

THE BEACON

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YOUR VOICES
HELP US ENSURE
COVID-19
LESSONS ARE
LEARNED



COVER STORY

THE RIPPLE EFFECT OF BREAST CANCER

**Grief,
gratitude
and pixie
dust**

**SALLY OBERMEDER
ON HER BREAST
CANCER JOURNEY**

DEMYSTIFYING
**palliative
care**

Letter FROM THE CEO

October is always a tricky time for BCNA. Internationally, the world seems to turn pink, in support of breast cancer. It is a time when a lot of money is raised to help charities supporting those with breast cancer, but it is also a time when many women and men living with metastatic breast cancer feel more isolated and alone.

At BCNA we constantly work hard to try and get this balance right and I hope the content in this first-ever digital only edition of *The Beacon* represents the different experiences of Australians with breast cancer that we support.

I hope you enjoy the stories in this edition and I would like to thank everyone who continues to generously share their experience with us. We know how important stories are in helping others feel less alone.

COVID-19 has certainly thrown many things at us as an organisation, at you, at our families and friends, and at our healthcare system. Our focus now is on addressing the issues that have arisen since the coronavirus first impacted Australia in March this year.

In particular, we have been using our voice to highlight the many challenges families right across Australia have been facing with palliative care. We have joined together with Canteen and Cancer Council Victoria to work with government on increasing community palliative care investment but also on hospitals and governments ensuring families can be together as they near end of life.

You can read more about this in the Latest News section of our website (bcna.org.au/news/2020/09/cancer-organisations-urgent-plea).

Thank you to everyone who completed our COVID-19 impact survey. This is the largest breast

cancer consumer survey completed in Australia. The team has developed a summary of the results, which you can view on page 10. If you need any additional support or have questions, please call our Helpline on **1800 500 258**. Our team is here to help.

COVID-19 has impacted more than just the healthcare system. It has meant that our May Pink Bun campaign was postponed to October. Our 20-year partnership with Bakers Delight means the world to us. We could not have continued to provide the information, support, connection and voice for everyone affected by breast cancer without them. I would love you to go into your local Bakers Delight store, buy a Pink Bun and say thanks. If there is no local Bakers Delight near you – don't worry! Simply learn how you can buy virtual Pink Buns by visiting pinkbunparties.com and support this amazing partnership.

2020 certainly has been a year many want to forget, but I do hope that if you need support you know that we are here for you. It is important that we all stay connected and feel supported. Finally, I wanted to say a very big thank you to our hundreds of volunteers across Australia. They are the women and men who have supported BCNA this year. Whether it be through being advocates for our network, sharing your stories, running events or processing our donations – we are a community network and we are so grateful for your commitment and passion for BCNA.

Kirsten Pilatti
Chief Executive Officer

► BCNA's webcast *Living well with metastatic breast cancer* is one of many resources available to members living with metastatic breast cancer that provides information, support and connection.



UPDATES TO GUIDANCE FOR MANAGEMENT OF EARLY BREAST CANCER

Cancer Australia has released updates to its Guidance for the management of early breast cancer, a document aiming to provide health professionals with up-to-date evidence-based guidance for the management of patients with early breast cancer.

The guidance aims to support the delivery of best practice patient-centred care and will assist health professionals and patients alike in shared decision making around the management of early breast cancer.

The scope covers management of early breast cancer across the patient journey – from breast cancer diagnosis, through treatment planning and information and support for patients prior to treatment, treatment delivery, to follow-up of after active treatment and survivorship care for people living with and beyond early breast cancer.

BCNA Consumer Representative Leanne Carlson contributed to the development of the Guidance through her position on the steering group; offering expert input, advice, insights and feedback. BCNA also provided feedback on the draft guidance during the consultation period.

To read more about the new guidance, visit Cancer Australia's website, guidancebreastcancer.gov.au

Compression garments for South Australians with lymphoedema

BCNA welcomed the announcement in July this year of the new South Australian Compression Garment Scheme.

The lack of a state compression garment scheme in SA was highlighted by BCNA in our 2018 State of the Nation report, and this announcement followed lobbying by many organisations and individuals who used their personal experiences of lymphoedema to advocate for change.

BCNA Consumer Representative Elizabeth Anttila who has been involved in the South Australian Lymphoedema Garment Subsidy Scheme Advisory Group since 2019, described a feeling of great satisfaction upon hearing the news.

'Even though the wait has been long, the scheme is one of the best in Australia. There are no exclusions and there is no cost. I fought particularly hard for there to be no exclusions so that people whose private health fund does not provide a rebate for compression garments would be eligible', Elizabeth said.

You can find out more about lymphoedema via the BCNA factsheet, bcna.org.au/media/7857/bcna_lymphoedema_factsheet_aug20.pdf.

CANCER ORGANISATIONS' URGENT PLEA FOR SUPPORT TO HELP FAMILIES CARE FOR DYING LOVED ONES

BCNA and Canteen have joined forces to push for more support for Victorians who are facing end-of-life care during the COVID-19 pandemic, with healthcare service visitor restrictions and reduced community support services placing additional strain on families.


The leading consumer cancer organisations say there is evidence of growing distress by more Victorian families being forced to care for dying relatives at home due to fear of restrictive visitor

policies and concern that COVID-19 screening requirements for palliative care patients could mean that loved ones may die alone in hospital.

BCNA CEO Kirsten Pilatti says, 'We know of families at breaking point because they are choosing to tough it out at home juggling work and home schooling while caring for dying relatives because they would rather spend their last hours with their loved ones than risk them dying alone in the healthcare system due to COVID-19 restrictions.'

We are calling for healthcare services to overturn bans on young people visiting family members who are unwell, increase compassion to families going through already difficult situations, and increased funding to ensure people can access timely and adequate palliative care community services to enable them to safely care for loved ones at home.

Read our full media release here, bcna.org.au/news/2020/09/cancer-organisations-urgent-plea.



NEW STANDARD ENCOURAGES DOCTORS TO DISCLOSE OUT-OF-POCKET COSTS

For many years, BCNA has heard from Australians diagnosed with breast cancer who have been hit with large unexpected bills for their breast cancer treatment; an experience known as bill shock. These bills often add to the distress of their breast cancer diagnosis, coming at a time when individuals and families are already coping with the fear, uncertainty and stress of a cancer diagnosis.

In an effort to increase transparency around out-of-pocket costs of treatment and encourage patients and doctors to discuss fees before treatment begins, BCNA collaborated with Cancer Council Australia, CanTeen and Prostate Cancer Foundation of Australia to develop a Standard for Informed Financial Consent (cancer.org.au/assets/pdf/standard_for_informed_financial_consent).

The standard aims to ensure that people diagnosed with cancer are given information by their treating team about the expected out-of-pocket costs for their cancer treatment and care. We hope this will help people to understand their potential out-of-pocket costs so

that they can include these in their budget or shop around for another clinician who might offer lower fees. This will help to reduce bill shock.

In 2017, BCNA surveyed over 2,000 people on the out-of-pocket cost associated with their treatment. Our research found a wide range in out-of-pocket costs. While 12 per cent of those surveyed reported having no out-of-pocket costs, 25 per cent reported out-of-pocket costs of over \$17,200. People having their treatment in the private health system were found to have higher out-of-pocket costs than those in the public health system, with a quarter of survey respondents with private health insurance reporting out-of-pocket costs of more than \$21,000.

BCNA believes it is vital that health professionals have upfront conversations with people diagnosed with cancer about the direct and indirect costs of their treatment and care. While it is not compulsory for doctors to follow the standard, we hope they will use it to guide conversations with their patients. The Standard sets out the types of expenses patients should expect their doctors to tell

them about, such as the cost of surgery, including anaesthetist fees and other associated fees, costs for diagnostic tests, and costs of supportive care services.

The standard also notes that doctors should have conversations about some of the more indirect financial implications of various treatment options, such as lost income due to time off work or reducing working hours.

To further support people affected by cancer and their families to understand the financial costs of cancer, Cancer Council has developed a new fact sheet, *The financial cost of healthcare: information for people with cancer and for those caring for someone with cancer* (cancer.org.au). A number of BCNA Consumer Representatives helped with the development of this information, and we thank them for their input and feedback.

More information about the financial cost of breast cancer, including financial support and assistance that may be available, and financial tips to help you, is available on BCNA's My Journey online tool, myjourney.org.au.

Demystifying palliative care

The term ‘palliative care’ is often misunderstood. It is frightening because mostly we associate it only with end of life.

While palliative care does support people through their final months and weeks to ensure they are comfortable, it actually offers much more and can have many benefits if used early.

Common misunderstandings with palliative care are that:

- it is only offered to you when you are in your last months or weeks of life
- you will no longer receive treatment aimed at controlling your cancer and prolonging your life
- you won't see your medical oncologist, breast care nurse or other members of your treating team.

In fact, none of these things are true.

Palliative care services can complement your breast cancer treatment and help you manage your illness so you can continue to live your life as fully and as comfortably as possible. You can dip in and out of it, using services just when you need them – for example, to get pain under control.

‘My palliative care team has been amazing. They linked me with services and supports that would have been great to know about three years ago when I was first diagnosed with metastatic breast cancer.’

– BCNA member

Getting to know your palliative care team early, while you are still feeling relatively well, can be helpful so that you know who they are and how they can support you in the future. Some of the services that you might find helpful at different times include:

- help to manage pain and other symptoms, for example vomiting or shortness of breath

- provision of equipment, such as a shower chair or special bed, to help you at home
- helping your family to have difficult conversations together, or to talk to children about your illness
- connecting you to other services such as home help and financial support
- support to help you with cultural obligations
- counselling and grief support
- referrals to respite care services.

‘I see a palliative care nurse practitioner regularly about prevention – deep breathing to prevent pneumonia, for instance.’
– BCNA member

Many people are surprised to learn that palliative care offers a family-centred model of care. It is there not just for you, but for your family as well. This means that your family and carers can receive practical and emotional support, as well as physical support such as home help or access to equipment that can help you live independently.

Many people find that support for their family is as valuable as the support they receive themselves.

BCNA has resources that can help you to better understand the benefits of palliative care.

In our podcast *How palliative care can help – symptom management*, BCNA Community Liaison Marie Pandeloglou shares her experience of using palliative care services, and Medical Oncologist and Palliative Medicine Physician Associate Professor Michael Franco explains, among other things, how palliative care can help with symptom management, when to access it, and what the costs are.

The Palliative Care Toolkit (palliativecare.org.au/living-well-with-metastatic-breast-cancer) is another online resource that is available free of charge. Developed by BCNA and Palliative Care Australia, it asks five questions about the concerns you may have related to your illness and provides you with information specific to your needs. It also has information about palliative care services that may be available in your area.

For more information about what palliative care can do for you and your family, visit the My Journey online tool: myjourney.org.au/article/1394.





GETTING THE MOST FROM YOUR TELEHEALTH APPOINTMENTS

Early in the COVID-19 crisis, the Australian Government extended Medicare rebates to allow more doctors to offer telehealth appointments to their patients.

You may have had a telehealth appointment in the last few months – a medical consultation done online using technology such as Zoom, Skype or FaceTime, or over the phone.

There are many benefits of telehealth appointments, including not having to leave home, but they don't suit everyone and don't suit every type of appointment. If you need a clinical examination, for example, you will probably need to go to the clinic or hospital.

BCNA believes that appointments where a person might be told about a new diagnosis or a change in treatment plan should also be done at a face-to-face appointment if possible.

Telehealth appointments can be used for:

- results of scans and tests
- advice on managing symptoms and side effects
- follow-up care
- repeat prescriptions
- advice on diet and exercise
- counselling
- referral letters.

There are some simple tips that can help you prepare for your

telehealth appointments so that you get the most out of them.

GET THE TECHNOLOGY RIGHT

Download and test the technology before the day of your appointment so any problems can be sorted out. You can use a smartphone, iPad, laptop or a computer that has a camera, microphone and speakers. You'll need a reliable internet connection. On the day of your appointment, set up your device 5 or 10 minutes before your appointment so you are ready to start on time.

Find a space that is quiet and where you won't be interrupted. Turn off the TV, radio and any other noisy appliances. Choose a spot where you are lit from the front – don't have a bright window behind you. This will let your doctor see you more clearly.

Have a pen and paper so you can take notes.

THINK ABOUT WHAT YOU WANT TO ASK

You'll get the most out of your appointment if you're well prepared with information and questions.

If you've noticed any new symptoms or side effects, keep a record of when they started, how bad they are and how often you are noticing them, so you can let your doctor know.

Write down any questions you want to ask when you think of them (before your appointment). Put them in order with the most important ones at the top of the list in case you run out of time.

It can sometimes help to have a family member or friend to support you. They can be in the room with you or on the call from their own home. Let your doctor's rooms know beforehand if you want to connect someone else in. If you have someone with you, ask them to take notes about what is discussed.

CAN I ASK FOR A FACE-TO-FACE APPOINTMENT INSTEAD?

You don't have to accept a telehealth appointment. However, they are often recommended to reduce the risk of exposure to coronavirus.

If you do need or prefer a face-to-face appointment, be assured that hospitals, specialists and GPs have put procedures in place to ensure that you will be as safe as possible when visiting a hospital or clinic. Don't forget to follow the social distancing and other safety rules that apply where you live.

Get more tips for telehealth appointments via the My Journey online tool: myjourney.org.au/article/3200.

YOUR VOICES HELP US ENSURE COVID-19 LESSONS ARE LEARNED

BCNA has heard from many women, men and families over the past several months about the impact of the COVID-19 pandemic on your lives. We know it has caused increased stress and anxiety for many people, and that for those currently undergoing treatment there may have been changes to your appointments and sometimes the treatments you have received.

After the initial outbreak of coronavirus around the country earlier this year, BCNA decided to survey our members to try to better understand how you were affected.

Our survey was open for two weeks from 22 June to 6 July (before the second wave of cases in Victoria). More than 2,300 people participated. If you are one of them, thank you for contributing to this important piece of research.

We are using the survey results, and therefore your voices, to help us in our work to ensure that breast cancer treatment and care continues to be offered in line with the breast cancer Optimal Care Pathway, and that lessons are learned on how to best deliver care in such difficult circumstances.

In particular we will be focusing our efforts on two key findings from the survey: delays to breast reconstruction surgery and the experiences of people using telehealth for their breast cancer appointments.

BREAST RECONSTRUCTION

We are particularly concerned about the impact of government bans on elective surgery, including breast reconstruction surgery, during coronavirus peak periods. We have heard from breast cancer surgeons that bans on elective surgery have meant that many women were not able to have immediate reconstruction as part of their breast cancer surgery. This was reflected in our survey, with 39 per cent of women wanting a breast reconstruction at the time of their cancer surgery not able to have it (110 women). We can assume that this number is now higher, as elective surgery was again banned during Victoria's extended period of lockdown from August to October.

Bans to elective surgery have resulted in a backlog of surgeries, which may further delay access to breast reconstruction. We will be monitoring waiting times around the country, and would love to hear from you if you find you have a long wait for your reconstruction.

TELEHEALTH

Another area of interest in our survey was telehealth services. While many people had very positive experiences with telehealth consultations, there were some clear areas where improvement is needed to make these better for patients. We will be working with health services and governments to encourage the following:

- greater use of video (instead of phone) telehealth consultations
- ensuring patients do not feel rushed and that complex issues are not explored in telehealth consultations
- providing in-person appointments when someone is newly diagnosed, meets their treating team for the first time or where a physical examination is required
- communication skills training to help doctors improve their telehealth consultations
- better support for patients who have trouble with the technology
- more research into patient experiences with telehealth to improve services.

OTHER PRIORITIES

Other actions that BCNA will be taking over the coming months include:

- encouraging people to continue their regular screening mammograms and encouraging anyone with a change in their breast or other new symptom to see their doctor
- ensuring people with breast cancer continue to have access to allied health services, such as physiotherapy and lymphoedema therapy, and mental health services.



SURVEY RESULTS

The survey found that the COVID-19 pandemic affected all aspects of breast cancer care, including diagnosis, treatment, follow-up care and supportive care.

Changes commonly discussed by survey participants included:

- the use of telehealth for consultations with cancer specialists, breast care nurses and GPs
- restrictions on family members or other support people being able to attend consultations or treatment sessions
- restrictions on hospital visitors
- new procedures at hospitals and clinics aimed at infection control.

'Didn't meet face to face with most of my team, medical oncologist, plastic [reconstruction] surgeon due to COVID-19. Had phone calls and sent photos.'

– survey respondent

More substantial delays and changes reported included:

- delays in being diagnosed due to the closure of screening services, or delays receiving tests and scans to investigate symptoms.

'BreastScreen bus not coming to perform routine tests, which delayed my findings.'

– survey respondent

- changes to the type of breast cancer surgery performed to reduce the time the patient needed to stay in hospital or to avoid post-surgery treatments such as radiotherapy and chemotherapy.

'My hospital stays with each surgery with shortened because of COVID. Sent home 24 hours after major surgery. Awful!'

– survey respondent

'A full mastectomy was performed to avoid radiation and additional hospital visits, however a double mastectomy was not possible during COVID.'

– survey respondent

- delays to breast reconstruction surgery

'Unable to offer immediate reconstruction due to COVID-19.'

– survey respondent

- changes to treatment plans

'Radiotherapy was delayed for six months. Began hormone-blocking therapy prior to radiotherapy.'

– survey respondent

'Post surgery I was given all the facts by my surgeon and oncologist and, due to COVID-19, we all agreed that chemotherapy was more of a risk for very little gain.'

– survey respondent

- delays and changes to clinical trials.

The survey also found a significant impact on follow-up care and survivorship care. Six hundred people reported delays or changes to follow-up care appointments, and 456 reported changes or delays to allied health services including exercise physiology, lymphoedema therapy, physiotherapy, group exercise programs and nutrition support.

'Physiotherapy delayed due to concerns around COVID-19. Plans to see exercise physiologist and re-engage with breast cancer rehab program delayed as program was ceased during COVID-19. Plans to utilise gym/class/pool membership delayed due to centre closure and restrictions during COVID-19.'

– survey respondent

THE USE OF TELEHEALTH

A commonly reported change was the use of telehealth for appointments, with 1,433 people having at least one telehealth appointment, mostly by telephone.

When asked if telehealth had been helpful, 775 said it had been, discussing benefits such as minimising the risk of being exposed to coronavirus, the convenience of being able to have the appointment from home, and that telehealth allowed treatment and care to continue during the pandemic.

Another 410 said they found it helpful but had some sort of challenge with it, such as:

- feeling uncomfortable lifting up their top
- appointments that felt rushed, short and less personal
- difficulties explaining complex health issues over the phone
- problems with technology
- difficulty finding a private space at home for the appointment.

'I found it difficult to discuss my concerns over the phone. I had questions about post-surgery pain and post-surgery scar puckering.'

– survey respondent

THE EMOTIONAL IMPACT

Worryingly, more than half of all respondents (1,639) reported some degree of anxiety about the impact of the pandemic on their care. Key concerns included:

- the impact of breast cancer treatment on their immune system
- worry about potential delays to treatment and care
- not being physically examined by doctors due to the shift to telehealth appointments
- contracting coronavirus while attending health services
- the lack of a support person at appointments or when receiving treatment
- the closure of allied health services and other supports.

'It has been a difficult experience finding out that I have cancer and it is compounded by the fact that I live on my own. My family, friends and I have all been in isolation. Distractions with social engagements, shopping, etc. have not been happening and even food shopping for myself initially was somewhat challenging.'

– survey respondent

BCNA will continue to investigate the ongoing impacts of the COVID-19 pandemic on Australians with breast cancer. If there is anything you would like to share with us, please email us at contact@bcna.org.au.



We caught up with BCNA Consumer Representative Jenny Muller, who was diagnosed with early breast cancer in 1996 and then metastatic breast cancer in 1998, to talk all things exercise, wellness and staying motivated (especially in the midst of the COVID-19 pandemic).

At what stage of your journey did you come to learn more about exercise and the role it can play after breast cancer diagnosis?

With my initial early breast cancer diagnosis, information and advice about breast cancer and exercise

was fairly scarce. For me then, the Encore breast cancer exercise program was superb.

With my metastatic breast cancer diagnosis in 1998, I benefited from specific rehabilitative exercise care. A complementary health professional noticed how I was weak and unsteady, and suggested a GP referral to a specialist rehabilitation doctor. This for me meant a prescribed exercise program in the hospital gym. The hydrotherapy pool made walking easier and I gradually became stronger.

Since then, I've understood exercise as a key to being as well as possible during cancer.

What kept you continuing to exercise once that initial program had ended?

The understanding and support of my family and the interest of my doctors helped me enormously. It was a relief for us all with me getting around more easily, able to walk for exercise and walk to the local pool.

Also it feels positive working on self-care. I experienced the pleasure that comes from the feeling of lungs expanding, muscles happy to be worked, knowing I'm helping my bones out, the sense of relaxation in between exercise sets, and the earth under my feet when I'm outside.

“

While I dearly miss get-togethers, exercising via telehealth has enabled me to join up with others who have similar health aims to me.

”

What does exercise bring to your life?

Beyond the benefits of working with an individual routine, the social aspects of exercise classes are both fun and, for me, good motivation to keep attending.

I find joy in moving as a group, feeling the instructor's expertise and care, and the collective energy when people share similar reasons for attending.

You can be stood there doing arm windmills, but put the music on and there is a real sense of fellowship.

At present, we need more information to help us say how people with metastatic breast cancer might or might not benefit when they choose to include exercise and nutrition guidance in their healthcare. Through my role as a BCNA Consumer Representative, I've had the chance to follow a University of Queensland clinical trial designed to investigate this area.

▼ Star jumps with family at home: Jenny finds joy in exercising outside with others



How has your routine changed in light of the COVID-19 pandemic?

Thanks to the gift of technology and the work of many health organisations, I've been able to keep up with exercise classes and a support group throughout the COVID-19 pandemic.

I greatly benefit from the motivation, structure and purpose that comes from committing to group exercise. While I dearly miss get-togethers, exercising via telehealth has enabled me to join up with others who have similar health aims to me.

You need a little online technology knowhow for video telehealth. It was a big relief for me to have kind extra help in my first session with my exercise physiologist. Her patience, and possibly my not giving up when I constantly lost the picture or sound, gave me the confidence to seek more video-based telehealth.

What's your advice for others living with metastatic breast cancer?

There's an energy balance to find that's a part of living with metastatic breast cancer. There's such a huge variety of ways that treatments, effects and timelines can impact people. So it's important to seek tailored plans, in line with the fitness

activity and sport we enjoy, with expert assessment.

Thinking beyond just exercise is also positive. Since the pandemic hit, it's been fun joining in to a host of other simple and enjoyable activities online; from art to drumming classes, offered by health organisations to help build a holistic sense of wellness.

There are many sources of support out there: physiotherapists, exercise physiologists as well as the not-for-profit health organisations who have put their endeavours into helping us out during COVID-19.

Phoning a hospital or McGrath metastatic breast care nurse can refresh knowledge of resources to help keep on track. A phone consultation with your GP can begin an application to Medicare for an Enhanced Primary Care Plan. Even if the first steps feel like baby steps, give yourself a tick for starting!

Right now, I'm doing my own small bit to keep myself moving. I know that starting to get active again, perhaps after a rough patch, sticking at it, and keeping in touch with experts and others in similar situations does help.

If you'd like to learn more about exercise and metastatic breast cancer, visit our My Journey online tool myjourney.org.au/article/1426.



ASK THE EXPERT

'I'M NOT PANICKED, I'M JUST FLAT'

– STRESS AND COVID-19

Dr Carrie Lethborg is a senior social worker at St Vincent's Hospital, Melbourne. She has been a leader in cancer and end-of-life care for over 30 years and has held numerous executive positions on cancer-related organisations. She has worked with BCNA for over a decade. In this article, she explains the psychological impact of COVID-19, and explores why you might be feeling drained and flat.

When the first wave of the COVID-19 pandemic hit, life changed for most people. However, many of us found ourselves adjusting, demonstrating the remarkable ability of humans to pivot (especially those who are around cancer).

At first, we were able to move past the initial disbelief of this major life change and shift to incorporate the new reality presented to us. The problem is that even this incredible capacity to adjust has its limits.

SO, WHAT'S ACTUALLY HAPPENING FROM A PSYCHOLOGICAL PERSPECTIVE TO MANY PEOPLE RIGHT NOW?

The COVID-19 pandemic has presented an ongoing accumulation of stress for many of us.

Cumulative stress is often explained in this way: imagine you have a bucket that you keep full of good things for your wellbeing – enough sleep, good nutrition, exercise, connecting with loved ones and pets, nature, work and so on (at least we aim to).

These positive things buffer the things that drain your 'wellbeing bucket', like juggling work and home, relationship issues, health concerns, worry and so on. Usually we are able to balance the inputs and outputs of our bucket, adjusting as needed but generally keeping it steady.

But when stress is prolonged and accumulates; when we get one worry after another without the time to release and rebalance, we can feel drained. That's where the symptoms of cumulative stress start to be seen.



▼ Dr Carrie Lethborg
is a senior social
worker at St Vincent's
Hospital, Melbourne.



WHAT'S THE IMPACT OF CUMULATIVE STRESS?

Unlike a sudden stress, where we might feel anxious and ready to run or hide, the build-up of stress over time can result in a 'flattening' of our mood as we hit overload.

We can feel bored, fatigued or unable to concentrate. We can lose our short-term memory, forgetting what we needed at the shop or what we were going to do when we walk into a room. To make this worse, we lose the energy to do the things that help to fill up our wellbeing bucket, because we feel listless.

This can move from relationship issues, 'numbing' behaviours such as alcohol or drug use, overeating and withdrawing from others to more concerning impacts on our health, ability to do work and connect with people who give us energy.

WHAT CAN WE DO ABOUT IT?

The same rules apply when it comes to managing cumulative stress as they would to any stress: you need to stop, remove yourself from the stress in some way and regroup, take a walk, turn off the news, make yourself go to bed at a reasonable time, call a friend and factor in some regular things that you know make you feel better.

It's time to start making time again to refill our wellbeing buckets.

Structure in regular walks, yoga, meditation or stretching (or a combination), pull-back on some of the unhealthy eating that might have been creeping in and start some small projects (e.g. cleaning out a cupboard, starting a puzzle, calling a different friend every couple of nights).

We need to identify the things that are raising our anxiety, and either avoid them or alter how we encounter them.

As humans, we are amazing. We have such an incredible ability to manage change and trauma, but none of us can do this for prolonged periods of time without rebalancing regularly. More stress requires more focus on wellbeing – know what sustains you and do more of it.

You will soon find your energy to manage and enjoy things gradually return.

If you need support, call BCNA's Helpline on **1800 500 258**.



HELP FOR
FAMILY AND
FRIENDS
WHO HAVE
QUESTIONS

HELP
WHEN
YOU HAVE
QUESTIONS
ABOUT
YOUR
DIAGNOSIS



1800 500 258

**Breast Cancer Network
Australia Helpline**

**Free, confidential support,
information and referral**

WITH YOU EVERY STEP

BCNA member and businesswoman Kate Goodman reflects on the impact of her breast cancer diagnosis on her work, life and identity, and why she feels compelled to give back to BCNA.

Finding BALANCE

Kate Goodman is used to life being a careful balancing act; working as a busy and successful winemaker. The irony is that in 2018 when she was crowned Australian Female Winemaker of the Year, Kate's life had little equilibrium; the fallout of a Stage 2 breast cancer diagnosis.

Well-accustomed to the physical commitment and challenges of a hectic work schedule, Kate remembers being completely exhausted from two surgeries and six weeks of daily radiation.

'I have never known fatigue like it but I think part of me was in denial. I felt like it wasn't serious enough,' she says.

She tried to lessen the impact by eating well, receiving acupuncture several times a week and working reduced hours. But what followed the week after her treatment finished took her by surprise. As she describes it, 'I just couldn't focus, I completely crashed.'

For many women slowing down and relinquishing control isn't easy. For Kate it was the brutal realisation that she needed to take time to heal and accept help.

A colleague took care of her business in Victoria's picturesque Yarra Valley, while the local community stepped in to help her husband and son with school runs

and meals. It was during this time that Kate also made use of BCNA's resources and did a lot of reading.

She credits a fantastic relationship with her GP for giving her the confidence to seek a second surgical opinion and arriving at a decision about chemotherapy.

'Chemotherapy was talked about as a back-up but I made an informed decision not to have it,' she recalls.

Part of Kate's recovery was also reassessing her work and life balance. There's no doubting that Kate is great at what she does; known for her brave approach to the craft and not afraid to take risks.

Prior to her diagnosis, she had been dividing her time and family between Victoria and South Australia, but in 2019 made the decision to base herself in South Australia full-time.

'Having breast cancer was a reality check and there wasn't much enjoyment in rushing between two states. Life has less stress this way.'

Now aged 50 and in good health, Kate feels passionate about paying forward the support she received. 'My life is great and I am in a position to give back', she smiles.

Kate has just released a limited edition Rosé; created under her Nikkal label, with 100 per cent of profits going directly to BCNA.

Grief, gratitude and pixie dust:

SALLY OBERMEDER ON HER BREAST CANCER JOURNEY

Sally Obermeder is a picture of good health. Her life looks perfect: a successful media career, thriving online business and a loving family. It's easy to forget that a few years ago, on the due date of her first baby, she was diagnosed with Stage 3 triple-negative breast cancer.

Sally remembers it as a day that started like any other. 'I felt well and it had been a great pregnancy. Even when I felt the lump, cancer was the furthest thing from my mind', she says. 'When I got the diagnosis, it was like the world just fell out from under me, and my question was – am I going to die?'

Sharing her vivid memories on the *Upfront About Breast Cancer* podcast, Sally recalls being induced the next day and daughter Annabelle arriving safely. But there was little time to celebrate, as the new mum began intensive treatment.

'It was a grief-stricken time. The first everything was out the door. They let me do one [breast] feed, and that was it.'

Nine months of gruelling chemotherapy and radiation took an enormous toll physically and mentally, but amid the sadness Sally says she still found comfort and joy in simple things such as holding her baby, smelling her and taking time to enjoy beautiful meals.

Another challenge for Sally was to accept that she not only needed a double mastectomy, but that she would need to undergo two separate surgeries several months apart, removing one breast at a time.

Sally admits to struggling during this period and having to wait for reconstruction. 'The shame I felt was surprising. I'd lost my hair, eyelashes, already lost my entire identity, and then I had this

emotion that I wasn't prepared for.'

Many of those who've had breast cancer or supported a loved one with the disease will identify with Sally's observations of the impact it had on her relationships and her own wellbeing.

'You have to go through the grief before acceptance. There are so many scars, but that's just who I am, and you work out what is important to you.'

She also encourages those undergoing treatment to be specific in articulating ways people can make things easier for you; whether it's cooking or cleaning, or sitting with you and saying nothing.

'People want to help you. It's not medicine but it's helpful. It's the pixie dust. Tell them – they want to know.'

Having another child after recovery was important to Sally and her family. She talks with candour about the surrogate process, remembering some of the crazy comments well-intentioned friends and strangers would make.

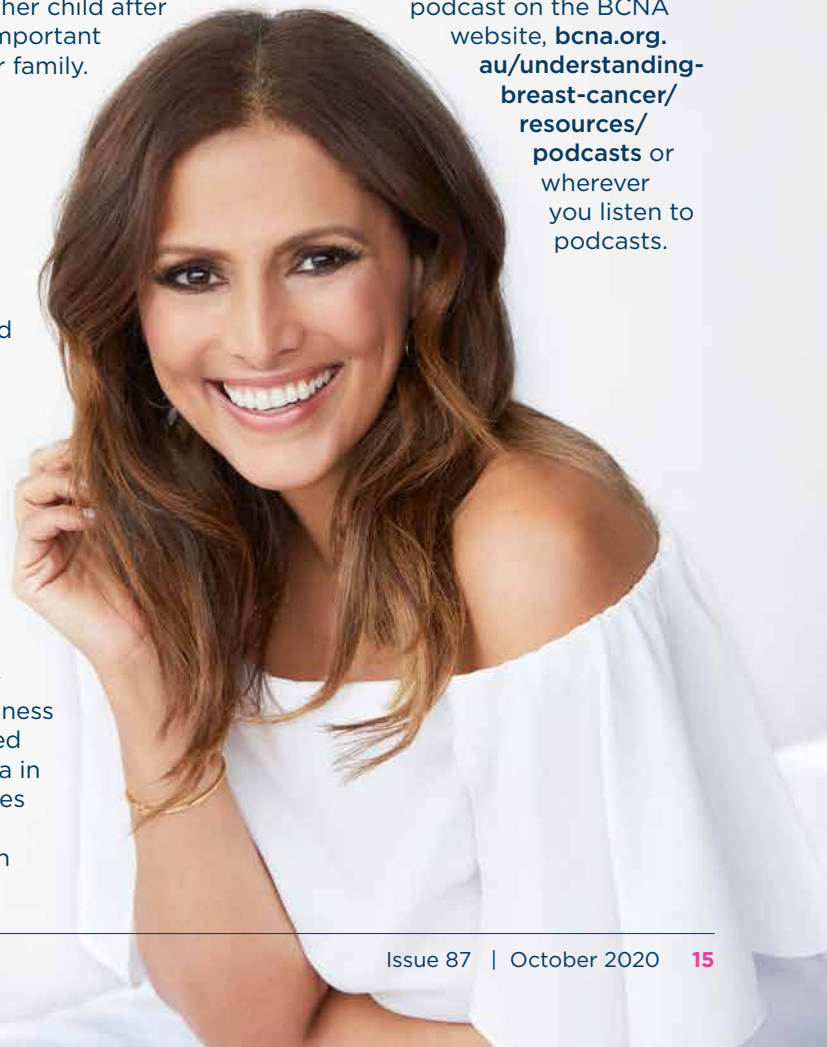
Now a mother of two little girls, life is busy both personally and professionally. Her online fashion, beauty and health business SWIISH, founded with sister Maha in 2015, encourages women to be the best version of themselves.

It is through her breast cancer experience that Sally believes she is a little more brave and fearless and shares with listeners why she has no time for second-guessing; 'I have a deep sense of gratitude, because every day is day I thought I wouldn't get.'

Even nine years on, the now 47-year-old admits sometimes she fears the breast cancer will come back, and triggers that remind her of her ordeal can sit just below the surface.

Sally uses her experience as a reminder that no one knows what tomorrow will bring, and the importance of being kind to yourself and finding things that make you happy.

You can listen to Sally on the *Upfront About Breast Cancer* podcast on the BCNA website, bcna.org.au/understanding-breast-cancer/resources/podcasts or wherever you listen to podcasts.



THE RIPPLE EFFECT OF BREAST CANCER

There are many things that forge strong bonds between sisters, and the McGrath siblings hoped that breast cancer would not be one of them.



Liz and her younger sister Felicity had watched their mother Gaye live with the disease from when they were just three and five years old.

Nine years later, Gaye's breast cancer became metastatic. For the girls and their three brothers, 'Mum's wig and treatments' over the course of 12 years – which included bouts of chemotherapy, radiation and mastectomy – was a way of life.

Gaye was determined to undertake any treatment that would prolong her time with her family, so her death at just 48 years old came as a shock, and at 18 Liz remembers 'having to grow up very quickly'.

It was when she turned 36, the same age her mother had been when she was first diagnosed, that Liz was told she had early breast cancer.

'I was pragmatic', she says. A mother of two young children at the time, Liz and her husband Chris had always planned to have a third child, and so decided to preserve her eggs before she underwent a double mastectomy, chemotherapy and radiation.

It would be another four years before she was able to consider pregnancy and, with several other changes to their family, Liz ultimately made peace with the fact that another baby 'was not meant to be'.

When Felicity turned 36, despite not having the BRCA gene, she had already decided to have an elective mastectomy given her family's history. A mother to three young children, she didn't want to take any chances.



The sisters opted to share a hospital room, with Felicity's surgery coinciding with Liz's reconstruction. It was only later that pathology revealed Felicity had DCIS in one breast.

'It was really comforting to have each other,' Liz recalls. 'You never think you will be on a breast cancer journey with your sister. Having already lost our mum, we were ready for the battle, but it was still tough.'

And it was tough not just on them but their families.

Fast forward seven years, and the pair exude happiness and good health. Liz has had a career change and now fits women with prosthetic breasts.

'I find it incredibly rewarding to be able to provide some comfort to women during a very difficult and emotional time in their lives', she says.

Liz and Felicity are closer than ever and their bond was evident at the photo shoot for the 2020 Pink Bun Campaign.

The theme of the campaign is the 'ripple effect' of breast cancer or, as Liz describes it, 'more like a tidal wave for our family'.

Amid the laughter, they admit that few people realise how many family and friends are affected by one person's diagnosis.

Liz recalls that breast cancer 'impacted our entire childhood and changed our family forever'. Then, as adults with the disease, the impact was felt all over again as 'Your kids, husband and extended family as well as your friends are impacted too and it lasts a long time.'

Liz and Felicity say they have been each other's mum, sister and best friend. 'We're so glad we got to go through it together.'

For more information on the Pink Bun campaign, visit bcna.org.au/news-events/pink-bun-campaign.

Marie is making a difference

Marie Daly was 76 when she was diagnosed with breast cancer in 2016.

Marie used the experience – and her gratitude for the help she received – to throw her support behind BCNA and its work.

'When I was originally diagnosed, I felt very alone. BCNA provided great support to me during my time of need, and I am forever grateful for the wonderful support I received during this time', she says.

'After my experience, I wanted to leave a legacy in the form of a bequest, and make a positive difference in helping people who may be diagnosed in the future.'

'I hope my bequest will make it possible for others to live long and happy lives.'

Marie says she wants 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 couldn't have been easier.'

She also says it's important to know all gifts make a difference, and are welcomed by BCNA. You don't have to be wealthy to include a gift in your will.

'I always say if you can't give now you can leave a gift after you go, so write it in your will. No matter how small, we can all do something, and every gift helps.'

If you are interested in learning more about leaving a gift in your will to BCNA, or would like a confidential discussion, please contact BCNA's National Manager Major Gifts Gerrard Peck on mobile **0402 124 624**, or email gpeck@bcna.org.au.



UPFRONT

ABOUT BREAST CANCER

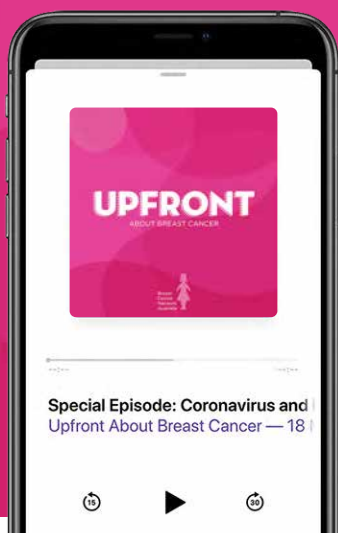
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THE PYJAMA PROJECT

BCNA and Sussan have been proud partners since 2005. In that time we have developed many beautiful gifts, but this year, we're taking it to a whole new level.

This October, look out for *The Pyjama Project*, an exclusive collection of unique sleepwear which directly supports BCNA.

The Pyjama Project 2020 features two exclusive designs and prints created by an artist who has been through her own breast cancer diagnosis, Lisa Swards.

The Sussan campaign heroes the real, human faces of breast cancer and the network of friends and family supporting their journey, with Kimmie Jonceski and BCNA Board member, Lisa Montgomery fronting the campaign.

Since her breast cancer diagnosis in 2005, Lisa has been a fervent supporter of BCNA. She began helping and giving back by writing a book to help parents talk honestly with their children about breast cancer. Entitled *My Mum has breast cancer*, Lisa wrote the story through the eyes of her son, Harrison, who was aged six at the time.

The Pyjama Project collection will be available in stores and online from 7 October 2020.

▼ Kimmie Jonceski and Lisa Montgomery pictured with their support people at the campaign photoshoot





WHAT A PARTNERSHIP!

Twenty years ago, the founders of BCNA and Bakers Delight foresaw the tangible difference their collaboration could make to women and men with breast cancer and their families. Now, we reflect on what it is that's made this 20-year partnership so very special.

Twelve months ago, if anyone had told BCNA that in its 20th year of partnership, Bakers Delight would break with tradition and run the Pink Bun campaign in October, promote virtual Pink Buns alongside real ones or launch the Pink Bun campaign via video conference, we wouldn't have believed them.

But with the benefit of 2020 hindsight, these changes to Pink Bun 2020, could not be more real or demonstrative of BCNA's partnership with Bakers Delight.

In the early days, BCNA founder Lyn Swinburne recalls the time when she bumped into Bakers Delight co-founders Lesley and Roger Gillespie at a dinner where she'd been the speaker. She was talking about her passion to establish a national organisation for women with breast cancer, and Roger and Lesley believed in Lyn's vision.

'I had no idea what I needed in those days. I was running on energy and passion and not much structure. When I finally worked out I needed an office space and everything that came with it, Lesley and Roger agreed in a heartbeat. The rest, as they say, is history!'

BCNA's CEO Kirsten Pilatti also reflects on the support BCNA has received since the start of the pandemic.

'Even as COVID-19 hit, while Bakers Delight CEOs Elise Gillespie

and David Christie were focused on their hundreds of bakeries staying open, they still called to make sure we were ok, and offer any help we may have needed. It is true friendship and true support,' Kirsten says.

In a year when Bakers Delight and its 383 franchisees could have said the Pink Bun campaign 'is just too hard', instead they asked, 'What can we do differently to make this work?'

So in recognition of our incredible longstanding partnership, we're asking you to support your local Bakers Delight. While you're in store buying your Pink Buns, pick up a loaf of bread as well. Tell your local franchisee how much you appreciate their support and then tell your friends and family on social media. And don't just visit your local franchisee in October; be sure to support them all year round.

Foundation Partner

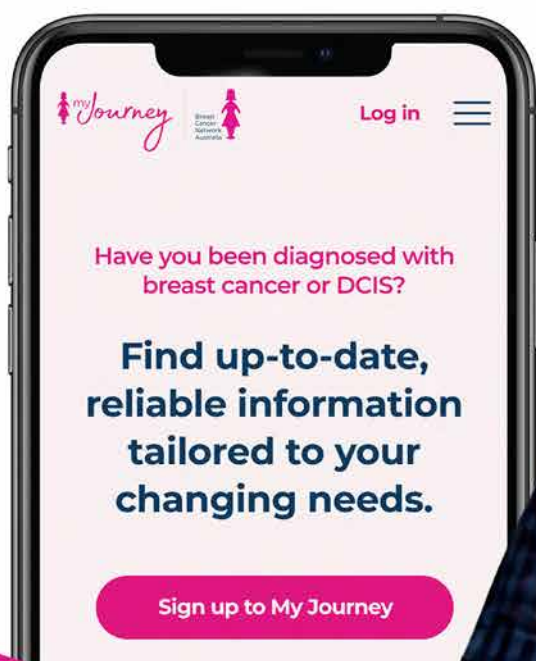
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