been one of our most inspirational speakers.

Some members join the group soon after diagnosis, and leave after treatment has finished. In their minds, the end of treatment marks the moment they’re done talking about breast cancer. They think of the disease as a small bump in the road. Other women, like me, find a lot of value in attending the group for many years. If I can offer emotional support to other young women at their time of need, then I am grateful for the opportunity to make their journey less scary. It’s incredibly powerful for someone to say they understand how you’re feeling, when they actually have been through the same experience.

When I was younger, I was probably intimidated by the term ‘support group’. Now I know it’s a great concept that ensures others don’t go through their breast cancer ordeal feeling isolated and afraid. Yes, we often have a cry, but more often we have a laugh. After all, how often do a group of women spend so much time talking about breast shape and nipple size!

* Anyone interested in joining this group should contact Breast Cancer Care WA for more details.
Thank you

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

- 8 Days Café – Jason Ennels and Ruairidh Gunn, VIC
- ACT Pink Ribbon Ride – Trish Holdsworth, ACT
- Adam Bath, NSW
- Adriana Hooper, NSW
- Alcoa Alm/AWN, Megan LeRoy, WA
- Alexandra Lawn Bowls, Maureen Edna Rikihana, VIC
- Artemis Lialio
- Ballarat Clarendon College Players for Pink, VIC
- Benalla & District Adult Riding Club – Issie Hill, VIC
- Beverly Brown, VIC
- Bride of the Year – Gwen Barr & Committee, VIC
- Broken Hill Pink Ball – Kerri Baker and Committee, NSW
- Campbelltown Liverpool District Pistol Club – Kristen Kable, NSW
- Canowindra Golf Club – Amanda Boserio, NSW
- Catherine Earl, VIC
- Coleambally Football Netball Ladies Day, Lauren Pound, NSW
- Darlington Pony Club – Julie Champ, WA
- David Desson, NSW
- Deb & Pearl’s Pink Party – Deb Murray and Sandra Parker, VIC
- Deloraine Bowls Club – Meredith Woods, TAS
- Eliza Perdikaris, NSW
- Geelong Cycling Club – Heather Christmas, VIC
- Hampton Park Bowls Club – Gwen Clough, VIC
- Harley’s Skate for Cancer – Harley Mackie, VIC
- Jog for Jugs Australia – Peta Burton
- John Roberts, NSW
- Josh Keyt, VIC
- Joy Ryan, SA
- Jump for Support with Moody Racing – Trish Joyce and Committee, VIC
- Keysborough Bowls Club – Gloria Munro, VIC
- Koo Wee Rup Quilt Fest – Diane Patten, VIC
- Manningham Juvenus Ladies Social Club Inc – Maria Della Rocca, VIC
- Mary Reader, QLD
- Melanie Warnock, NSW
- Melbourne City Baths – Liz Beardall, VIC
- Melissa McMillan, VIC
- Mount Cootoom Golf Club – Vicki Garrood, QLD
- Mount Hawthorn Primary School – Vicki Roberts, WA
- Myrt雷锋 Football Netball Club – Narelle Breen, VIC
- National Council of Jewish Women of Australia – Wendy Bookatz and committee, NSW
- NHB Girls, Sarah Darlison and Committee, VIC
- Perisher, Thredbo & Charlotte Pass Resorts – Helen Blackmore-Lee, NSW
- Power Living Studios Australia, Hannah Chapman
- Red Finch Boutique – Sarah Woolway, VIC
- Redcliffe Golf Club – Elly Squire, QLD
- Richard Metcalfe, NSW
- Rose Stratton, NSW
- Russell Kennedy – Marika Hubble-Marriott, VIC
- Settlement Village Christmas Island – Rebecca Karr, WA
- Shannon’s car rally – Kerrie Skene, VIC
- Shirley Gilmore, QLD
- Sonya Langelaar, NSW
- St Catherine’s Junior School, VIC
- Stroud Country Fair – Karen Hutchinson, VIC
- Sue Harding, NSW
- Tammy Keszes, QLD
- Thirteenth Beach Ladies Christmas Golf Day – Lois Marriott and committee, VIC
- Victorian Pink Ribbon Ride – Terry Caffery, VIC
- Victorian Tennis Academy – Rufus Keown, VIC
- Water Industry Operators Association of Australia, VIC
- Wentworth Community – Shirley O’Brien, NSW
- Werribee Baseball Club – Jessica Curnow, VIC
- Werribee Pink Ladies making a difference – Tracey Taylor and Committee, VIC
- William Blue College of Hospitality – Elizabeth Stern, NSW
- Willowbank Raceway – Terri Sander, QLD
- Yvonne Hargreaves, VIC

A special thank you to those who attended and contributed to the fundraising efforts at our annual Pink Lady Luncheon in Melbourne and Brisbane. Also, thank you to the participants and fundraisers of Miss Muddy and the Blackmores Sydney Running Festival.

Corporate supporters
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Workplace Giving

We thank the organisations that have chosen BCNA to be part of their Workplace Giving programs including:

- BHP Billiton
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- City of Boronondara
- Collins Foods Limited
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- Konica Minolta Business Solutions Australia
- Macquarie Group Foundation Limited
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- Myer Knox
- National Australia Bank
- Telstra
- UXC Australia
- Westpac Group
- Windsor Recruitment

Memorials

We pay tribute to the lives of:

- Anne Crowe
- Anna Wellings-Booth
- Bronwyn Wells
- Hazel Barker
- Jill Lemmer
- Rosina Trombetta

We are grateful for all donations in their memory.

Celebrations

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

- Dianne Dunbar
- Pauline Reichstein

Steps for Support Team

Aileen Keogh, NSW  
Ann Dickson, VIC  
Ann Lyons, NSW  
Belinda Behr, VIC  
Bernard O’Hara, SA  
Carolyn Dessent, VIC  
Cathryn Bower, NSW  
Coralie McInnes, VIC  
Curtis Jack, WA  
Diana Ortega, VIC  
Elizabeth Taylor, QLD  
Heather Christmas, VIC  
John Ballantyne, WA  
Judith Shirmpston, VIC  
Julee Rich, VIC  
Karen Colliver, VIC  
Kathleen (Kate) Smith, VIC  
Kylie Behr, VIC  
Lyn Brayshaw, ACT  
Lyndall Horne, NSW  
Lynette Sgambelloni, VIC  
Margaret Papps, SA  
Melissa O’Hara, SA  
Natalie Kelly, VIC  
Patricia McDonell, ACT  
Rosemaree West, VIC  
Samantha Warren, QLD  
Shabnam Nigar, NSW  
Sue Ewin & family, VIC  
Vicki Jack, WA  
Vivienne Freeman, NSW
A special BCNA collection by Sussan

In October, our long time sponsor Sussan launched a beautiful new range of jewellery as part of their BCNA collection. This stunning jewellery range would make a great gift for someone special and adds the finishing touch to any outfit.

You can choose from:

- a multi-charm necklace, with metallic charms inscribed with ‘hope’ and ‘live’.
- a single charm necklace with a single charm inscribed with ‘believe’.
- affirmation bangles, with two bangles inscribed with ‘love’, ‘hope’, ‘believe’ and ‘courage’.
- an affirmation bracelet with stretchy beads and inscribed with ‘love’.

These pieces are exclusive to Sussan with some of the proceeds from each item to be donated to BCNA so we can continue our important work.

There will be plenty of other gift ideas in store in time for Christmas. We encourage you to head in to your nearest Sussan store or online at www.sussan.com.au to spoil yourself or someone you love. While you are there please take the opportunity to thank the Sussan staff who give so much of their time to help women affected by breast cancer on their journey.

Pink Lady Luncheon

Top (left to right): Jo Lovelock, Sara Griffiths, Shane Crawford; Hayley Grimes, Jennifer Watt; table hosted by Carolyn Stubbs;

Bottom (left to right): The Hon. Quentin Bryce AD CVO; Roger and Lesley Gillespie, Ron Gordon; Jennelle Devereux, Robyn Batson, Rebecca Hard.

BCNA gratefully acknowledges our partnership with Bakers Delight.
When someone’s world is turned upside down

I want to share my story of a typical day at work as a BCNA team member.

It is 8.00 am on a Tuesday. I sit down and open my emails. A young woman called Madeline has contacted us. The subject line reads: ‘My world has been turned upside down’.

Her email is not a request … it is her story.

I keep her email in mind as I open a report that shows 70 women from across Australia have ordered resources overnight.

My phone rings. It is Stella, who is keen to register for one of our forums. She is desperate for more information. Stella tells me her ‘world has been turned upside down’.

I register Stella and let her know about BCNA’s Local Services Directory for other support services near her.

I turn back to my email. ‘Dear Madeline, thank you for your email.’

The doorbell rings and volunteers stream in to start sending out free resources.

Jenny calls. She was diagnosed with breast cancer yesterday and wants to order the My Journey Kit.

‘How much does it cost?’ she asks. I let Jenny know that all of our resources and support are free. I order her a kit and suggest she joins BCNA’s online network to connect with others.

‘Thank you,’ she says. ‘I really feel as if my world has been turned upside down.’

The phone continues to ring with questions and orders. Before I know it, it’s noon and I sit down to finish my email to Madeline.

Dear Madeline, thank you for your email. I’m sorry to hear you’re feeling so alone. BCNA was founded for this every reason; we don’t want you to feel alone.

Women often tell us that when they are diagnosed their world is turned upside down. Let me suggest some ways we can help …

Each year we receive thousands of calls from people looking for help. I would sincerely like to thank everyone who supports BCNA. Your generosity ensures we are always here to answer the call when someone’s world is turned upside down.

Simonne,
Member Services Team

Seeking stories – How far we’ve come

We are seeking stories for the Winter 2015 issue of The Beacon about how far we’ve come in breast cancer treatment and care.

Were you diagnosed many years ago? What was your experience when you were first diagnosed? If you have been diagnosed recently, how has your experience differed from what you expected?

The stories should be about half a page long (200–300 words) and can be posted to BCNA, 293 Camberwell Rd, Camberwell 3124 or emailed to beacon@bcna.org.au by the end of March 2015. Please also include a high-resolution photo.

Donate to BCNA today

We rely on the generosity of our supporters for us to continue providing free information and support. Make a secure online donation at www.bcna.org.au or phone 1800 500 258 during office hours.

Join our mailing list

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

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