

THE BEACON

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Coronavirus

(COVID-19) SPECIAL

HOW BCNA CAN HELP

MEDICINAL
CANNABIS:

THE FACTS

Scamxiety:
A VERY REAL
EXPERIENCE

A DIFFERENT DIRECTION:

motherhood
after **breast**
cancer

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UPFRONT

ABOUT BREAST CANCER

PODCAST

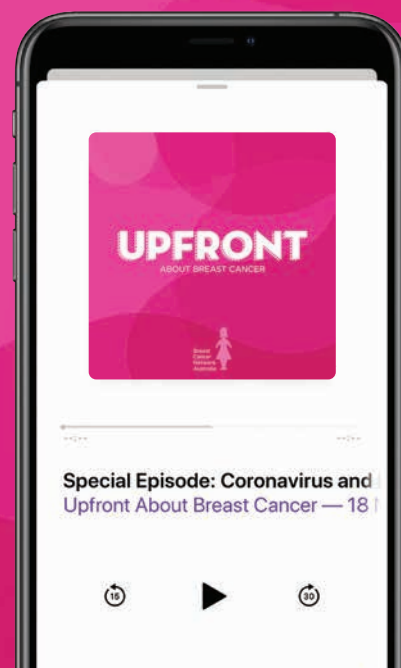
Breast
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Network
Australia



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"To meet other women with young children and similar circumstances as myself made it totally relatable and made me feel like I wasn't alone in the journey."

KEIRA

Breast cancer can feel lonely but you don't have to face it alone.

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Letter FROM THE CEO

Welcome to the April edition of *The Beacon*. It has been a difficult start to 2020 for many Australians. The devastation of the recent bushfire season and its ongoing impact on those living in affected areas coupled with the outbreak of coronavirus (COVID-19) has left many of us feeling overwhelmed and uncertain.

We know that living with a breast cancer diagnosis adds to the distress many of our members are feeling at this time, both for those who are in active treatment and those who have completed treatment.

In these unprecedented times and with the situation changing so rapidly, BCNA is committed to being a reliable source of information and support around coronavirus and breast cancer. We have extended the opening hours of our Helpline to include Saturdays and Sundays until further notice, are regularly updating

content on our My Journey online tool in response to the enquiries we are receiving from our members and producing podcasts that address common questions and concerns. I encourage you to access these services and resources that are based on information from key government agencies and clinicians.

Unfortunately, following discussions with our wonderful foundation partner, Bakers Delight, the 2020 Pink Bun campaign, which was due to run in May, has been postponed until later in the year. We will keep you updated as to the new date as we learn more.

More than ever, BCNA needs your support to keep supporting those living with breast cancer in what is an anxious and distressing time.

While we are in challenging financial times we are asking anyone that is able to donate to our services to please do so as part of our 2020 Tax Appeal.

To my mind, the emotional impact of coronavirus on our communities will be just as significant as the physical one.

Elsewhere in this edition we focus on a subject we hear about a lot from our members; scans, tests and the anxiety that can often accompany them. We examine the much-discussed issue of medicinal cannabis and present the facts, and continue to share the inspiring personal stories of BCNA members. While many of the faces featured are of our younger members, I hope there is something in here for all of you.

Stay safe and always reach out when you need help and support.

Kirsten Pilatti
Chief Executive Officer

▼ BCNA CEO Kirsten Pilatti at the Aboriginal and Torres Strait Islander Cancer Forum



Coronavirus (COVID-19) SPECIAL

Uncertainty around coronavirus continues to raise questions and concerns for people living with breast cancer, highlighting a need for up-to-date, clear and readily accessible information.

Over the past month, BCNA has been working hard to ensure that our members have been kept up-to-date with the latest information through regular updates on BCNA's My Journey online tool, podcasts and by increasing the hours of the BCNA Helpline.

MY JOURNEY ONLINE TOOL – MYJOURNEY.ORG.AU

BCNA's My Journey online tool is a free information resource for Australians affected by breast cancer. The tool exists to provide the information and support you need, when you need it. Information is being updated regularly as the situation around coronavirus changes.

To ensure that the information is accurate for your individual diagnosis, we have updated the information in the tool to reflect the situation for those with DCIS, early breast cancer and metastatic breast cancer diagnoses.

We encourage health professionals and those diagnosed with breast cancer to sign up to the My Journey online tool at myjourney.org.au, as it continues to remain our most reliable source of information in this unpredictable situation. It can also provide answers people may have around their breast cancer diagnosis, including information on treatment, care and wellbeing.

HELPLINE – 1800 500 258

Our Helpline is open and offering support on Saturdays and Sundays until further notice. To speak with an experienced cancer nurse call **1800 500 258**. Please check the website for up-to-date opening hours.

PODCASTS – UPFRONT ABOUT BREAST CANCER SERIES

During this time, we are also releasing special episodes of our podcast Upfront about breast cancer series in response to the enquiries we are receiving from our members. To listen to our podcast, visit: bcna.org.au/understanding-breast-cancer/resources/podcasts. We will continue to break down the information about Coronavirus for our members living with breast cancer to ensure you have the most reliable and accurate information to make important decisions about your health.



LOOKING AFTER YOUR WELLBEING IN A TIME OF UNCERTAINTY

We understand that many of you with breast cancer, or a history of breast cancer, are feeling quite unsettled as the coronavirus (COVID-19) situation changes daily, disrupting your usual routine.

You are not alone. It's important to understand that fear and stress is normal in a situation where we are dealing with the unknown.

It's important to manage distress in the same way you would manage any symptom you may experience as a part of your breast cancer diagnosis.

Breast cancer social worker, Dr Carrie Lethborg, has provided some information and practical strategies for dealing with the unknown, staying connected, managing distress and finding support. This information can also be found in BCNA's My Journey online tool at myjourney.org.au.



A TRUSTED VOICE: *The Helpline*

BCNA's Helpline has been responding to an increase in enquiries resulting from coronavirus (COVID-19) and the risk for those with breast cancer.

We are proud of the leadership role we played when coronavirus first started to impact the Australian community.

In mid-March you and your families started reaching out to BCNA because the government helplines and the hospital administration lines simply could not cope. We took the decision to bolster our Helpline team and move to seven days a week. A commitment we will continue, until we are no longer needed.

The rapidly changing advice has concerned our members who have called our cancer nurses seeking reassurance, clarification and guidance.

For those in current treatment, the most common question has been around potential delays in treatment and medical appointments. Their concern is that hospitals might need to prioritise and focus on patients with coronavirus. Others are seeking information as to whether it is advisable to go to a hospital with a fever related to chemotherapy and what are the best procedures to follow.

Our team has spent considerable time explaining what medications, treatments and surgical procedures affect the immune system. One member wanted to know if an axillary clearance where a number of lymph nodes had been removed might place her at a higher risk. She was relieved to be told that it wouldn't.

Many contacting the Helpline haven't been in active treatment

for some time but the current pandemic has renewed concern about their health being compromised. Their questions are largely centered on the long term impact of medications and whether they should reduce their external activities. In the initial phase of social distancing, people were unsure whether they were safe to go to places of worship and wanted advice on whether to go to work or stay home.

As enforced community restrictions have intensified, so too has people's level of anxiety. Callers to the Helpline are experiencing job losses and are seeking emotional and practical assistance on ways to best navigate the health system and maintain physical and mental wellbeing in this difficult time.

During these times of uncertainty the BCNA Helpline is a trusted and empathic voice. We are extremely proud and grateful for the expertise and empathy of our cancer nurses who are literally answering the call of our members.

Dealing with the unknown

Much of the stress around the coronavirus is about the unknown. To help reduce this stress it's important to bring your focus back to the here and now, rather than worrying about what's going to happen next week, next month, or next year.

Identify the support system you currently have in place and consider what additional support or information you may need, and start focusing on ways to reduce stress.

Staying connected

Social distancing and quarantine are important ways of protecting yourselves and others in the community, but these measures can cause feelings of distress and isolation.

Finding a balance between social distancing/quarantine and connection with others is critically important. With internet-based communication platforms, like

FaceTime, Skype, WhatsApp, Messenger and email, keeping in touch with your village can help to ease feelings of loneliness.

Accessing the BCNA Online Network is a way to connect with a whole community of people who are going through what you are. You can visit the Online Network at any time of the day or night at: onlinenetwork.bcna.org.au.

Managing distress

While staying in regular contact with others is important, there are a range of other things you can do to manage feelings of distress during a time of social isolation.

Doing 30 minutes of exercise several times a week can help lower stress while online exercise, yoga and relaxation sessions can also be of great benefit. Try to maintain a healthy, balanced diet and get seven or more hours of sleep each night. Open the windows, get some fresh air, feel the sunlight and hear the

sounds of nature, or take the time to do an activity you find relaxing, like reading a book, watching TV, gardening or listening to music.

Consider managing your time on social media to make sure you are using information to guide your actions, not feed your fears. Keep informed on developments, but limit the time you spend browsing social media and watching or listening to the news. You really only need to update twice a day to keep informed.

MANAGING DISTRESS:

- » Exercise regularly
- » Get some fresh air
- » Talk to family and friends
- » Eat well
- » Get plenty of sleep
- » Join a support group
- » Schedule daily relaxing time

What cancer has taught me

BY KATHRYN ELLIOTT



I remember precisely the moment my life changed forever: 8:10 am, Wednesday 21 August 2019.

Just shy of my 47th birthday, I was getting dressed for work when, for some reason, I stopped to look down at my right breast. Immediately I noticed a strange raised lump under the skin that I'd never observed before.

I've always been very fit, active and led a busy family life with my husband and three boys. I was in complete shock when, two days after noticing the lump, I was diagnosed with locally

advanced triple positive breast cancer. The results showed it was six centimetres in size and growing aggressively.

Inside a week I'd been through 15 appointments, numerous scans, a procedure to have a port inserted into my arm, and started an intense, six-month program involving 16 rounds of chemotherapy. My life as I knew it had been turned completely upside down and I found myself travelling along a path I had never expected.

Receiving a diagnosis of breast cancer is a scary, confusing and lonely time. The first two weeks for me were brutal – I not only had to accept and process my diagnosis

and treatment schedule, but had the emotionally challenging task of communicating the news to my husband, children, family, friends, work colleagues, school community just to name a few.

But I quickly made a decision to accept my diagnosis with positivity and to see the challenge as an opportunity to heal myself physically, emotionally and spiritually. My approach specifically combines conventional medicine with alternative therapies, which I believe has kept my body and mind clear, strong, positive and healthy during the treatment process.

I couldn't have made it this far without my husband Paul and our

kids. They're my life; they truly see the best and the worst of me. They are living and breathing the experience of breast cancer. They have seen me at my darkest times, but they've also been able to support me and there's no doubt it has brought us closer together as a family.

To make sense of breast cancer I began journaling and started an Instagram account (@healingbreastcancer) and website (healingbreastcancer.com.au). As part of learning to accept it, I also wrote it a letter. It was a way for me to start to come to terms with what was happening to me and my body. Here it is, in full:

Dear breast cancer

The first two weeks were the most brutal. I felt like I was on a crazy nightmare ride. Shocked, scared, alone. I'd been pushed into another reality I wanted to run from.

Sharing the news with people who loved me most was the hardest. I wanted to protect them from the fear and pain they would feel but I couldn't.

But something changed after those first two weeks as the new normal settled and I started to focus on my healing. I wanted to make peace with you. I decided to accept you, talk to you, message you and connect with you.

I'm also grateful for teaching me some valuable life lessons ...

- *You're teaching me to be present each day and to be grateful for what I have.*
- *You're showing me that my family loves and accepts me more than I ever understood.*
- *You're helping me to slow down and stop being so hard on myself.*
- *You're introducing me to some incredibly courageous and generous people who I wouldn't have met if it wasn't for you.*
- *You're showing me that you have to keep a good sense of humour during this process or you could lose your mind.*
- *You're reminding me that life can change direction in an instant without reason or warning.*
- *You're conveniently saving me six months worth of haircuts and waxing.*

There are of course some things I wish you had not brought into my life ...

- *The dreaded cold cap. It's a love/hate relationship as I've managed to keep some hair but the fact it adds at least two hours to every treatment is not fun. Particularly as wearing it feels like my head is stuck in a tight-fitting freezer.*
- *The loss of my long, thick eyelashes and eyebrows.*
- *The fact I can't enjoy the simple pleasures of washing, brushing and blow drying my hair.*
- *The nasty skin rashes I've developed in response to chemotherapy.*
- *The underlying question that edges its way into my mind each day that I have cancer and whether it may cut my life short.*

Breast cancer – I wouldn't wish you on anyone. You have the power to steal a very happy and healthy life and turn it upside down.

I look forward to the day I can't feel you and that we've healed you out of my body. By then I will have learnt a lot from you and you from me and I'm confident we will both have decided that you won't come back.

Much love,

Kath

ASK THE HELPLINE

BCNA's Helpline is staffed by experienced cancer nurses who provide support and information. While the Helpline can't provide personalised medical advice, the team can talk you through concerns you may be experiencing and refer you to support services available. Here, the Helpline answers some common questions about breast cancer and its treatments.



‘Scanxiety’: A VERY REAL EXPERIENCE

Scanxiety describes the sense of uncertainty and fear following a breast cancer diagnosis, specifically around tests, scans and the period spent waiting for results.

We receive a number of calls to the BCNA Helpline from members immediately after they receive the news of their breast cancer diagnosis as they try to make sense

of what the diagnosis means and what they need to do next. Some of the typical questions we receive via the Helpline on breast cancer tests and scans include:



Q: WHAT TESTS WILL I NEED FOLLOWING TREATMENT FOR EARLY BREAST CANCER?

After treatment for early breast cancer, you will need to have a period of monitoring, known as a follow-up. The purpose of a follow-up is to check if the breast cancer has come back, monitor for side effects of treatment and see how you are feeling and healing more generally.

The chance of breast cancer coming back is different for each person and depends on a number of factors including the stage of cancer at diagnosis, genetic factors, type of treatment and time since treatment. We know from Cancer Council Australia statistics that cancer is most likely to recur in the first five years following treatment.

You can ask your specialist to discuss the risk of breast cancer recurrence in your case.

The recommended follow-up will be different depending on your breast cancer treatment.

In general the follow-up involves a physical examination of your breast/breasts or chest wall, armpit and arm on the breast cancer side, a mammogram and/or ultrasound, and questions about how you are feeling physically and emotionally. Mammograms and/or ultrasounds are usually done annually, with the first one a year after diagnosis.

Q: HOW OFTEN AND FOR HOW LONG SHOULD I HAVE FOLLOW-UP APPOINTMENTS AND TESTS?

The recommended timing for follow-up appointments, per Cancer Australia guidelines, is:

- every 3-6 months for the first 1-2 years after treatment
- every 6-12 months for years 3-5 after treatment
- annual reviews following the 5 year-mark after treatment ends.

This schedule may vary depending on your treatment and recovery. Follow-up care may be shared between your breast surgeon and medical oncologist or one of your specialists and your GP.

Q: WHY DON'T I HAVE MORE OR DIFFERENT TESTS? HOW DO I KNOW IF THE TESTS ORDERED FOR ME ARE ENOUGH?

Some people find follow-up tests and appointments give them reassurance that the breast cancer has been treated effectively. Conversely, some find their anxiety is heightened at this time and some might request additional tests to allay their fear.

Cancer Australia's *Influencing best practice in breast cancer* statement notes that additional tests are only recommended if symptoms suggest that cancer has spread or a new breast cancer has developed.

If you do not have any symptoms, additional tests do

not provide any benefit and cause you unnecessary harm and anxiety.

More intensive testing, involving chest X-rays, bone scans, CT or PET scans, or blood tests, does not improve survival or increase the quality of life of patients who do not have symptoms.

You can learn more about Cancer Australia's 12 practices at: thestatement.canceraustralia.gov.au/breastcancer.

HELPLINE



Call our Helpline
1800 500 258 for free and confidential information, support and referral.



You can also contact our Helpline by emailing contact@bcna.org.au.



You can join our online network at bcna.org.au/onlinenetwork.

BCNA News

ONCOTYPE DX AGAIN REJECTED FOR MEDICARE SUBSIDY

Oncotype DX was rejected for a government subsidy on 20 February, even though it would mean thousands of women could avoid harrowing cancer treatment.

The Medical Services Advisory Committee (MSAC) said there is not enough evidence to support a Medicare rebate for the test that can indicate whether a breast cancer patient needs chemotherapy.

"MSAC advised the Minister for Health that the evidence presented for Oncotype DX did not give the committee confidence that the test would identify those patients who could safely avoid chemotherapy or those patients who would benefit from adding chemotherapy," it said in its report.

BCNA is disappointed the test has been rejected again, urging the companies supplying these tumour profiling tests to get together with the government to find a way forward.

'Women and men with breast cancer want to get the very best treatment, but not at all costs. If we can identify those people who will benefit from not having chemotherapy, it is essential that we save them from over-treatment,' said BCNA CEO, Kirsten Pilatti.

'Chemotherapy has a significant influence on a person's life in treatment and well after their treatment has finished, ranging from loss of work to long-term cognitive side effects.'

Without a Medicare rebate the Oncotype DX test will cost Australians up to \$5,000, which we know is out of reach for many. This test is widely available in the US and BCNA wants to see Australians have access to this important diagnostic tool.

For more information on Oncotype DX visit the My Journey online tool article on genomic testing (tumour profiling) at myjourney.org.au/article/2181.

BCNA's My Journey online tool has further information and suggestions for how to manage scanxiety. You can watch a video at myjourney.org.au/article/2835. If you would like to sign up for the tool go to myjourney.org.au

If you need to talk and would like to speak to an experienced cancer nurse, please call the BCNA Helpline on **1800 500 258**.



Reducing bill shock

A WORK IN PROGRESS

There's no denying that the experience of cancer is an expensive one. At BCNA, we regularly hear from members about overwhelming and unexpected out-of-pocket expenses; an additional burden for people already coping with a breast cancer diagnosis.

Back in 2018, we spoke with thousands of Australians affected by breast cancer whose experiences formed the basis of the *State of the Nation* report. The report identified eight priorities for urgent action, many of which relate to out-of-pocket costs for breast cancer treatment and care.

Since then, reducing out-of-pocket costs and increasing transparency around those costs – so you know what you are up for before you have a test or treatment – has become BCNA's top priority to drive change.

Over the last 18 months, we have worked to raise attention to the 'bill shock' caused by unexpected out-of-pocket costs, and called for greater transparency around fees and charges.

Standard for Informed Financial Consent

BCNA along with Cancer Council Australia, Prostate Cancer Foundation Australia and Canteen have developed a Standard for Informed Financial Consent; aiming to ensure that Australians receive comprehensive, upfront information about the out-of-pocket costs of treatment and what options may be available to them to help reduce or meet these costs.

The standard, which you can read here: cancer.org.au/about-cancer/patient-support/informed-financial-consent.html will be officially launched this year.

Specialist medical services fees website

Prior to the last federal election, Health Minister Greg Hunt announced a working group tasked with developing a website listing fees charged by individual specialists and other related out-of-pocket costs.

From a consumer perspective, this would mean the ability to compare fees on the website, and either choose a specialist

accordingly or use the information to negotiate lower fees with their preferred specialist. BCNA CEO Kirsten Pilatti was appointed to the working group.

Despite the best intentions of the Health Minister, Kirsten and other patient advocates, specialists have been slow to come on board. While our friends at Breast Surgeons of Australia and New Zealand volunteered to be the first group to provide details of their fees, this information is not yet publicly available.

The Australian Department of Health has launched an online Medical Costs Finder (which you can view here: health.gov.au/resources/apps-and-tools/medical-costs-finder), but rather than allowing people to search and compare individual specialists' fees, it only provides general information on what people in a local area can expect to pay out-of-pocket for a particular procedure. There are no specialists listed on the website, and there is no information that provides a reliable quote on what a particular individual will have to pay.



What can we do?

There are some things we can all do now to help improve our understanding of the potential out-of-pocket costs of tests and treatments. BCNA is asking doctors to provide full financial disclosure at every point in an individual's treatment pathway and to talk to patients about options for treatment in the public health system as well as the private setting.

As individuals, we can explore our insurances – remembering that some superannuation funds include insurance – and ask for referrals to other health services we might need, such as counselling.

BCNA continues to work on your behalf, advocating for improvements to the health system, such as better Patient Assistance Transport Scheme, Medicare rebates, and private health 'no gap' programs.

REDUCING YOUR OUT-OF-POCKET COSTS

BCNA's My Journey online tool provides information to help you reduce out-of-pocket costs. Tips include:

- Consider having some or all of your treatment in the public health system, even if you have private health insurance.
- If going private
 - ask for a written quote from your specialist/s so you know what your out-of-pocket costs will be – shop around if you're not happy
 - talk to your private health fund before booking any surgery – they can tell you which surgeons participate in their no-gap or known-gap schemes.
- Ask if you can have tests and scans bulk-billed.
- Radiotherapy treatment is not covered by private health insurance - investigate your options for having treatment in the private and public system to see if you can reduce your costs.

Your hospital or cancer centre may have a social worker who can talk to you about services that can help you and give you some advice on ways to manage out-of-pocket costs. Don't be afraid to ask for an appointment.



MORE INFORMATION

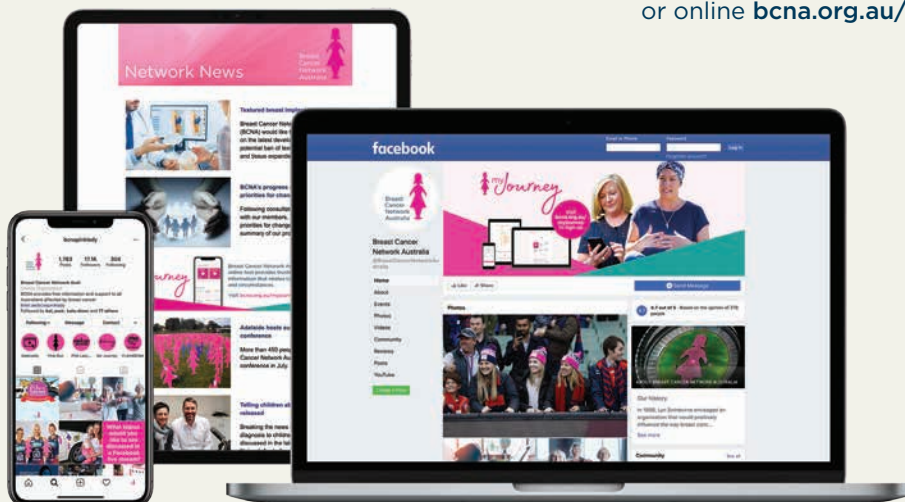
Read BCNA's Financial and practical assistance fact sheet, available at: bcna.org.au/media/4520/bcna-fact-sheet-financial-and-practical-assistance-march-2017.pdf.

Download BCNA's financial tracker to help you keep a record of expenses: bcna.org.au/media/7519/bcna-financial_tracker_sep2019.pdf

Sign up to the My Journey online tool at myjourney.org.au.

STAY UP TO DATE IN BETWEEN BEACONS

Subscribe to our monthly email newsletter *Network News*. Call our Helpline on **1800 500 258**, email contact@bcna.org.au or online bcna.org.au/news-events/network-news-newsletter.



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BreastCancerNetworkAustralia



BCNAPinkLady



bcnapinklady



A DIFFERENT DIRECTION: motherhood after breast cancer

Shari was 27 and well on the road to realising her dreams. Recently engaged, she and fiancé Travis were nearing completion of building a new home, complete with nursery for the children both of them wanted to add to their lives.

Life was motoring along smoothly until the discovery of a lump in her breast led to a radically different direction for the young couple.

'At first I assumed it was just a cyst, but after an initial consultation with my GP, he referred me to a breast surgeon. That led to a biopsy and the news I had returned positive for stage one hormone receptive positive breast cancer. It's fair to say the news rocked our world,' said Shari.

Unfortunately, the next roadblock did not help improve the young couple's outlook.

'We had a meeting with an oncologist who brought up the issue of fertility. It was the first time I learned that my breast cancer treatment could affect my dreams of being a mother.

'I had heard words like in-vitro fertilisation (IVF), egg freezing and sperm donors, but to be forced into thinking about these options was difficult given the uncertainty.'

Shari turned to BCNA for trusted advice and spent time on the Online Network to reassure herself.

Shari was referred to fertility specialist Kate Stern (see page 13), who discussed the various options available to the young couple. Egg freezing was not an option, given Shari was already booked in for chemotherapy. Kate suggested ovarian suppression, using Zoladex.

'As part of my plan, I knew that following chemotherapy I would be on tamoxifen, for around five years and wouldn't be able to fall pregnant. I also knew there were no guarantees I would still be fertile at the end of my treatment.

'It was challenging, but Kate explained the process to me in detail, which helped enormously. Five years was a long time to wait for results, but I felt comfortable I was making an informed decision that was the best option for me at the time.'

Four years later, Shari was having her annual review her oncologist, Michelle, when she was advised a new study into tamoxifen was recommending a 10-year hiatus before trying for a baby.

'It clearly wasn't the news I was expecting to hear. I thought I was near the end of my wait, and suddenly I was contemplating having another five years to go.'

At that point, her oncologist advised she would approve an immediate break in my medication regime to give Shari the opportunity to have a baby.

After trying for six months to fall pregnant naturally, Shari and Travis met with Kate and Michelle to consider IVF.

'From there, things moved quickly. There were lots of

ASK THE EXPERT

BREAST CANCER AND FERTILITY PRESERVATION



Kate was involved in the development of our fertility preservation tool which is available on BCNA's My Journey online tool, at myjourney.org.au.

Associate Professor Kate Stern is a fertility specialist, gynaecologist and reproductive endocrinologist based at the University of Melbourne and Royal Women's Hospital. She is the Head of the Endocrine and Metabolic Service and Acting Head of Reproductive Services both at the Royal Women's Hospital Melbourne and also the Clinical Director and Head of Clinical Research at Melbourne IVF. We sat down with Kate to talk about breast cancer in young women and its impact on fertility.

What is the biggest issue facing young women with breast cancer and fertility?

The fact that some are not informed of the risks chemotherapy poses to their fertility and the many options available to them. A lot of young women diagnosed with breast cancer will have chemotherapy, which is very effective against cancer cells, but can reduce the total number of eggs. It's vital for young women to consider future fertility as part of their treatment regimen.

How many women are not being informed?

Research conducted by BCNA as part of the development of a new resource for fertility preservation showed one in six young women were not informed of their fertility options.

Do they have time to consider their fertility options after diagnosis?

There is always time to have a discussion about fertility preservation, and almost always time to proceed with options including egg freezing. Sometimes, there may be time for more than one attempt at fertility preservation prior to starting chemotherapy. It is critical that women have all the facts they need to make informed decisions that deliver the best possible outcome.

What's the biggest obstacle you face as a fertility specialist with this issue?

The most important thing is ensuring young women receive all the relevant information. It's so important to get this advice early in the piece because there are lots of options available to help preserve their fertility. They include injections during chemotherapy, egg and embryo freezing or freezing ovarian tissue for future use.

Is it safe for young women to have babies after their treatment?

For most young women diagnosed with breast cancer, we know that having a baby in the future is not risky. And it doesn't matter whether the tumour was receptor positive or receptor negative. Of course, everyone's situation is different. But we know for most young women who have low-risk disease, it's safe to have a baby and it's safe to have fertility treatment as well.

What about women living in rural Australia?

We can organise phone conversations, use telehealth and send information to make sure women are well-informed. A woman's postcode is not, and should not, be a barrier to getting the best treatment. We have transport services now well-organised so geography should not stop women getting the advice and treatment they need.



appointments, lots of scans and, most importantly, support from the medical team.'

Doctors retrieved three eggs from the first IVF cycle. That resulted in the formation of one good embryo and the birth of Shari's daughter, Kaia.

Two years later, the couple approached Michelle to discuss another break from tamoxifen to try for a second child. Michelle agreed, and the couple prepared to ready for another round of IVF when they received the surprising – but welcome – news Shari had fallen pregnant naturally. Later that year, Shari, Travis and Kaia welcomed little Kobe into their home.

'It's hard to remember that dreadful day when our lives were turned upside down and our plans put into turmoil. But now, our lives are exactly where we wanted them to be. We have a happy marriage, two beautiful children, and most importantly, my health.'

MEDICINAL THE FACTS CANNABIS:

The use of medicinal cannabis has been a popular and often controversial topic for public conversation in recent months. We've explored the issue in depth, and in this article, cut through the background noise to bring you the facts about its potential use in the treatment of breast cancer.

Recent changes in Commonwealth and state laws mean that medicinal cannabis products can now be used in Australia to assist in the treatment and management of cancer-related symptoms and side effects.

In terms of cannabis and its relationship with cancer, it's important to note there is currently no evidence that medicinal cannabis is an effective treatment for cancer. Anecdotal evidence from people diagnosed with cancer say it helps to relieve symptoms such as pain, nausea and vomiting, and there is some evidence to support this.

Equally, there are many conventional drugs available that also help to manage these symptoms, meaning medicinal cannabis may not be the answer for everybody.

There is a crucial distinction to be made between medicinal and recreational cannabis.

According to the Australian Alcohol and Drug Foundation, medicinal cannabis is prescribed to relieve symptoms of a medical condition, such as epilepsy, while recreational cannabis is the form of cannabis that people use to get 'high'.

There are more than 100 cannabinoids in the cannabis plant, including THC, the cannabinoid associated with the psychoactive effect associated with smoking or ingesting marijuana recreationally.

The pharmaceutical products derived from the cannabis plant involve isolating useful cannabinoids and refining their production to minimise harm.

Legalisation of medicinal cannabis in Australia

With the exception of one type (for multiple sclerosis), medicinal cannabis products are not registered for use in Australia. This means they can only be legally accessed through Australian pathways for unapproved medicines.

Doctors can apply for approval to prescribe a medicinal cannabis product through two pathways: The Special Access Scheme (SAS) is for individual doctors wishing to apply on behalf of an individual patient. The Authorised Prescriber Scheme (APS) is for individual doctors wishing to prescribe for a class of patients with the same indication.

Some people may also be able to access medicinal cannabis through a clinical trial. Your breast cancer clinician will be able to tell you if there are any suitable trials available for you.

Who can prescribe medicinal cannabis?

Medicinal cannabis can only be prescribed by a registered medical practitioner if they receive approval from the Therapeutic Goods Administration (TGA) and the relevant state or territory government.

Before prescribing medicinal cannabis, your doctor will assess you to decide whether a medicinal cannabis product is appropriate for your condition and individual circumstances. Your doctor will take a medical history and a family health history, while also taking into consideration your current medications and any problems

THE RESEARCH

Tetrahydrocannabinol (THC) is the main psychoactive chemical component in cannabis, and the most biologically active. Some small laboratory studies have indicated that THC can slow tumour growth in animals. However, a small clinical trial targeting THC to brain tumours in humans was unable to conclude whether it had an impact on patient survival.

Research shows that smoking cannabis (marijuana) may be a risk factor in the development of lung disease and some cancers, as well as mental illness, however research into the link between marijuana use and cancer risk has been inconsistent.

Cancer Council supports further research into this area, such as the current clinical trial of nabiximols (a cannabinoid based product) and the cannabis clinical trial being planned at the ONJ Centre at Austin Health.

with drug dependence and substance abuse.

If your doctor decides a medicinal cannabis product is appropriate, they will apply on your behalf for approval to import and supply these products through the SAS.

If the particular medicinal cannabis product recommended for you is not currently available in Australia, your doctor can apply to the Office of Drug Control to import it.

What does it cost?

Reports indicate most medicinal cannabis products are very expensive and, as it is not included on the Pharmaceutical Benefits Scheme (PBS), individuals will pay the full cost.

If you are enrolled in a medicinal cannabis clinical trial, the cost is covered by the trial.

How is medicinal cannabis taken?

Medicinal cannabis can be taken in a number of ways: raw cannabis, which is vaporised (not smoked), cannabis extract in oil, tinctures (extracts soaked in ethanol), oro-mucosal spray (i.e. sprayed onto the cheek inside the mouth), and topical gel, cream or patch.

Smoking the cannabis plant is harmful and is not recommended.

What are the side effects of medicinal cannabis?

The side effects of medicinal cannabis are not well understood and can vary depending on the type and dose of the product, and between individuals. Known side effects include: fatigue and sedation,

vertigo, nausea and vomiting, fever, decreased or increased appetite, dry mouth, diarrhoea, impaired coordination and anxiety.

Cannabis and palliative care

There is minimal evidence around the effectiveness of medicinal cannabis for people suffering chronic pain caused by metastatic cancer.

It is also possible that medicinal cannabis may interact with chemotherapy and other palliative care medications, making them less effective.

For this reason, medicinal cannabis is generally only considered after standard conventional treatments have stopped working.

More research is needed

Research is currently being undertaken in Australia and overseas to understand the potential benefits, limitations and safety issues associated with medicinal cannabis for people with cancer.

In Australia, trials are investigating a range of uses, including whether medicinal cannabis can improve quality of life in people with metastatic cancer, and whether it can prevent chemotherapy-induced nausea and vomiting where standard treatments are ineffective.

Where to find more information

Your breast cancer specialist is the best person to talk to about whether medicinal cannabis may be helpful for you.

If you are looking for information about medicinal cannabis online, ensure it is accurate and up-to-date.

FURTHER INFO

There is no information available on the most effective or safe dose of medicinal cannabis for various conditions and symptoms. For this reason, starting doses should be low and increased over time.

Measurable concentrations of THC can be detected in urine many days after the last dose. It may take up to five days for 80 to 90 per cent of the dose to be excreted. Drug-driving is a criminal offence, and patients should discuss the implications for safe and legal driving with their doctor.

MEDICINAL CANNABIS IS NOT APPROPRIATE FOR:

- people with an active or previous psychotic or active mood or anxiety disorder
- women who are pregnant, planning to become pregnant or breastfeeding
- people with unstable cardiovascular disease
- patients with neurological conditions may be more likely to experience negative effects from medicinal cannabis.



BEST PRACTICE IN metastatic breast cancer CARE

In October 2019, Cancer Australia launched its *Influencing best practice in metastatic breast cancer* Statement.

The Statement of which BCNA was involved in the crafting, aims to deliver better care and ensure people living with metastatic breast cancer know what their treatment options are, and are involved in the decisions around that treatment.

We know Australians living with metastatic breast cancer need support, information and access to treatment and supportive care. Many BCNA members report frustration and disappointment about the gaps and disparity of care that exist in meeting those needs.

The Statement hones in on the critical importance of helping and empowering people with metastatic breast cancer to live as well and fully as possible.

What does best practice look like?

As someone living with metastatic breast cancer, you should feel supported to make evidence-informed and shared decisions

about the treatment and care that is right for you and empowered to participate actively in conversations around the key practices outlined in the Statement.

The goal of the practices outlined in the Statement is to drive practical change so that all Australians receive the information and support they need to work through complex and sensitive decisions about treatment and care.

The Statement highlighted 10 key appropriate and inappropriate metastatic breast cancer practices to ensure that patients receive consistent care.

Appropriate practices include:

- Enabling access to effective pain and symptom management and psychosocial support, including multidisciplinary supportive and palliative care services.
- Offering participation in suitable and relevant clinical trials from the time of diagnosis and throughout treatment.
- Offering biopsy of accessible metastases to assess biological markers (such as oestrogen and progesterone receptors,

and HER2 status), and to offer germline genetic testing for BRCA1/2, if the result is likely to lead to a change in the management of patients.

- Involving a multidisciplinary team to consider evidence-based anti-cancer and supportive therapies.
- Communicating effectively and sensitively in a culturally safe environment with metastatic breast cancer patients and their families, and provide timely, comprehensive, patient-centred information.
- Considering single-fraction radiotherapy initially for uncomplicated painful bone metastases in patients with metastatic breast cancer, rather than routinely using radiotherapy with extended fractionation schemes (>10 fractions).

Inappropriate practices include:

- Using chemotherapy in patients with metastatic breast cancer who are unlikely to benefit.
- Using chemotherapy in preference to endocrine therapy

BUILDING A STRONGER VOICE FOR PEOPLE WITH METASTATIC BREAST CANCER

On launching its *Influencing best practice in metastatic breast cancer* Statement, Cancer Australia also released a suite of videos featuring three of our BCNA champions with metastatic breast cancer: Marie Pandeloglou, Julia Domigan and Kim Parish.

Kim was diagnosed with metastatic breast cancer in 2017 after a previous diagnosis of early breast cancer in 2011.

Kim said she was proud of the work that had been done around the statement and the promotion, and particularly felt the need to make a strong case around the importance of communication.

'Communication is more than health professionals providing the appropriate information at the right time. It's about delivering it in a form people can understand. It's about listening, it's about responding, it's about sensitivity, it's about cultural differences and it's about supportive care,' she said.

Kim also reflected on the broader importance of the Statement.

'We wanted to address the issues of inequity and access to care in Australia and provide clinicians with guidance around appropriate practices.'

'For us, it was about providing a stronger voice for people with metastatic breast cancer.'

'In just the few months since the Statement was launched, women have already told me they feel more able to go to their clinicians and ask "what about this? I have a paper in my hand that says x, y, z may be appropriate for me."'

'Even if a particular practice isn't appropriate, it ensures that discussion takes place and enables a person's voice to be heard in a way it may not otherwise have been. It equalises what can sometimes be an unbalanced relationship and enable people to be an active participant in decisions made.'

For Kim being a part of the project was a vital opportunity to represent the voice of all Australians.

'I have no doubt the input of people living with metastatic breast cancer has made it a better product,' Kim said.

To view the videos, visit: thestatement.canceraustralia.gov.au/metastatic.

as initial treatment for patients with metastatic breast cancer that is hormone receptor positive and HER2 negative, unless there is a visceral crisis.

- Routinely using extensive locoregional therapy in those with minimal symptoms attributable to the primary tumour.
- Using whole brain radiotherapy for those with brain metastases without considering initial surgery or stereotactic radiosurgery.

To read more about the Statement, visit: thestatement.canceraustralia.gov.au/metastatic.

PAYING IT FORWARD

Sherone Brown was first diagnosed in 2005 and, after attending a BCNA Forum in Townsville in 2010, took up the challenge to become a BCNA Community Liaison and Consumer Representative.

"I lived through the time when women were mortgaging their homes to raise the money to buy Herceptin and I was well aware of the campaign by BCNA to get that drug onto the Pharmaceutical Benefits Scheme. I was one of the lucky ones, but if it weren't for BCNA, many women wouldn't have been able to afford it," Sherone said.

"I wanted to pay it forward and decided to volunteer for BCNA. I wanted to be one of those people gathering and disseminating the information to members to help BCNA fight for us and what we need."

"Working as a Consumer Representative has helped me realise the power of our stories and how, together, we can effect great change to help all Australians affected by a breast cancer diagnosis to ensure the journey is better for the next woman diagnosed, and the next."

BCNA will be running Consumer Representative training throughout 2020. If you are interested in hearing more, please visit: bcna.org.au/get-involved/volunteer-for-bcna/become-a-consumer-representative.





HAVING THE CONVERSATION: TALKING ABOUT PROGNOSIS

Talking about your breast cancer prognosis with an oncologist can be extremely confronting. Many people with breast cancer naturally have questions about their prognosis, while others prefer not to know. But while prognostic estimates are uncertain, they can be a source of hope for some people.

To unpack more about prognosis and answer some of the more commonly asked questions on the topic, we spoke with Dr Belinda Kiely, Medical Oncology Research Fellow at the National Health and Medical Research Council Clinical Trials Centre.

What is prognosis?

For people affected by cancer, prognosis usually refers to likely future developments and life

expectancy. Information about prognosis is important because it helps people make decisions about treatments and plan for the future. People affected by cancer often have questions about their prognosis, whether their cancer is at an early stage or advanced stage.

Who should I talk to about my prognosis?

Your oncologist is the best person to ask about your prognosis because they know about you, your cancer, and the treatments you have received. They also have experience looking after many people with the same type of cancer. The information you receive from your oncologist will be more specific to your situation than the information you find searching the internet.

Talking about your prognosis is confronting so it is good to take a family member or friend to the consultation. It can be helpful to tell your oncologist that you would like to discuss your prognosis at the next visit so you can bring others along and allows your oncologist to make sure there is enough time. If you have specific questions, write them down before the consultation.

Can the oncologist tell me how long I will live?

It is impossible to see into the future, and nobody, including your oncologist, can tell you exactly how long you will live. I never give patients a single-number estimate of their expected survival (e.g. two years or six months) because this implies a level of accuracy that is impossible to provide.



Some people prefer not to speak about it at all, or prefer their oncologist to discuss it with family members instead.

What prognostic questions should people with early-stage breast cancer consider asking their oncologist?

- What is the chance of cure?
- What are the chances of the cancer coming back?
- How much will this treatment increase my chance of cure?
- How will I know if the treatment has worked?
- What is my chance of surviving 10 years?
- What happens if the cancer reappears?

What prognostic questions should people with metastatic breast cancer consider asking their oncologist?

- What can I expect in the future?
- Will this cancer shorten my life?
- How long can I expect to live?
- Will the treatment help me live longer?
- What happens if I stop treatment?
- Can I continue working?

How do oncologists estimate prognosis?

Oncologists consider many factors when considering someone's prognosis. These include factors about you, your cancer, and your treatments, as well as their experience treating other people in similar situations.

What factors are associated with a better prognosis?

In early-stage breast cancer:

- Small tumour size
- Low grade
- Lymph nodes negative (no cancer cells seen)
- Hormone receptors positive

In advanced stage breast cancer:

- Longer time from original breast cancer diagnosis to cancer reappearing
- Small volume of cancer or cancer only in the bones
- Good general health and support
- Good response to initial treatment
- Hormone receptors positive
- HER2 positive

Your oncologist can give you an idea of how your future might look. I find many people find it helpful to think about scenarios: a best-case scenario, a worst-case scenario, and a typical scenario, which is somewhere in between.

For example if someone asks for information about their likely survival time and I know from a clinical trial that the median survival time in a group of similar people starting similar treatments is four years, then I would give the following explanation:

If we imagine 100 people in exactly the same situation, then we'd expect:

- the five to ten who did best would live longer than 12 years (best-case scenario)
- the five to ten who did worst would die within 1 year (worst-case scenario)

- the middle 50 would live two years to eight years (typical scenario)

Most people find this information more helpful than being told only the median survival for your cancer is four years.

Some people want less detailed information and may simply want to know if their survival time is measured in years or months. Other people want to know their chance of being alive for an important event such as the birth of a grandchild, a wedding, or an anniversary.

It is important to talk to your oncologist about the type of information that you would like, and in how much detail. It is also okay to tell your doctor if you do not want information about your prognosis at the present time.

BY DIMITY PAUL



Waiting

It seems crazy to me now that I was surprised by my triple negative breast cancer diagnosis two weeks after turning 31.

Technically, I had been waiting 10 years for it.

Since learning of my BRCA1 gene mutation at 21, the wait subconsciously followed me.

Of course, I'd hoped that planned preventative surgeries would mean I would never actually get cancer. But there it was. All 0.9 millimetres of it.

Which led me to a new wait: to get to five years post diagnosis when my risk of secondaries would reduce significantly.

Liver, lungs, brain: that's the organs where triple negative breast cancer most commonly metastasises.

I've been on the OlympiA drug trial, evaluating a new adjuvant therapy drug. But with no standard treatment for triple negative breast cancers post mastectomy and chemotherapy, there's nothing to do but wait.

I'm waiting to reach my mid-30s. There's a multitude of things to do to distract yourself while waiting.

In the hospital waiting room,

somewhere many of us in the BCNA community frequent, I busy myself with work emails.

For my five-year wait, I started distracting myself with keeping busy. Filling it with meaningful work in the energy sector, on a board of a women's health prevention organisation, advocating for greater women's participation in politics and sending kids to Germany on scholarships to build their language skills and confidence.

But I filled my life with that kind of busy before cancer. It was the kind of busy that was trying to prove my right to live, the right not to get cancer. To prove I was successful and worthwhile.

The best thing about cancer is it focuses the mind. I've noticed a shift in how I wait in the last six months.

Indeed, the wait is being replaced with self-discovery and self-love.

I'm filling the wait with learning how to live. To believe I'm enough without the job title, the board positions, and the driving ambition that ramped up at 21 when I began being in a hurry to achieve as

much as possible - just in case the wait ended.

I am trying to embrace who I am, being a friend not just to the ones I love but to myself. And the kinder I am to myself, the more love I have for others.

I'm being a friend to my body and prioritising exercise and eating good food. I've become a new friend to my mind and regularly practise self-reflection and being curious about my feelings.

Do not be in any doubt though. I'm still waiting for that elusive five-year post-diagnosis day, finally removing the heavy weight of waiting.

However, the weight is getting lighter. Not with the passing of each year, but every time I give myself a break.

I think the hardest thing that many of us with a BRCA gene mutation or being diagnosed with breast cancer at a young age subconsciously carry is the fear that our life may not be fully lived.

It's truly scary.

Now, rather than just waiting, I'm learning how to live. And I'm getting better at it. Every day.

Life is too good to wait for.



▲ Alliance Airline Hangar2Hangar charity corporate cycling event, raising \$100k for BCNA.

▼ BCNA member Julia Domigan selling her late mother Mitzi's artwork, with 100 per cent of proceeds coming to BCNA.



► The Carman's Women's Fun Run 2019.



▲ Manildra Foundation visit BCNA with a very generous Christmas donation.

AROUND THE Network



▲ Pink Sports Day participant.



▲ BCNA members at the Sydney Paint the Town Pink dinner.

▲ Inspirational messages at our 2019 Gold Coast Survivorship conference.



ANYONE CAN LEAVE A GIFT

Maureen Stevenson was aged 73 when she was diagnosed with breast cancer in 2016. The news came just one year after the passing of her husband, Barry.

The Gold Coast resident used the experience – including the help she received – to back BCNA and its work ensuring all Australians affected by breast cancer receive the very best care, treatment and support.

Such is her commitment to the cause, Maureen has become one of BCNA's largest individual donors.

"After my experience with breast cancer, I wanted to leave a legacy, to support people who may be diagnosed in the future," she said.

Maureen said she wanted people interested in helping out BCNA with a gift to know how easy the process was.

'I thought it was going to be very complicated, but it was simply a matter of telling my solicitor how much I wanted to leave BCNA in my will.

'It makes me feel good that my gift is helping future generations of women on their breast cancer journey. It's nice to know my gift is helping make it easier for them,' said Maureen.

Any person interested in leaving a gift in their will to BCNA should contact National Manager, Major Gifts Gerrard Peck on mobile 0402 124 624 or email gpeck@bcna.org.au.

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SUSSAN SUPPORTING YOUNG WOMEN WITH BREAST CANCER

Funding from long-term BCNA partner Sussan will support the delivery of activities and resources dedicated to young women living with breast cancer in 2020.

Acknowledging the unique needs of young women, we will be creating specific content including podcasts, resources in the My Journey online tool, BCNA conferences for young women and consumer representative training designed specifically for young women.

Sussan proudly supported our State of the Nation project in 2018, as well as funding a BCNA research project and providing HR advisory expertise to explore the return-to-work-experiences of women following breast cancer. Through Sussan's continuing support of the project, we are developing a 'work and breast cancer' hub on the BCNA website with resources for employees, employers, self-employed and colleagues.

Since partnering with BCNA in 2005, Sussan has raised more than \$2,500,000 to support Australians living with breast cancer.

San Antonio symposium update

The 2019 San Antonio Breast Cancer Symposium, held in December, reported on clinical trials being held around the world, including by the Australian-based Breast Cancer Trials.

Below is brief summary of three key study findings for people with early breast cancer. More trial results can be found in the Research Blog at breastcancertrials.org.au.

Hormone receptor positive

Long-term follow up results from the IBIS-II clinical trial found that taking anastrozole (Arimidex) for five years can reduce the risk of a new invasive breast cancer or DCIS by almost a half (49 per cent). The preventative effect for post-menopausal women at high risk of breast cancer lasted for at least 12 years – seven years after women on the trial stopped taking anastrozole.

HER2-positive

The APHINITY clinical trial has shown that adding pertuzumab (Perjeta) to the standard treatment of trastuzumab (Herceptin) and chemotherapy reduces the risk of breast cancer recurrence (returning).

After six years of follow-up, researchers found that people who received the pertuzumab combination had a 24 per cent reduced relative risk of breast cancer recurrence or death compared with those who received standard treatment of trastuzumab and chemotherapy alone.

Radiotherapy

A 10-year follow up study of women who had been treated with accelerated partial breast radiotherapy after surgery showed their results were similar to that of women who received whole breast radiotherapy. These results suggest radiotherapy to just part of the breast, rather than the whole breast as is usually done, may be an acceptable option for some women with low risk early breast cancer.



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**"To meet other women
with young children and
similar circumstances
as myself made it totally
relatable and made me
feel like I wasn't alone."**

KEIRA

**"The beauty
of the Online
Network is you
are never alone.
You have no idea
what a gift that
is to me."**

ROS

**"Raising awareness
and sharing stories
destigmatises breast
cancer, encourages people
to self check and ultimately
saves lives."**

AUNTY JOSEY

**Together, we can *connect*
people so they feel less alone**

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