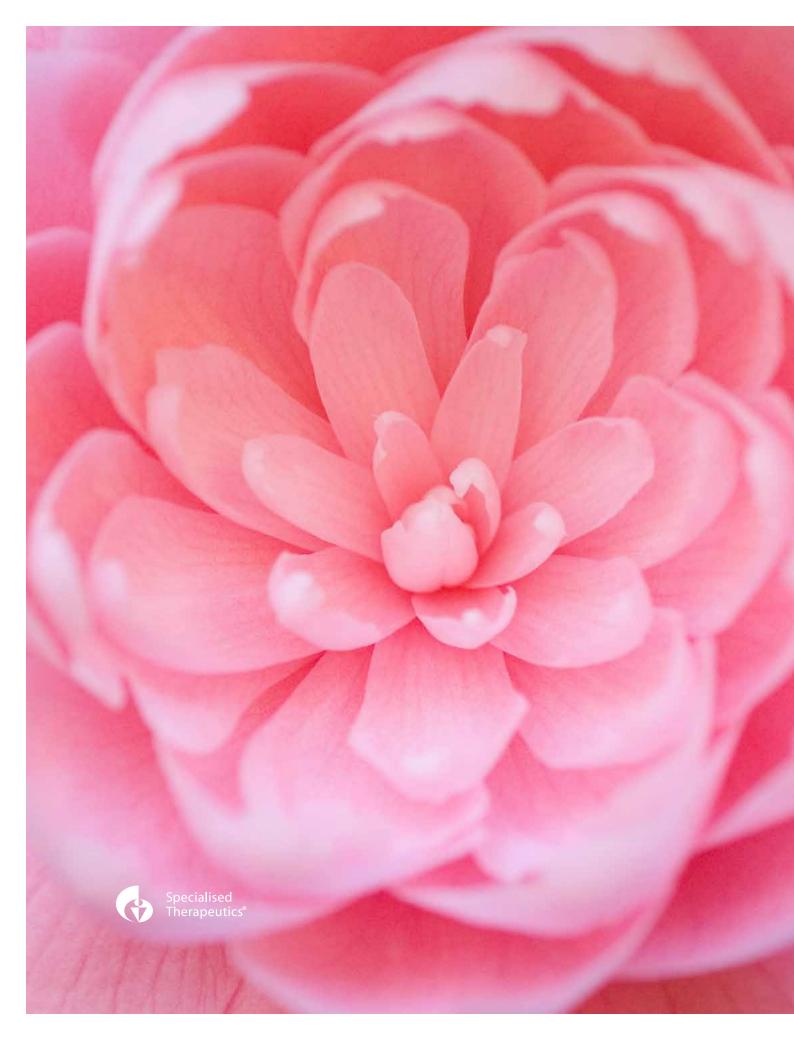
# BRAST





# El Co Breast



When a woman is diagnosed with breast cancer, she receives an avalanche of information. Amid the shock, all this detail can be difficult to process. With this in mind, and with our commitment to making a difference in breast cancer, Specialised Therapeutics decided to provide women with relevant, up-to-date and useful information about the breast cancer experience. We wanted to share personal stories, but also frank and factual information that has been reviewed by breast cancer oncologists. We wanted to address some of the issues women face during breast cancer.

#### The end result is BREAST.

We hope you are inspired – as we are - by the courage, resilience and endurance of all the women who generously agreed to share their stories, in the hope that other women may benefit.

Our special thanks must also go to those doctors and other healthcare professionals who contributed to or agreed to be interviewed for this publication, and who shared the questions they hear regularly from their patients.

The information they have shared is practical and personal. Like us, they are striving every day to make a difference in the lives of breast cancer patients.

We trust that some of the information in this magazine will make a small difference – either by pointing you in the right direction for information, or by answering a question you were afraid to ask.

We wish you and your families all the very best and look forward to your feedback.

Warm regards,

Chief Executive Officer,
Specialised Therapeutics.

Carlo Montagner

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 $\label{thm:publication} \mbox{Views expressed in this publication are the opinions of individual patients and healthcare professionals.}$ 



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## By Associate Professor Etgene lim

"One of the women I have been lucky enough to call both a patient and a friend was Connie Johnson - the woman who inspired the Love Your Sister charity which has to date raised more than \$10 million for breast cancer research. I am reminded of Connie every day, as the research laboratory I lead is named in her honour and was founded thanks to Love Your Sister's extraordinary generosity and determination for breast cancer research.

When Connie died, she requested that her body be delivered directly to our research team, so we could collect tissue samples to further our battle against this disease. Research is the only way we will continue to improve survival rates for the estimated 18,000 Australian women who face this life-changing diagnosis every year.

We have already come a long way. An Australian woman diagnosed with breast cancer today now has greater than 90% chance of surviving five years, thanks to better treatments and early detection. While we aim for a cure for the vast majority of patients, this is of little comfort to the women who either relapse or are diagnosed with metastatic cancer. As a community fighting this disease, we are heading in the right direction, but a lot more needs to be done.

Patients are critical partners in our research endeavour. They are not just recipients of the progress made. They are change makers, and help to improve the standard of care. We can do all the research we like on mice and in a petri dish, but the most relevant model of all is the patient. At St Vincent's Hospital, we invite all patients to donate a piece of their tumour to our researchers - effectively becoming our research partners. They are also invited to participate in our many clinical trials, as partners to define a better standard of care for the next generation of patients.

Breast cancer is not one disease

– there are many sub-types. Much
of the research is focussed on
providing targeted, or customised
therapies for different sub-types of
the disease and to the patient. While
it is still not routine to use genome
sequencing to guide therapies for
breast cancer, this is an active area
of research and I think it will be the
way of the future.

Patients often ask about immunotherapy, which is having great success in other cancers. In breast cancer, the only mature data we currently have is in triplenegative breast cancer, which represents around 10 – 15% of breast cancers. The benefits in this sub-type have been modest. But there is a small group of responders who get a very prolonged response. Research is now being done to understand why.

As we strive for patients to live longer with this disease, we must also ensure we do not compromise their quality of life. Helping a woman to live well, even when their cancer is metastatic, is an important imperative. De-escalating unnecessary treatment and new therapies with better side-effect profiles represent just some of the strategies in this space.

#### Connie Johnson said:

"I think about my children growing up and them experiencing in their lifetime cures, better treatments and a world where cancer doesn't tear families apart the way it does

That is also my hope, and the hope of our extended breast cancer research community.

The fight against breast cancer requires a team approach, including clinicians, researchers and most importantly, patients and their loved ones. It is our hope that this publication will inspire and inform you and your loved ones."

Associate Professor Elgene Lim

Associate Professor Elgene Lim is the head of the Connie Johnson Breast Cancer Research Laboratory at the Garvan Institute of Medical Research in Sydney. He also oversees breast oncology services at the Kinghorn Cancer Centre, St Vincent's Hospital.

with Dr Chantel Thornton

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Within 72 hours of her breast cancer diagnosis four years ago, Ally Fairbairn found herself in the offices of Melbourne breast cancer surgeon Chantel Thornton. She was pragmatic, telling the surgeon to just "do whatever you have to do and tell me everything you are doing". Ally was diagnosed with an aggressive early breast cancer that had begun to spread to her lymph nodes. Chantel remembers being impressed by Ally's no-nonsense, projectoriented approach. "I knew she was a coper." Chantel has since guided Ally through a range of surgeries and breast cancer treatments – including a full breast reconstruction.

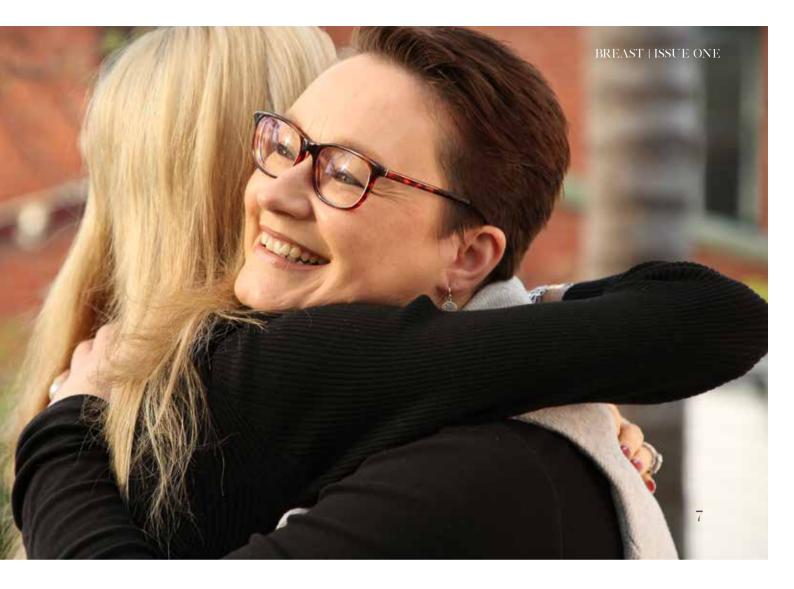
Today, it is clear the pair regard each other as friends, rather than merely doctor and patient. Both say this mutual trust is vital because a breast cancer journey means surgeon and patient are linked for a lifetime.

"I started checking my breasts every week in the shower a couple of times a week after Kylie Minogue was diagnosed and she was so young.

I had done it on the weekend, but then on the Tuesday I found a lump. It had not been there on the Saturday morning.

I took myself off to the GP and that's where it all started. I had a mammogram and within 24 hours I had an appointment with Chantel.

The GP told me I would get on really well with her, and she was right. Chantel has an ability to quickly assess the person on the other side of the desk and give that person exactly what they need. She worked out I was not highly emotional, and also that I needed lots of information. I told her I wanted a really aggressive treatment plan. I am pretty competitive, so I decided to tap into that personality trait and give it everything I had to beat it. I wanted to do everything which was immediate removal, surgery, lymph node removal and temporary reconstruction. About three weeks after the temporary reconstruction I started five months of chemotherapy and radiotherapy, then stage 1 of permanent



reconstruction, hormone treatment, and then the final stages 2 and 3 of my reconstruction.

I think all in all, from diagnosis to that stage was about 2.5 years, which sounds like a long time, but when you are in the middle of it, it does not feel like that long.

The worst bit? I don't tend to think of negative things, but the side effects of chemotherapy were challenging. But my breast care nurses were great and I had a good pharmacist on speed dial.

I worked throughout my treatment and this was really important to me, to get up and keep going to work. My partner was really fantastic as well. We had already made the decision not to have children, so the risk of infertility from any treatments wasn't really a big issue for us.

Before breast cancer I had quite small breasts and I had never ruled out a boob job. So, when this all happened, I opted for tissue expanding surgery initially (which can be quite uncomfortable) and then after all my treatment, I went for a full deep inferior epigastric perforator (DIEP) flap reconstruction, which takes tissue from your abdomen to build new breasts. I went up a breast size and I had a tummy tuck at the same time. I am really happy with the result. Soon I will get the nipple area tattooed and that will complete the reconstruction. I am in remission and I will be on treatment for the next 10 years and I will come to see Chantel every year for a check-up.

Breast cancer has meant I have definitely changed the way I go about life. I tend to say yes to more experiences. I do more charity work and I like giving back. Sometimes I talk to other patients Chantel is seeing about their surgeries or their treatments. That is really rewarding. I live in the moment a lot more. I don't worry about what's going to happen in the future. It may or may not be there, so what's the point in worrying about it?"

Ally Fairbairn

"I still remember Ally coming into my office. She said, 'let's just do it Chantel'. Like Ally, I do get to know a lot of my patients very well.

I think showing them that you care is so important. I believe our immune systems are integral to fighting cancer and from the moment we meet a patient we should make them feel safe, secure and well-looked after. I truly believe it can change their mindset and even their survival. We can't prove that yet with science, but one day I hope we will be able to.

I always do my best to make their breast reconstructions look beautiful. I think it's really important, because women with breast cancer can live a very long time. I don't want them waking up every day and looking at my work with disappointment. If the breast looks as normal as it can, then that is one thing a woman does not have to worry about.

Probably 70% of patients these days are having breast conservation surgery, and previously many of these ladies would have had mastectomies. We know that survival outcomes are the same, whether they have mastectomies or conservation surgery. Some women are uncomfortable with this though, because they are worried that if tissue is there, then they may have a recurrence.

I want women to know that we do have excellent reconstructive options now, using either implants or tissue or muscle that's taken from elsewhere in their bodies.

You can use the gluteal muscle, inner thighs, the back. It depends on where the patient has appropriate tissue to remove. Some ladies don't have a tummy, so there is just not enough abdominal fat.

Ally had a temporary tissue expander in first, then we moved to full reconstruction after all her treatment. She had the DIEP flap surgery, which has been an option since the early 2000s. With this surgery, you effectively get a tummy tuck as well because we make an incision from hip to hip, and lift the tissue from there.

I would not typically offer a DIEP flap as a reconstructive option straight away to patients though, because it is a massive operation and it can take six to eight weeks to recover. If the chemotherapy is delayed, then that could impact survival.

The reason I would put in a temporary implant or a tissue expander, is because you can't just remove the breast and then do nothing, because the skin will collapse and you won't have anything to work with later.

The beauty of using a patient's own tissue is that it grows with the patient – when they grow, their breast grows. And they look more natural. If you see someone undress who has had a DIEP flap reconstruction you might never know.

Some ladies do still choose to have an implant, under their pectoral muscle. But it does depend on the age of the patient. I think some women are becoming less satisfied with having implants and particularly now, because they have been a bit controversial.

Women should know that they can get a beautiful result from reconstructive surgery these days and not feel self-conscious. Surgery has come such a long way. It really is a privilege doing this job, becoming a part of their lives and helping these women affected by breast cancer. What an honor it is, to also call them friends."

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Dr Chantel Thornton





Dr Lisa Beatty is a Senior Clinical Psychologist and Cancer Council South Australia Senior Research Fellow at the Flinders Centre for Innovation in Cancer. She has expertise in psycho-oncology - the scientific exploration of the psychological impact and treatment of cancer.

BETWEEN 30 and 40%<sup>1</sup> of breast cancer patients will experience what psychologist Dr Lisa Beatty calls "clinically significant distress".

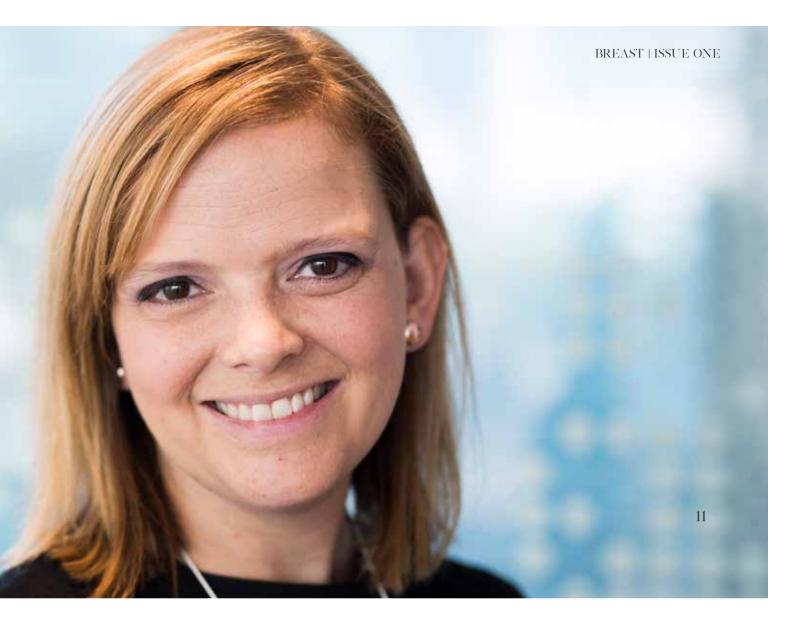
This might present as anxiety, depression, adjustment difficulties and an overwhelming fear of cancer recurrence which can impact daily life and a woman's ability to carry out her normal roles.

While rates of distress are similar for those women with early or metastatic disease, those with a documented mental health history, and those who have less support, are more likely to struggle.

Dr Beatty acknowledges that when it comes to managing breast cancer, some studies indicate that older women seem to have lower distress rates, "but that's because they are at a very different life stage, and the worries they experience tend to be different than younger women who may have fertility challenges, younger/dependent children, and may be managing work and mortgage commitments. It's not necessarily easier for them, just different."

Distress screening is vital, because untreated distress in breast cancer patients has been shown to lead to an increase in the range and severity of symptoms and side effects experienced.<sup>2</sup> "Moreover, we see a three-fold reduction in a patient's ability to adhere to cancer treatment if they are distressed,<sup>2</sup> and research shows us that untreated distress is associated with a 17% higher mortality rate.<sup>3</sup> Managing distress is critical."

Dr Beatty says it is common for women to experience symptoms of grief, but it is the fear of recurrence that is predominant "and this is a universal fear".



"When you have women who say they don't fear recurrence, well I would really question whether they have processed what they have been through," Dr Beatty says.

"A normal level of worry would be becoming anxious just before a scan or an anniversary.

"But some women are consumed by their fear and are unable to let it go. One woman I spoke to said it was like doing head miles, cycling through her head all the time. And it led to a lot of unhelpful behaviours like constant body checking, which can drive the anxiety further. It is when they are consumed by their thoughts and are really vulnerable that expert help is needed."

That expert help may involve cognitive behavioural therapy, which involves re-training thought patterns.

#### Identity & Body Image

A cancer diagnosis can also affect a woman's whole sense of identity and role in family life.

"Anecdotally, women will often say they tire of being the ones within a family who carry the mental load, and manage children and work, but that they then find it quite emotionally challenging when they are suddenly not able to do that," Dr Beatty says. "In addition, their work roles might change, and they may find the very visible changes in their body, from hair loss to surgical changes, quite confronting."

### Breast Cancer and Relationships

Relationships are also frequently impacted – and not just intimate relationships, because friendships can also change.

"Some women who are undergoing treatment for breast cancer report feeling socially isolated, and feel that they are getting less support from their friends when they really need more," Dr Beatty says.

"We do see some friends really step up – and they might be unexpected supporters. It's often the people who women predict will be their best supporters that might not be there.

continued next page

"With intimate relationships, we find a cancer diagnosis will amplify existing dynamics.

"A lot of people make the assumption that cancer will bring them closer together and that can be the experience, but they are the people who have had stable foundations before cancer. Those that had a slightly rocky relationship before the cancer can find that this may be the thing that drives them apart.

"What we do know from research is that marital support has just as much of an impact on outcomes as chemotherapy. <sup>4</sup> Support has a huge impact on how someone will cope afterwards - it is a huge protective factor."

#### Career Path

Dr Beatty's interest in the psychological impact of cancer began when an aunt was diagnosed around the time she was determining her own career path.

"For me it was seeing the resources she did not have access to that really propelled me forward," she says.

"She had a lot of support, but at that stage psychology and cancer wasn't really an established area (either in research or clinically). This made me broadly interested and when I started my PhD it became a real passion. I wanted to make sure there were resources available for all women, and not just those who live in major urban areas."

So, for her PhD project, Dr Beatty developed and trialled a print-based workbook to support women through their diagnosis and treatment of breast cancer.

This workbook then became the foundation of an online program called 'Finding My Way' that she developed with a team of collaborators, including medical oncologist Professor Bogda Koczwara and clinical psychologist Professor Tracey Wade.

This online resource helps patients navigate each stage of the cancer journey beginning with diagnosis, assisting with decision making, providing advice and directing them to relevant resources throughout the treatment pathway.

A national trial funded by the National Health and Medical Research Council demonstrated that the program helps people manage and live with distress, and reduced the need for people to access additional health services.

The program is now freely available, thanks to generous sponsorship by the Flinders Foundation, and in partnership with Cancer Council SA.

It is now being investigated with funding support from the Beat Cancer Project, in partnership with The Breast Cancer Network Australia (BCNA), for women with advanced breast cancer, and is the subject of new studies in the US, Romania and the United Kingdom.

#### Finally

Dr Beatty says a good psychologist, social worker and/or mental health nurse can be great support, "and also don't underestimate the importance of your family GP".

"I would advise women to keep working in some capacity if you can (but this will vary from person to person), as this has been shown to help women emotionally. Exercise also has a huge beneficial impact.

"Breast cancer is never going to be easy, but we know if you have good supports around you, someone you can talk to, and solid internal coping strategies, then they are great steps forward."

For more information, go to: www.findingmyway.org.au

Dr lisa Beaty

This is an open access/ free website for anyone with early stage breast cancer.

www.findingmywayadvanced.org.au is a new adapted version of the website for women with metastatic breast cancer.

It is currently only available as part of a clinical trial to evaluate efficacy. Women interested in being involved should contact:

info@findingmyway.org.au

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<sup>3.</sup> Pinquart M, Duberstein PR. Depression and cancer mortality: a meta-analysis. Psychol Med. 2010;40(11):1797-810.

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## STRATEGES o assist your children

It can be difficult to know how to help your child during your diagnosis and treatment. Below are some practical strategies that you can use for each age group and you can then add your own ideas for your children, including who may help support them.

Infant-2 Years	3-5 Years	6-8 Years	9-11 Years	Teens
Affection Provide frequent hugs & cuddles.	Information Let your child know you are sick and what that means (tired but not dying).	Education Tell your child you have cancer and explain treatment.	Education Give more detailed information about your cancer and explain treatment	Education Give detailed information about your cancer and explain treatment.
Consistency in caregiver Have a consistent and trusted caregiver (parent or relative).	Daily child care & maintain routine Have a consistent substitute caregiver.	Consistent caregiver & routine Have a consistent substitute caregiver.	Family approach Cancer is stressful for the whole family, but you will manage the uncertainty together.	Maintain normality This is important at home and school. Remind teens it's okay to still have fun with friends.
Maintain routine Have your relative or partner maintain your child's routine.	Address guilt Tell them cancer is not their fault.	Address guilt Tell them cancer is not their fault. Offer repeated reassurance.	Address guilt Tell them cancer is not their fault and it is not contagious.	Encourage emotional expression  Teens may do this by writing or talking (to you or others) about how they feel about your cancer.
Have regular contact with your child Even if you are sharing	Play & artwork Use these opportunities with	Inform school & teachers This will help to ensure	Inform school & teachers This will help to ensure	Inform school & teachers This will help to ensure
care, ensure that you see your child frequently.	your children to express emotions & provide education.	that your child will be supported at school.	that your child will be supported at school.	that your child will be supported at school.
Special treats	Question time	Question time	Question time	Support groups
Read books together, record lullabies and leave voice-messages for them.	Arrange a time each day (e.g. after dinner) when children can ask you questions and share feelings.	Answer your child's questions honestly. Also let them know it's okay if they don't want to talk.	Answer your child's questions honestly. Also let them know it's okay if they don't want to talk.	If your teenager is interested, contact CANteen for support, or investigate other online resources.
Visits to the hospital Let your child see where you are receiving treatment.	Show your emotions Assure your child that expressing your emotions for brief periods is helpful.	Visits to the hospital Let your child see where you are receiving treatment and introduce them to your doctor.	Maintain normality After-school activities, sports and time with friends are important to maintain.	Check out your expectations Don't expect your child to take on caregiving or challenging roles.
Provide reassurance That Mummy or Daddy will be home soon.	'Mentor' Have a relative or friend show a special interest in your child.	'Mentor' Have a relative or friend show a special interest in your child.	Reading & Writing about your cancer Encourage your child to do this if they are interested.	Family Time Try and spend time together as a family.

"Faith gives you a great sense of hope. Family gives you love and strength, and medicine gives you an opportunity. You can fight anything when you have those three things."

Heather

# AN EARLY BREAST, CANCER Jurgnosis

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Heather Plaister clearly remembers the moment she found a breast lump. A woman of great faith, she had said a morning prayer before asking God if there was someone she should be praying for. "Then it was just like a thought process went through my head - 'you have not done a breast check for a while'." Heather was only 48 at the time but did a check and found a lump. Tests revealed she had a stage 3 aggressive breast cancer that had spread to her lymph nodes. She and her husband David were devastated, and worried about how to break the news to their teenage daughter, Elenarose. Since her diagnosis in 2017, Heather has endured surgery, chemotherapy, radiotherapy, targeted therapy and a further year of therapy to try and reduce her risk of recurrence. Now, she says she has done all she can and "faith, family and medicine" help her to remain positive.

"Our daughter Elenarose was just about to go into Year 9 when I was diagnosed with an aggressive, advanced breast cancer. She was almost 14 and we all know that can be an incredibly difficult time for teenage girls.

Only weeks earlier we had given her a letter from us both as part of her birthday present, telling her all the things we would like her to achieve and talking about what makes her special. She read it and said, 'Is one of you dying?' And we said, 'No, it's a big year for you and we wanted you to know all of this'.

And then of course two weeks later we were sitting her down and telling her I was not well.

From the start, we decided to be very honest with her. Elenarose is a mature girl anyway and a great communicator.

We discussed what the approach was moving forward, and we talked about faith.





Through all of it, she has been incredibly calm. That doesn't mean she hasn't cried, because she has. But she has been positive and very aware. So, we would tell her everything that was going on, and I think that helped.

Her school was amazing. I went and spoke to them and they provided phenomenal support right from the start. They made sure all her relevant teachers knew and they spoke with all her close friends. Our wider family was also very caring, regularly checking in. My Mum also travelled from the country every few weeks to be there for us.

I did find the treatment very hard, particularly the 24 weeks of chemotherapy. I was always the person who got the very worst side effects that only 2-5% of women get. I was having double doses every three weeks and the first time, I was sick for a week. The second dose, it had

extended to two weeks. By the third dose, I was very unwell. I ended up with nasty anal fissures and various gastro issues which were exceedingly painful. Sometimes I would just sob into David's arms, but I am so grateful that although my body began to break down from the treatments, my heart and mind stayed strong.

Then, when you are thrown into early menopause with the hormone therapies, it is hard. I was having terrible hot flushes, waking every night.

We have since talked to Elenarose about how she managed, through those first few months in particular. She told us, 'I made a choice in that first week — I thought, 'I can get really angry and react badly, or I can have faith'. She chose faith and the 'cup half full' approach and seeing how she has handled everything makes me so proud.

As a family we have thrown everything we can at this cancer. I have done everything I can to fight it.

And Elenarose said the other day, 'You know what? One good thing came out of all of this – because of your hot flushes, we got ceiling fans!'

Heather Paister



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"What we know from research is that marital support has just as much of an impact on outcomes as chemotherapy. Support has a huge impact on how someone will cope afterwards - it is a huge protective factor."

Phsychologist Dr lisa Beatly





# COOLING

Angela was first diagnosed with breast cancer seven years ago. It was a triple negative cancer and she endured six gruelling months of chemotherapy, losing her long blonde hair in the process. She recalls, "I looked like a cancer patient". The Director of Research kept working in her leadership role, but felt that she lost her physical identity. When she faced a second diagnosis last year - this time with a completely different, triplepositive breast cancer - her oncologist Dr Yoland Antill discussed the newlyavailable option of a cooling cap, to be worn before, during and after chemotherapy sessions in an effort to minimise hair loss. Angela received three months of chemotherapy with an agent normally associated with complete hair loss and opted to use a cooling cap to try and retain her hair. While uncomfortable – cooling caps basically reduce blood flow to hair follicles via a freezing process – Angela says the results have been "absolutely worth it". She has retained "I would say 99%" of her blonde hair. But Angela admits the cooling cap process was difficult both physically and emotionally, and she is not sure she could have continued had she required a longer stint of chemotherapy. In this piece, Angela and her oncologist discuss the pros and cons of cooling cap technology.





"When Angela was first diagnosed in 2012, she had chemotherapy over a sixmonth period and we did not have scalp cooling at that time, so there was not that opportunity and she did lose all of her hair.

Disappointingly, she had been recommended to have further chemotherapy for a completely different cancer but again, in the curative setting. This time around, she has had chemotherapy over a three-month period and this regimen would normally be associated with 100% hair loss.

Because Angela did not want to lose all her hair again, I discussed the use of cooling caps, something that was not available when she had her chemotherapy the first time. She finished her treatment ten days ago and has managed to retain most of her hair.

For her, it's been worthwhile, but cooling caps are not for everyone. It really depends on many factors, including pain tolerance, anxiety, tolerance of cold, claustrophobia and the ability to tolerate additional discomfort in an already stressful situation. Some may need an anti-

anxiety medication to help them relax – particularly for that first half an hour when their head is so cold, and they get that very constricted feeling. Some women find that nausea is increased with the use of cold caps and require additional medications on the day to manage this

Cooling caps appear not to work so well for all hair types. The more hair a woman has, the less cool the scalp actually becomes. This technology is about reducing the temperature in the follicle, in the bulb. If you have very thick hair, then it may be more difficult to get penetration. There has also been a recent study in Japan and the rates of success in Asian hair are lower than with Caucasian hair, which seems to be best suited. For elderly women, when hair loss may already have been experienced, the cooling cap technology may not work as well. .

Women do need to be careful which products they are using on their hair while they are undergoing treatment. I recommend avoiding products with parabens and sulphates, I have seen some women end up with a chemical clump — literally, a lump of matted hair that is fused together and there

is no other option but to shave it to the scalp. This of course is an extremely distressing scenario, and one to be avoided if at all possible. While the scalp cooling companies do not include this as part of their recommendations, anecdotally I have found that the less a woman does with her hair like washing, colouring and brushing, the more she will retain.

It's fair to say cooling caps are of benefit to many women, but they are not for everyone. About 20% of patients will discontinue due to things like pain, nausea, claustrophobia or headaches. I can remember seeing someone and she had made a celebratory and affirming sign to say 'I am giving up scalp cooling today'. It was a liberating decision for her. The process of doing this to try and save her hair was creating such additional anxieties with each session and finally felt she could not do it anymore. She was very relieved when she made the decision to discontinue."

Dr Yoland Antill





"When I was diagnosed for the second time, I knew I could do the treatment, but I really did not want to lose my hair again. Having hair is significant for me. I remember touching my hair the first time around and it was just coming out in my hand. I found that really challenging. When you lose your hair, everybody knows you have cancer.

So, I was very open to using a cooling cap this time around, but it was not easy. The first 10-15 minutes after they put the cap on are the worst in terms of discomfort. You wet your hair first and put conditioner through it, and then the oncology nurse puts the cap on really firmly – it's quite claustrophobic.

When the machine is switched on, it starts cooling and it tightens up – that coldness is very difficult to explain. They say it is like an icecream headache, but it's not really. It's so intense and you do want to rip the cap off.

That really uncomfortable feeling seems to dissipate after about 15 or twenty minutes. After that, it is still uncomfortable, but certainly doable. I did take Panadol to help me manage the process.

I was paranoid every time the cap was fitted. It has got to be fitted exactly right, because if it is not tight enough, you will lose your hair. If you have gaps, you will lose your hair in those places and then you are back at square one.

After I got through the first couple of treatments and I saw that I was retaining my hair, I became quite positive. You do have to be careful about not washing your hair too often, not manipulating it too much, not styling it or brushing it too often, and sleeping on a silk pillowcase to prevent friction.

I usually wash my hair every day, but I was lucky if I washed my hair every 10 days to two weeks. This was okay, because I think the treatment dries your hair out anyway. The real advantage of scalp cooling is that you can go around and look as normal as you can, because you have not got that visible sign of being on treatment. But this can also be a disadvantage, because people forget you are going through quite a difficult treatment process.

If I was one of those women who had to go through another few months of chemotherapy, I don't know that I could have endured more of the cooling caps. The last few times I was counting down to the finish line. If I had to do this more, I would really have had to reconsider the ongoing use of the cap. But the positive outcomes can outway the trauma.

Now I have had breast cancer twice and I really don't want to get it again. I just want to live my life and put this behind me and be healthy. My next goal is to finish working and just enjoy life. I am planning a big holiday and I want to be well."

Angela



## BEFORE, DURING AND AFTER BREAST CANCER

Good nutrition can impact breast cancer treatment tolerance and recovery,<sup>1</sup> as well as reduce the risk of recurrence<sup>1,2</sup> and improve long-term health, according to Accredited Practising Dietitians (APDs) Lauren Atkins and Elise Den. The pair, who co-founded OnCore Nutrition two years ago, also note that research suggests as many as 30-35% of cancerrelated deaths are linked to diet.<sup>3</sup>

Today, they're passionate about helping patients live well before, during and after cancer therapy, and have so far supported thousands of breast cancer patients nationally and internationally.

OnCore Nutrition is based in Victoria, however Lauren and Elise also offer telehealth and Skype-based consultations. They are involved in the education and training of allied health professionals across multiple universities in Melbourne, and have presented and published their research and other projects at national and international conferences and in respected journals.



### WE ASKED THEM TO ADDRESS SOME OF THE MOST COMMON QUESTIONS RAISED BY BREAST CANCER PATIENTS.

#### Do I need to follow an alkaline diet?

As cancer dietitians, we often get asked if the alkaline diet can cure or prevent cancer. The short answer is no. We wish it was that simple. The theory behind this claim stems from the concept that cancer only grows in acidic environments. Therefore, make everything alkaline and you're good as gold. Rejection, your honour!

Comprehensive reviews have been conducted and no direct link has been found between diet-induced acidosis and cancer. We know that food pH does not influence blood pH. Normal body tissue has a slightly alkaline pH of 7.4, meaning that, if this theory was correct, cancer wouldn't grow in any of these tissues. Cancer cells can grow in alkaline environments too. While it is accurate to say that tumours grow more aggressively in acidic environments, the tumours actually cause this acidity themselves.

Cancer cells can't thrive in an overly alkaline environment, but neither can any of the other cells in our body.

### Do I need to give up chicken because of the hormones?

Absolutely not! Lean poultry has been shown to be protective in the context of breast cancer.<sup>4</sup> You need to remember that hormones have been banned in Australian chicken production for decades, and this means chicken is absolutely safe to eat.<sup>5</sup>



Put simply, no. Women can still consume products like soy milk and tofu when they are being treated for breast cancer. 6 Most observational studies indicate that consumption of soy products may actually reduce the risk of developing hormonally driven cancers such as breast, prostate, or gynaecological cancer. This might be because the isoflavones found in soy products can actually block the more potent natural oestrogens in the blood. Soy consumption has been linked to a longer lifespan after a breast cancer diagnosis. In a review of five long-term studies, women who ate soy after diagnosis were 21% less likely to have a recurrence of cancer and 15% less likely to die than those women who avoided soy.6,7

What we do encourage is that you don't go from 0 to 100 or from 100 to 0. So, if increasing your soy intake, do so moderately, starting for example with tofu or tempeh a couple of times per week and increase that over a few weeks. If you are currently including a regular soy intake in your diet, and would like to cut down, try to reduce it gradually.

## Is it common to gain weight during breast cancer treatment? How much weight gain is 'average'?

It is common to experience weight change during breast cancer treatment. Everyone is different, however some women will gain weight and others will lose weight. A weight change of 5-10% either way can have a profound impact on a woman's health, therefore it is important to seek support from a specialised oncology dietitian who can provide tailored and specific nutrition interventions.

# What has caused my weight gain during my breast cancer treatment? Is it reversible, or is it something I have to accept? Will diet and exercise be enough to reverse this?

There are many reasons why weight gain occurs for women undergoing breast cancer treatment.

Some combinations of chemotherapy drugs can bring on hormonal changes that trigger premature menopause. With this may come a slowed metabolic rate, and a change in body composition. The use of corticosteroids can also predispose women to weight gain. These drugs are necessary to help reduce swelling, manage nausea and downregulate chemo-related toxicities. But steroids can also increase appetite and lead to muscle wastage and increase central adiposity (fat around your middle). Fatigue is a common side effect of chemotherapy, which makes exercise and physical activity challenging. This in turn may lead to a reduction in incidental and conscious activity - sometimes leading to weight gain.

A woman's food choices may also be affected by cancer treatment. It's common to see changes in taste and appetite when women are affected by nausea and diarrhoea. This may lead to a tendency to eat more refined carbohydrates (like white bread and pasta) or convenient food options. Fatigue can also make food choices and meal preparation more challenging. Hormone-based therapies can also cause weight gain. These treatments can lower the levels of oestrogen and progesterone in the body, which can lead to body composition changes, with more fat and less muscle. Having said all this, a tailored diet and exercise plan can most definitely help. Support from an oncology dietitian as well as an exercise physiologist or physiotherapist can assist with weight management and improvements in body composition.

### What sorts of foods do I need to eat **more of** during treatment?

#### Eat more protein

High cell turnover (which is what happens during chemotherapy and radiotherapy) can increase energy and protein requirements, often elevating these to up to 125-150% of usual baseline needs. This means that someone undergoing high risk chemotherapy may need to eat enough protein for 1.5 people!

This can be really challenging, particularly if you are experiencing side effects like nausea. As a general rule, we recommend including a source of protein at each meal or snack - e.g. poultry, fish, meat, eggs, dairy products, nuts, seeds, tofu or legumes like chickpeas, lentils, kidney beans or cannellini beans. A serve is roughly the size of the palm of your hand. It's also important to make sure you are eating 5 serves a day of vegetables and 2 serves of fruit.

### Choose low glycaemic-index (GI) carbohydrates to reduce impact of fatigue

We've all felt the 3pm slump after a big bowl of pasta or fluffy white sandwich. Imagine the slump on top of chemotherapy-induced fatique! Low GI carbohydrates will provide a sustained release of energy to avoid the blood sugar highs and lows. Opt for wholegrain or sourdough breads and cereals over white varieties. Choose basmati, wild rice, barley or quinoa over more refined grains, and go for sweet potato over white potato. You could also include legumes, nuts, seeds and full cream dairy.

#### Keep hydrated

Meeting your fluid needs post chemotherapy can help to flush it all through your system. The body is made up of 60% water and the brain more like 73%. Most will need about 35-45ml of fluid per kg body weight per day (e.g. someone who weighs 60 kilograms needs 2.1 litres per day) but check with your treating team in case your needs are different.

## What else do I need to remember about my diet when going through chemotherapy?

#### **Drug-nutrient interactions**

Some nutrients when taken in high doses can interfere with chemotherapy agents and medications. High doses of antioxidants, like vitamins A, C, E, selenium, copper and zinc, as well as other supplements such as whey protein, may increase our body's own natural antioxidant levels. These can act to protect cells from damage, but during chemotherapy we are actively trying to damage cells. High doses of these nutrients in the form of supplements and concentrated powders are best avoided, particularly alongside radiotherapy and some chemotherapy agents.

#### Zinc is important for taste

It could be worth checking serum levels if taste disturbances are ongoing. Always speak with your treating team before supplementing.

#### Vitamin E and glutamine

These supplements may be beneficial for chemotherapy-induced neuropathy. Speak to your dietitian, doctor or pharmacist to explore if appropriate for you. 8.9

#### Optimise medications

Many people don't like taking medications but these can make a significant difference and if you need to take it, you might as well take it right! Some anti-nausea medications work best if taken 30 minutes prior to eating to help the stomach to empty efficiently. Digestive enzymes should be taken at the exact same time as a meal. If the timing of your medications isn't right for you, you may not be reaping optimal benefit

## What sorts of foods do I need to eat **less of** during and after treatment?

- High glycaemic index carbohydrates, like white bread, refined cereals and short grain white rice.
- Refined carbohydrates and processed foods like cakes, biscuits, pastries, sweets, soft drink, juice and cordial.
- Foods containing trans-fats, like take-away foods and commercially prepared cakes, biscuits, pastries.
- Processed meats, like ham and salami.
- Overly-charred foods.

  This process can produce heterocyclic amines (HCAs) and polycyclic aromatic hydrocarbons (PAHs) that can increase cancer risk. 10
- Avoid probiotics when neutropenic. This includes probiotic supplements, kefir, kombucha, kimchi and yoghurt with added live cultures. 1, 11
- Employ good food hygiene
  to avoid the risk of food-borne
  illness like salmonella. If you
  are immunocompromised,
  it is best to avoid foods that
  may harbour pathogens.
  This includes things like soft





cheese, unpasteurised dairy, deli meats, raw or undercooked meat, poultry, seafood or eggs. Be careful to keep cold things below 5 degrees, consume leftovers within 24 hours and reheat meals until scorching hot.

## I am having chemotherapy. What is causing the metallic taste in my mouth?

There are many different reasons that taste changes occur. Very simply, chemotherapy targets rapidly dividing cells which is great because cancer cells are rapidly dividing. However, this can also affect our healthy cells, including those that line our gastro-intestinal tract (including mouth).

### Strategies that may improve taste during treatment include:

- Add herbs and spices to sauces to enhance flavour.
- People who are experiencing a metallic taste may benefit from using plastic or ceramic plates, cutlery and utensils.

- If you're sensitive to smell, avoid cooked foods with strong aromas. Cold and room temperature options may be better tolerated.
- Ensure zinc levels are adequate as zinc deficiency can contribute to altered taste.

## I am having trouble keeping food down during chemotherapy and I am losing weight. Is this a problem and do I need to eat a high fat diet to return to optimal health?

A high-fat diet is unlikely to be necessary. Focus on consuming high protein, good quality fats (mono and omega-3 poly-unsaturated fats), low GI carbohydrates as well as a variety of 'whole foods' like legumes, wholegrains, vegetables, fruits, nuts, seeds, dairy and lean meat, poultry and fish to maintain an optimal micronutrient profile.

We say it is important to aim for nutritional adequacy overall.

This may mean eating well when you are feeling well and trying to compensate in these times for periods when you will eat less.

Small, frequent meals can help. Nourishing fluids (e.g. smoothies) are a good option for some patients and it is important to ensure these are nutritionally valuable rather than just energy or calorie-dense. We would suggest including things like nuts, seeds (try LSA mix from the supermarket!), avocado, yoghurt, spinach and berries in your smoothies.

Food fortification to maximise the nutritional content of every mouthful might be helpful. If weight loss is a problem, we suggest adding ingredients such as extra virgin olive oil, avocado, ricotta or nut butters to increase the energy and/or protein content of each mouthful without adding too much additional volume.

You should speak to your oncology dietitian or oncologist if you lose more than 5% of your body weight (e.g. if you weigh 60kg this is just 3kg).

#### What about supplements? Are there any you can recommend I take during breast cancer treatment and beyond to ensure I return to optimal health?

Our best recommendation is to aim to get sufficient macronutrients and micronutrients from whole foods to negate the need for supplementation. This is the recommendation of the World Cancer Research Fund also<sup>2</sup>. If there are particular inadequacies or deficiencies in your diet identified by an Accredited Practising Dietitian or on a blood test, individual supplementation may be recommended. We would encourage you to supplement only the nutrients that are lacking, rather than a broadspectrum supplement.

Having said this, a ginger supplement - 1.5g per day taken in a capsule - can reduce the severity of chemotherapy-induced nausea and vomiting. 12, 13, 14, 15 Patients should be aware of the potential effects on blood thinning and blood glucose levels. 16, 17, 18

Low Vitamin D levels may be associated with reduced outcomes. We recommend having your levels checked and supplementing as required. 19,20

#### I am being treated with a therapy that is making me nauseous and causing diarrhoea. What foods do I need to avoid?

Some therapies can cause a number of side effects, including nausea, diarrhoea, loss of appetite, fatigue, muscle and joint pain, fluid retention and headaches.

#### There are a range of strategies to help manage these symptoms.

- Consume small and frequent meals.
- Sip on liquids (e.g. water or a ginger spritz)
- Eat bland foods (e.g. dry biscuits or toast) and try to do so often to avoid an empty stomach.
- Eating foods cold or at room temperature can minimise strong aromas.
- Avoid fatty, oily, rich foods.
- Have the foods you enjoy available.
- Eat in a positive environment.
- Use anti-nausea medication as directed by your oncologist. Ensure that you understand how these work so they can be best timed to your food intake (e.g. metoclopramide 30 minutes pre-meals)

 If your therapy is causing diarrhoea, consuming a modified fibre diet can assist in managing the severity of symptoms. Eat more soluble fibre and less insoluble fibre.

Foods to eat include the flesh of fruits and vegetables, legumes such as lentils and peas (avoid the skins or blend them, e.g. try hummus instead of whole chickpeas), wholemeal bread and cereals, grains such as barley, flaxseed, oatbran, psyllium and soy products.

#### If you are experiencing diarrhoea, you could try the following:

- Remove skins, seeds, stems and pulp from fruit and vegetable products.
- Choose wholemeal, sourdough or rye breads rather than wholegrain.
- Avoid whole nuts, seeds and dried fruits. Ground or paste varieties (e.g. nut butters, almond meal) are generally better tolerated.
- Be cautious of tough, stringy foods such as pineapple, celery and rhubarb.
- Cook high fibre foods well and chew thoroughly to reduce the digestive effort required by your gut.

For more information, go to www.oncorenutrition.com

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## Breakfast

#### Monday

Baked egg muffins: Whisk eggs and bake in muffin pans with grated sweet potato, capsicum, onion, and reduced fat cheese

#### Tuesday

Fruit smoothie:
Combine 1 cup of milk with
1/2 cup Greek yoghurt and
1 cup of fresh or frozen fruit
and 2 tbs of nuts or LSA mix.
Add cinnamon, turmeric to taste

#### Wednesday

150-200g Greek yoghurt topped with 1/4 cup rolled oats or untoasted natural muesli and 1 piece of fruit. Add cinnamon, turmeric to taste

Lynch

Wholegrain wrap with 65g roast chicken (skin removed), 1 tbs cream cheese, 2/3 cup salad and 1/4 cup grated carrot

Mediterranean tuna salad: 1x 95g can tuna in spring water or olive oil (drained) served with 2 1/2 cups salad vegetables, 8 olives, 2 tbs feta cheese and 2 tsp extra virgin olive oil dressing 1 slice wholegrain bread 2 slices wholegrain bread with 50g shaved turkey breast, 1 slice cheese, 1/2 cup salad and avocado as spread

Dinner

100g baked salmon served with 1/2 cup cooked quinoa, 1 cup of spicy cabbage slaw (2 tsp vinaigrette per serve)

Prepare 1/2 cup black beans seasoned with 1/4 tsp cumin, paprika, turmeric, 1/2 clove garlic, salt and pepper. Serve with 1/2 cup brown basmati rice, 2 cups shredded lettuce, 1/4 cup corn, 1/2 tomato diced, 1/4 avocado, 2 tbs Greek vogburt. Jime wedge

Lemon garlic baked chicken breast (65g cooked) with 1 medium baked potato, 1 1/2 cups of rocket and walnut salad, 2 tsp extra virgin olive oil and lemon dressing per serve

Snacks\*

3 wholegrain corn thins or crispbread with 3 tbs cottage cheese and 1/2 a sliced tomato

Piece of fruit plus 1/4 cup

50g shaved turkey breast or 1 boiled egg with 2 wholegrain crispbreads and 1/2 a sliced tomato

1 piece fruit or a milk coffee

3 tbs hummus with 1 cup of vegetable sticks

Fruit smoothie made with 1/2 cup milk, ½ cup plain Greek yoghurt, 1 cup of frozen fruit and 2 tbs nuts

<sup>\*</sup> Maximum 2 snacks per day

Breast cancer treatment can be physically gruelling. The foods we eat can be a powerful tool when striving to improve or regain health both during and after therapy. Many women don't know what or how much they should be eating, but building a nourishing meal really is simple.

The guide below has been prepared by Oncore Nutrition specifically for women during and after breast cancer therapy. The meal and snack suggestions provided are both nourishing and delicious, while also helping women to meet their nutritional requirements and manage their weight, if required. It is important to remember however, that every woman is different, and this is a general guide only. For more tailored advice, it is recommended you seek guidance from an Accredited Practising Dietitian.

Thursday	Friday	Saturday	Sunday
2 eggs served with 1-2 slices of wholegrain toast, 1/4 avocado, sliced tomato, mushrooms and spinach	Apple cinnamon overnight oats: Mix 1/2 cup rolled oats, 1/2 cup plain Greek yoghurt,1 grated apple, 2 dates (finely chopped), 2 tbs walnuts. Add cinnamon, turmeric to taste	Baked eggs (2 eggs) Bake and serve eggs in passata tomato sauce with 1 slice of wholegrain toast	1 slice of wholegrain toast served with 150g tofu scrambled with onion, capsicum and mushrooms
Chicken, apple and quinoa salad made with 80g cooked chicken, 1 cup mixed salad greens, 1/2 cup cooked quinoa, 1/2 apple thinly sliced and 2 tsp dressing per serve	1 1/2 cups Greek lentil soup served with 1 medium wholegrain roll	Lemongrass tofu and rice noodle salad: 150g tofu marinated in chopped lemongrass, garlic, honey and soy. Serve with 1/2 cup cooked rice noodles, 1 cup shredded cucumber and carrot and a 1/2 cup of cherry tomatoes	Loaded baked sweet potato: Prepare 1/2 medium sweet potato and 'dress' it with 1 small can of tuna in springwater, mixed with spring onion and 1/4 of an avocado on a bed of spinach
2/3 cup chickpea and eggplant curry served with 1/2 cup basmati rice or barley	100g baked snapper served with 1 cup of sweet potato chips, 1 1/2 cups of green salad and 2 tsp vinaigrette dressing	Prawn, chilli and tomato pasta: 100g cooked prawns in tomato sauce and spinach, mushrooms, 2/3 cup wholemeal or pulse pasta	Slow cooked lamb shank (1 small shank) served with 1 1/2 cups of pumpkin and cauliflower mash and your choice of green vegetables
3 wholegrain corn thins or crispbread with 3 tbs cottage cheese and 1/2 a sliced tomato 200g plain Greek yoghurt with 1 piece of fruit - OR - 1 piece of fruit with 1/4 cup of walnuts	Frozen yoghurt: made with 1 frozen banana, 1 cup plain Greek yoghurt, 2 tsp cacao powder and 1/2 tsp vanilla, blended 2 cups air popped corn	Frozen yoghurt: made with 1 cup of frozen berries, 200g plain Greek yoghurt and vanilla or cinnamon and turmeric 1 piece of fruit and 1/4 cup walnuts	Fruit smoothie: made with 1/2 cup milk, 1/2 cup plain Greek yoghurt, 1 cup frozen fruit and 2 tbs nuts or seeds blended



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"When you are thrown into early menopause with the hormone therapy, it is hard. I was having terrible hot flushes, waking every night"

Heather Arister

Diagnosed in 2017



68 year- old Judy\* was diagnosed with breast cancer in January 2018.

After a lumpectomy and adjuvant radiotherapy, she began treatment with tamoxifen.

Six months later, she was disappointed to discover she'd gained 12 kilograms, despite eating what she considered a 'healthy' diet and watching her weight.

Senior Oncology Dietitian Lauren Atkins tells Judy's story.

"Judy presented with solid nutritional knowledge. She was eating a diet shake for breakfast, a small salad for lunch and chicken or fish plus veggies for dinner. She avoided bread, potatoes and pasta and would snack on low-fat yoghurt and 1-2 pieces of fruit. She rarely drank alcohol. Her intake was well below her caloric needs, so understandably she felt she should be losing weight. But when we scientifically analysed Judy's weight, food intake, exercise and blood results, it was revealed she was in fact, undereating.

#### Step one

For Judy, this was about improving her baseline diet. Because she was undereating, her body had become accustomed to this state of caloric insufficiency.

#### Our focus initially was on:

- Whole foods, plenty of fresh vegetables, legumes, fruits, wholegrains, nuts and seeds (Mediterranean style diet)
- Meeting Judy's protein needs with a variety of poultry, fish. lean meat, tofu, eggs and legumes
- Choosing low GI carbohydrates wisely and including good quality fats
- Steering away from 'low fat' options when these weren't required.

#### Step two

This was about achieving a metabolic shift. We changed Judy's eating patterns and aligned her



diet with her exercise routine. She was surprised that her weight didn't increase, even though she was eating more. She was actually enjoying the enhanced variety of foods and noticed improvements in her energy levels and mood.

We then worked with her sleepwake cycles, social and exercise routines to change the windows in which she ate. This gave her body more of a chance to access her fat stores for fuel while maintaining her muscle mass.

I collaborated with Judy's Exercise Physiologist to ensure we were fuelling her optimally to get the most out of her workout, recover well and feel great in the gym. Judy increased the number of resistance/strength training sessions she was doing, and added some intervals and high intensity work under the exercise physiologist's guidance. She continued to enjoy her walks twice a week with friends.

After only three weeks of 'step two'
Judy had lost four kilograms. This
was after many months of gradual
weight gain followed by stagnant
weight. Judy was thrilled and
motivated.

We continued with this routine, tweaking the plan along the way to ensure her nutritional intake was adequate, fit her lifestyle and aligned with her exercise program. After four months, Judy had lost 10 kilograms, and to date, ten months post-treatment, she has lost a total of 17 kilograms. Judy continues to get stronger in the gym and is improving her 'six minute walk test'

so she is preserving her lean body mass and feeling more energised and comfortable in her skin.

With an individualised, tailored and supportive approach to Judy's nutrition, we were able to achieve her health goals and get her feeling amazing. Judy has had to buy a whole new wardrobe (although she isn't complaining!) and is looking forward to a trip to Europe in the coming months."

\* Judy was a client of Oncore Nutrition



#### WHY EXERCISE IS VITAL BEFORE, DURING AND AFTER BREAST CANCER



Dale Ischia is an accredited exercise physiologist and a cancer exercise specialist. She says it's now "beyond doubt" that exercise is vital before, during and after a breast cancer diagnosis, with the benefits not only physical.

"Exercise can improve mood, symptoms of depression and also have an impact on the body's immune system and chances of overall survival," 1,2 Dale says.

"The benefits of exercise in cancer are so widely supported that it is now recommended by the Clinical Oncology Society of Australia that exercise be a part of everyone's cancer care. "Patients should remember that 12 weeks of chemotherapy creates a decline in cardiovascular fitness typically only seen in a decade of ageing.3 "It is a perfect storm of deconditioning. Combine the cancer itself with chemotherapy and hormonal treatment and you have this rapid ageing

process."

The good news is, that exercise can slow, prevent or even reverse this deconditioning process. A major US study in 2014 showed that some cancer patients were actually able to increase their cardiovascular fitness by 13.3% when prescribed a specific program of interval training, that allowed for treatment fluctuations and was appropriately progressed.4 Another study examined 50.000 cancer survivors. It found that those who were physically active after their diagnosis had a 48% greater chance of overall survival and an 28% greater chance of breast cancer survival.2,5

"We do know exercise works," Dale says. "I would encourage all women who face this diagnosis to start moving – start small and build up - it is never too late. And we can help you.

"If a woman doesn't know where to begin, she should consult an accredited exercise specialist and we will help. It might be as simple as starting with a walk. The important thing is to keep moving." We asked Dale to address some commonly asked questions about exercise and breast cancer.

# How can exercise help manage the side effects of breast cancer treatment?

- Improves muscle tone and helps to combat loss of strength
- Protects bones
- · Fights fatigue
- Improves balance
- Improves cardiovascular fitness
- Restores range of movement in the shoulder
- Helps manage peripheral neuropathy

### Not only does it help with the side-effects of breast cancer treatment, exercise also:

- Improves the efficacy of chemotherapy
- Improves the chance of overall survival
- Boosts the body's own immune function

It is best to use a combination of cardiovascular, strength, flexibility, balance, core and repetitive movements. For cardiovascular fitness, we recommend things like walking, running, swimming, dancing or hiking.

A minimum of 90 minutes per week is the basic recommendation. That is, three thirty-minute sessions working at moderate intensity. This will benefit body composition, cardiovascular fitness, and heart health. You may have to build up to this gradually, or split this up into 10-minute blocks throughout the day.

Walking outside is one of the simplest exercises you can do. It gets you in the fresh air, is free, can be done anytime and helps your cardiovascular system and the health of your mind.

## What's your definition of moderate intensity exercise?

Moderate exercise is when your heart is working at 55-70% of its maximum rate. To work this out, minus your age from 220.

You can also do a 'talk test'. Your breathing rate should be such that you can talk, but not sing.

## Why do you recommend strength training?

Strength training exercises improve both your strength and your muscle mass. We know that muscle mass is a good indicator of survival, so the more muscle mass the better. Strength training exercises have also been proven to stop the bone loss that occurs in hormone treatment.

Strength exercises might use someone's own body weight, free weights, and machine weights.

Please note though, if you have recently had surgery, you must get the okay from your surgeon before lifting heavy weights. I would say to women to make sure they have a full range of movement in their arm and shoulder before performing certain resistance training exercises.

You need two to three 30-minute sessions per week. You should start with fairly light weights and progress slowly. A 20 percent increase every couple of weeks is a good guide. Begin with one set of 10 to 12 repetitions of eight different strength-training exercises using major muscle groups and multi joint functional exercises. When you are stronger, you can progress to doing 2 to 3 sets of 6 to 10 repetitions with an increased load.

#### Can women exercise during chemotherapy?

Exercise is safe during chemotherapy. Energy levels fluctuate throughout the cycles of chemotherapy. There are going to be days when you just can't face it, and other days when you are feeling better. An Exercise Physiologist can prescribe you an exercise program that includes exercises for what we call good days, flat days and no-way days.

A flat day program might involve a small series of exercises sitting or lying down. It may be enough to just walk to the letter box and back. Keep it simple, but keep moving.

#### What if I am just too tired?

Rest and recovery are just as important as exercise. Midafternoon is a great time to lay down. If you fall asleep, great, if not, enjoy the rest. Limiting a midafternoon nap to 45 minutes should ensure you are not negatively impacting your evening sleep.

Work out the time of day when you are least fatigued - typically this is mid-morning and you should exercise then. Often the hardest part is getting out the door or off the couch. Once you have started exercising you might feel more energised and completing the exercise is manageable.

#### What if I have a central port?

Once the central port has healed, there aren't many limitations, except when it is attached to chemotherapy – please speak with your nurse, exercise physiologist or oncologist.

Be guided by your own perceived rate of exertion.

# What about after surgery? Is exercise recommended? Can it hurt healing mastectomy sites?

Immediately after surgery, it is important to move around gently to reduce the likelihood of a blood clot, or deep-vein thrombosis (DVT). Walking is best, however, simply pointing and flexing your feet can help pump blood around. Once cleared by the surgeon (usually after 6 weeks) you can gradually increase range of movement exercises and resistance exercises and increase walking. Doing this under the guidance of your exercise physiologist or physiotherapist is best. If there is unusual swelling at the operation site, please refer to the doctor and do not continue with exercise. If time allows, it is helpful to get as fit as you can prior to surgery.

#### What about lymphoedema?

Many women are fearful of developing lymphoedema and often don't want to lift anything heavier than the initial weight restriction given to them immediately after their operation.

The good news is, it is perfectly safe to lift very heavy loads, provided you gradually build up. Start low and progress slow when it comes to resistance training and lymphoedema.

Exercise can help move lymphatic fluid around the body, which can reduce swelling and symptoms, but it won't cure lymphoedema.

Repetitive movement for the arms is good for lymphatic flow, such as marching on the spot, wiggling the fingers, rowing or pole walking.

#### Why have I been told to do balance exercises?

Balance is commonly affected by chemotherapy, especially if you experience peripheral neuropathy or hair loss. Balance exercises, as their name implies, help to maintain balance, which is particularly important for those who are at risk of bone fractures from osteoporosis or bone metastases. Simple balance exercises such as standing on one leg will help challenge and maintain your balance. Core strengthening exercises are also vital, especially if breast reconstruction involves the abdominal muscle.

## How can exercise improve chemotherapy benefit?

There have been some really exciting results published on how exercise increases the efficacy of chemotherapy in mice models. These results are extremely positive, however should be viewed with cautious optimism. A study was undertaken where mice were injected with breast tumour cells. Tumours actually grew slower in those mice who ran on a treadmill everyday.6 Another study, which examined lung, melanoma and liver cells in mice, showed a 60% reduction in tumour numbers and size in those running on a treadmill. Immune cells released by the body during exercise slowed tumour growth. When these natural killer cells were blocked. the tumours grew at the normal rate.7 Studies in humans are currently underway.

#### It is very important to seek the advice of an Accredited Exercise Physiologist with further training in oncology if any of the following are present:

- Bone Metastases
- Lymphoedema
- PICC line
- Tendon issues
- Low WBC or RBC (White Blood Cells/Red Blood Cells)



#### What else should patients be mindful

#### Take it easy

You may not be able to do what you used to be able to straight away, so build up gradually. Breast cancer patients also need to make sure they are absorbing enough nutrients to fuel an exercise program. They need enough fat, carbohydrates, proteins, vitamins and minerals.

#### Fatique levels

These will fluctuate, especially during treatment. It's important to move, but not to move until you are exhausted. Exercise to tolerance and monitor recovery.

#### Avoid guarding behaviour

Rounding your shoulders and not moving the arm on the affected side can lead to shoulder impingement syndrome or frozen shoulder.

#### Infection

If your neutrophil levels are low, you should avoid public places with high risk of infection, like public swimming pools.

#### Anaemia

This is self limiting. You will not be able to push yourself to exercise.

#### Peripheral Neuropathy

This is a common side effect of chemotherapy. It will not be worsened by exercise. It can reduce your balance, especially your proprioception (sense of movement and body position), so it is important to minimise tripping hazards. Moving your feet and hands can help with your proprioception. Massage can also help reduce the feeling that your foot is one block, and make it feel like individual bones and joints again.

#### **Cramps**

These may be a sign of something else and you should check with your doctor. Cramps can be common and are best managed by hydration (drinking 1.5-2.5 litres of water per day), stretching the affected area, and good nutrition. A healthy diet will provide all relevant nutrients. No supplements are required if your nutritional intake is sufficient.

#### When you should stop exercising and consult your doctor:

- If you experience dizziness or fainting while exercising
- If there is swelling in your ankles, neck, face or arms, seek immediate medical help
- If you experience shortness of breath with only a small amount of exertion
- If you have chest pain or palpitations
- If you become nauseous during exercise
- If you experience chills/ shaking during exercise
- If you develop severe diarrhoea or vomiting.
- If you have a high temperature.

Dale Tschia

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Betof AS, Lascola CD, Weitzel D, Landon C, Scarbrough PM, Devi GR, et al. Modulation of murine breast tumor vascularity, hypoxia and chemotherapeutic response by exercise. J Natl Cancer Pedersen L, Idorn M, Olofsson GH, Lauenborg B, Nookaew I, Hansen RH, et al. Voluntary Running Suppresses Tumor Growth through Epinephrine- and IL-6-Dependent NK Cell Mobilization and

Redistribution. Cell Metab. 2016;23(3):554-62



Can you imagine getting straight out of the chemotherapy chair and into an exercise room for 45 minutes of strength training? That's exactly what a group of patients at Sydney's The Kinghorn Cancer Centre and Garvan Research Institute are doing, as part of a PhD project being undertaken by medical oncologist Dr Sara Wahlroos. She's examining the effects of exercise, when combined with chemotherapy, on breast cancer biology.

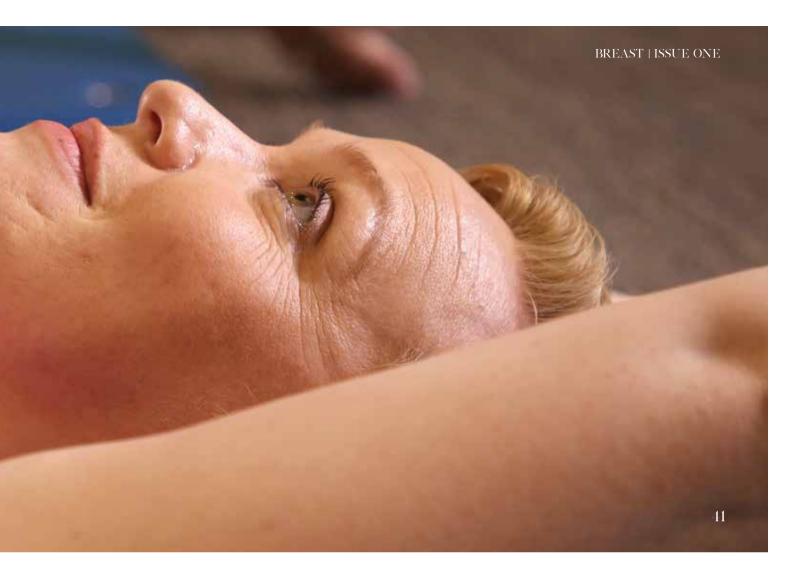
Seventeen women are already enrolled in the study and all are undergoing neo-adjuvant chemotherapy (treatment before surgery). They have a supervised exercise session straight after their first four sessions of chemotherapy. In addition, the participants are given a set of dumbells and are prescribed an individualised home-based training program that they undertake three times a week for the first six months of treatment. They are also being encouraged to do at least 8000 steps a day.

"Ninety percent of these women have never done weights before, so you see a difference in their strength very quickly," Dr Wahlroos says. "While we have no firm data yet as the study is still ongoing, the women involved are really enjoying the process.

"What we have seen is that they are all at least maintaining their muscle mass, upper and lower body strength, and some have even gotten stronger, despite being in the middle of chemotherapy."

Dr Wahlroos says there is a strong body of evidence demonstrating that women undergoing chemotherapy lose condition and muscle mass, as well as aerobic fitness.

"Many women temporarily or permanently go into menopause as a result of therapy. And when you reduce oestrogen, it results in a loss in muscle mass. Women end up with more fat than muscle, and therefore burn fewer calories.



"They often say, 'I cannot shift these kilos and it was never this hard'.
Our aim is to help them preserve as much muscle as possible by doing strength training.

"If they can maintain muscle mass, they are going to have a much easier time recovering their aerobic fitness as well, because they have the strength."

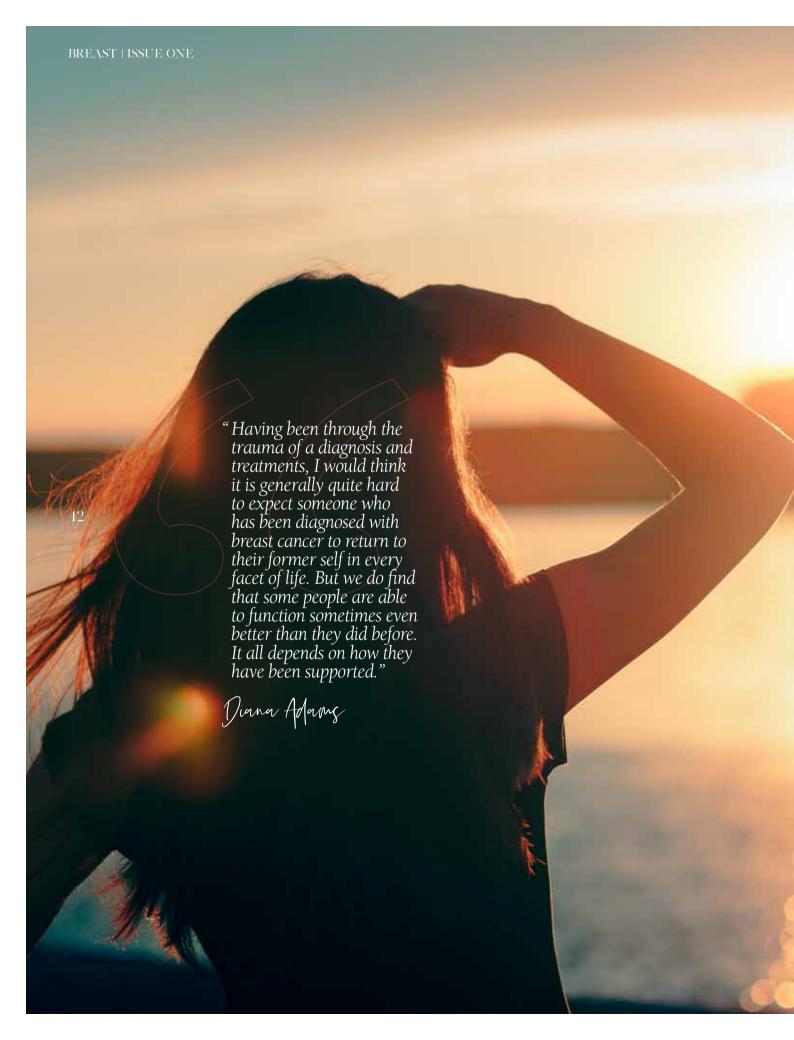
Dr Wahlroos' motivation to keep patients moving is simple. She says as survival rates for breast cancer improve, it's important to look ahead and ensure quality of life is maintained, so that patients don't end up with other ailments like cardiovascular disease and osteoporosis.

"We used to tell women they should be in bed and rest after treatment. But that's gone out the window. "That's the worst thing you can do. We used to say that about back problems. As soon as you decondition, it is so hard to come back from that. I am not saying all of a sudden do 100 burpees. I am saying start small and we will work from there"

The research is expected to be finalised at the end of 2020.

Dr Sara Wahlroos





# Offife

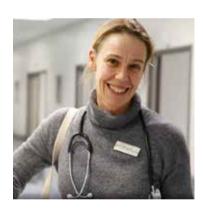
Medical Oncologist Dr Diana Adams is also a Cancer Survivorship Physician – working closely with breast cancer patients to help them achieve quality of life both during treatment and beyond. She believes women can live well through these stages, but what's crucial is support.

"Many women need help navigating all that a breast cancer diagnosis brings," she said. "It's not only physical support, it's psychological, spiritual, emotional and financial." One thing she is particularly passionate about is the importance of exercise. "I cannot say strongly enough that exercise in cancer care saves lives. We know it can reverse treatment related side effects, improve muscle mass, stamina, self-esteem and quality of life. Importantly, it can slow disease progression and improve the chances of survival." Diana also says it's a common misconception that suffering during therapy is a sign the drugs are doing their job. "Some women believe they have to feel horrendous, but if they are experiencing a problem, we need to make them feel better. We have come a long way in the past 15 years and there are things we can do now to help women tolerate treatment better and to move forward beyond treatment."

#### These are some of her insights.

#### Fatigue

Many women report sleep disturbances and feeling profoundly tired during and after treatment. Fatigue typically starts to lessen around three months post-completion of therapy. By 12 months, most women will return to previous energy levels. Undiagnosed depression, an underactive thyroid or diabetes can worsen this fatigue and need to be treated. About 10% still experience profound fatigue and we need to understand more through research and support these patients better.



The shock of a diagnosis is enough to set you into a bad sleep pattern. Depression can cause some women to wake very early. Also, we use steroids during chemotherapy and that can interrupt sleep cycles. But getting enough sleep is really important for patients, because we process things at night as well as during the day. It is important that women discuss their sleep patterns with their doctors. We should be saying not, 'How did you sleep?' but 'What was the quality of your sleep?' There is a lot of work being done on sleep at the moment and I think it is intertwined with cognition. If you are fatigued, you might feel unable to exercise, although exercise can actually improve fatigue and improve sleep. Women report that they are 'kind of resting but not really resting enough', or 'sleeping but not sleeping enough' - it's a vicious cycle. We know exercise can help and we know that yoga can help. The sooner you intervene with a sleep pattern, the better.

#### Cognitive changes or 'chemo-brain'

Many women report that simple things they once found easy to remember are now difficult. They report vague or 'fuzzy' thought patterns. Writing lists can help. Challenging your brain with tasks that are different to what you are used to can help restore some of the brain's neuroplasticity. These symptoms often start

improving at the 6 to 12 month mark post-therapy. It is important that undiagnosed depression is not worsening any cognitive changes and is treated. Exercise can also help to improve cognitive function.

#### Taste and appetite

Some patients report a metallic taste in their mouths as a result of therapy; others can suffer quite serious mouth ulcers, which can impact their appetite. There are management strategies we can employ to help women through these symptoms, but generally speaking, I would say that taste and appetite generally return within about three months of completing therapy.

#### Lymphoedema

Even in this age of sentinel node biopsies or removal, about one in five patients will still experience lymphoedema, which is a swelling of the arm that can occur after treatment for breast cancer.

It is a consequence of removing lymph nodes from under the arm, so the body's lymph system is not draining effectively. There is no cure for lymphoedema, but there are management strategies to alleviate symptoms and to minimise the chance of swelling. It first needs to be identified by an occupational or lympoedema therapist. We have moved away from advising not to use the arm and actually encourage exercising the arm actively.

#### Weight gain

Many women gain weight as a result of their treatment and this can impact their general body image. Weight gain can occur for a variety of reasons, including medication-induced menopause, or reduced activity levels because of fatigue and not feeling well. Again, exercise is really important and referral to a dietitian where possible.

#### Hair loss

Often a woman's hair is linked to her identity and her femininity and as we all know, chemotherapy can result in hair loss - and not just from your head, but on all parts of your body, including eyelashes, eyebrows, nasal hair and pubic hair. Some centres - including ours - use 'cooling caps' which keep your scalp at a very low temperature during a chemotherapy infusion. Research has shown that these caps can prevent hair loss altogether for some people. For women who do lose their hair, it can take three to four months following the completion of treatment before they see any meaningful new growth. It tends to grow back curlier or different in texture than before and maybe coarser, even when it has previously been straight. In many cases hair does not stay curly, but it may still have a wave.

#### Neuropathy

Many patients who are free from breast cancer report a persistent sensation of pins and needles or a loss of feeling in their fingers and toes. This is known as neuropathy and it results from the nerve damage linked to some chemotherapy agents. Neuropathy can be debilitating and sometimes it is never resolved - impacting quality of life for the rest of a patient's life. Neuropathy usually resolves with time, usually by one year post chemotherapy. For some, it can impact quality of life long term. Exercise can help maintain core body strength to reduce risk of falls

#### Hot flushes

Hot flushes are a commonly reported menopausal symptom associated with breast cancer treatment. Up to 80 per cent of women with breast cancer, particularly younger women, experience hot flushes. They can be more severe for breast cancer patients than they are for naturally menopausal women without breast cancer, and may persist for many years beyond treatment. Some women notice that caffeine (including tea). stress, red wine and chocolate can worsen flushes. Avoiding these triggers can improve symptoms. There are many medications available to reduce flushes and best discussed with your doctor.

#### Joint pains

Some hormone therapies may cause joint pain as a side effect. This most commonly occurs in the morning upon waking. Gentle exercise can help. A small number of women need to trial different hormonal therapies with their doctor.

#### Decreased Range of Motion

Women who have had breast surgery often notice they have a decreased range of movement in their shoulders, so are less able to do stretching exercises. Seeing an accredited exercise physiologist or physiotherapist increases confidence and ability to regain or even improve upper body function.

#### Osteoporosis

Brittle bones, or osteoporosis, can be a result of some therapies. It is something we worry about for our patients, but some survivors don't seem to think as much about this. Keeping a healthy vitamin D level and performing weight bearing exercises, such as walking or running, can protect against osteoporosis happening in the first place. There are also medications to treat osteoporosis.

#### Depression

Some women experience depression during or after treatment and it is completely understandable - it is a reaction to an abnormal situation. Women are often dealing with partners - some are supportive and some unfortunately, are not. Dealing with children, depending on their age, can also be exceptionally difficult. Women might also be dealing with employers and negotiating reduced hours or fewer days.

#### Fertility

Breast cancer may have affected a woman's fertility, either permanently or for a period of time. It depends on the type of breast cancer and the type of treatment. Many women wonder how they will explain to a new partner that they have had treatment when they were younger, or that they can't have children. There are so many issues and there are breast cancer counsellors who can help women navigate these kinds of conversations.

Dr Diana Adams



"There are going to be days when you just can't face it and other days when you are feeling better. Keep it simple, but keep moving."

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Exercise Physiologist

Dale Tschia



# Cancer Survivorship Physician Diana Adams notes that the fear of cancer recurrence is an almost universal anxiety for cancer survivors.

"I would say that every cancer patient at some stage worries about the fear of a recurrence," she says. "We are doing a study into this fear at the moment and it is recruiting very quickly. I would say that it is important for clinicians to tell patients what their personal likelihood of a recurrence really is, because for some people, it's very low. Some women will be able to reduce their fear by having all the information and all the facts. Patients and their doctors need to work out whether their fear is a rational one or an irrational one. Some might need to

have a plan for what they will do if their cancer does recur.

"A lot of patients need the support of a clinical psychologist, to help them unpackage what's going on.

"Sometimes this support is needed when treatment is actually finished When they are on treatment, they are focused on what needs to be done. At the end they are almost in shock, and it's a case of 'What was that all about'?"

Dr Diana Adams



Monique was 49 years old and juggling three teenage children, an extremely demanding job and an ageing, unwell father when she was diagnosed with breast cancer.

That was two and a half years ago. In hindsight, she recognises that she was "incredibly stressed" and had sustained this lifestyle for more than two years.

"I was not getting a break and I was juggling way too many balls," she recalls now. "I was keeping them all in the air, but I can see now that I was not coping at all.

"I am a high achiever, but I drove myself into the ground. I needed a gun to be held to my head for me to accept that this lifestyle could not be sustained ... that gun to my head was breast cancer."

Monique's diagnosis was atypical. She had noticed a strange red mark underneath her right breast – it was not a lump, but rather, it appeared as a graze.

She thought she had perhaps scraped herself in the garden, but it did not resolve after about three months.

"It did not go away, but I was massively busy at work. When I went to the doctor, she said it was unlike anything she had seen before."

Further tests revealed she had stage 1, non-invasive breast cancer (Ductal Carcinoma In-Situ).

Doctors also discovered a separate, invasive tumour.

The DCIS was HER2-positive; the tumour was HER2-negative. She immediately underwent a double-mastectomy followed by six months of chemotherapy and five weeks of daily radiation.

"I just said I want them both off ... I don't want ticking time bombs on my chest.

"I had my breasts rebuilt at the time they were removed and I had them rebuilt from the back of my legs. Because I had three children in three years and three caesareans, I had a tummy tuck done after my last child, so they could not remove tissue from my tummy, which is what they would normally do. So, surgeons cut all of the tissue and the muscle out from under my buttocks."

The day after finishing chemotherapy, Monique took on a new job teaching two days a week at a school near her home. She did this for a year and then also undertook further university studies. Again, she became exhausted trying to hold on to her vision of her former self, before finally admitting enough was enough.

Monique chose to retire, but admits she is still struggling with this new identity.

"I feel like I have gone from one life to another life - like sliding doors with no preparation whatsoever. "Even though it was 2.5 years ago, I was struggling because I am not the person I thought I would be.

"You are effectively saying, 'This is the end of the youthful part of my life'. But (stopping work) and being present here is probably the best reward for the people that love me that have been through this horrible experience with me."

Monique says the fear of a recurrence is ever-present. She will now remain on hormone therapy for up to 10 years, but says if she was eligible for any new medicine to further reduce her risk of recurrence, she would "absolutely" choose more treatment.

"When you are having chemotherapy and you talk to people in there ... you are constantly surrounded by people who have relapsed. There is not a day that goes by that the fear of a cancer recurrence isn't there. It is certainly there, but I am a glass half full person. You can't control what you don't know and it is pointless worrying about something that might happen to you. All you can do, is do everything you can to reduce your risk of recurrence. If it doesn't work, you want to know you have tried everything, and given it a redhot shot. Women should be given every bit of information they can be given to make their own decisions and choose the right treatment path for them."

Monique

"There's not a day that goes by that the fear of a cancer recurrence isn't there."

Monique



"What matters most is how well you walk through the fire."

# lets akabout

It's a topic many breast cancer patients feel self-conscious discussing with their doctors, but Dr Belinda Kiely believes sex during and after breast cancer treatment is "a big deal".

The Sydney-based oncologist specialises in breast cancer and says sex and relationships are almost "inevitably" impacted by a breast cancer diagnosis and the subsequent side effects of treatment.

"Many women I am looking after are having a lot of problems with relationships, intimacy, and sex," she admits, "but many are afraid or embarrassed to talk about it".

"A breast cancer diagnosis and all the treatments that follow this can bring both emotional and physical side effects, impacting a woman's body image, sexual function and wellbeing." Dr Kiely said one of the effective ways to treat breast cancer is with hormone therapies that reduce the oestrogen levels in the body but unfortunately, reducing oestrogen has many side effects, including problems with sexual function. The most common sexual problems are a loss of libido, vaginal dryness and pain during intercourse.

"Young women can really struggle as breast cancer treatments often result in a premature menopause," she says. "Young women can be put into menopause quite suddenly so the menopausal symptoms can be more severe.

"I am treating a 35-year-old woman at the moment and we have put her into menopause with hormone blocking treatment. Almost overnight she developed hot flushes, sweats, reduced libido and vaginal dryness. These things can happen really quickly at an age when she should not be dealing with them."

For women who are already post-menopausal when diagnosed with breast cancer, hormone therapies can further reduce oestrogen levels.

"This can be like a 'double menopause' and the side effects are often greater.

"It is a big problem and can result in women stopping their hormone therapy because of the impact it has on their quality of life. This is concerning because they are stopping the treatments that are reducing their risk of breast cancer returning."

Dr Kiely says the important thing for women to remember is that they are not alone and "there are many things we can do" to try and manage the symptoms during and post-breast cancer treatment.

#### Vaginal dryness

A major side effect of hormoneblocking therapies is vaginal dryness.

"For a number of women this dryness can be so painful, that they can't handle any sort of penetration at all," Dr Kiely says. "Even a pap smear is impossible.

For vaginal dryness the main treatments are moisturisers and lubricants.

"Vaginal moisturisers should be used on a regular basis independent of sexual activity.

"Lubricants can also reduce discomfort during penetrative sexual activity. There are water-based, oil-based and silicone-based lubricants available so women may need to try out a few different ones or speak to someone who specialises in this to determine which lubricant is best for them."

Dr Kiely says those women still experiencing difficulty might want to try vaginal dilators to help stretch the vaginal tissues. "Women can start with a very small dilator and then gradually increase the size. A pelvic floor physiotherapist can provide guidance. Vibrators can also be helpful."

If vaginal symptoms do not improve, a low dose vaginal oestrogen can be considered. These are available as tablets, creams and pessaries that are inserted directly into the vagina. These work best if inserted daily for two weeks, to allow the vaginal wall to heal and then decrease to twice weekly to maintain the benefit.

"There is a bit of controversy about whether vaginal oestrogens are safe to use in breast cancer," Dr Kiely says. "There has never been a study looking at whether women who use vaginal oestrogens have a higher risk of their breast cancer returning but some small studies have measured oestrogen levels in the blood in women using low dose vaginal oestrogens and these have not shown a significant rise in oestrogen levels.

"I do think we need to explain the risks and benefits to women to help them decide if they want to use a vaginal oestrogen. I am comfortable with women using a low dose vaginal oestrogen in small amounts, especially if it helps them stay on the hormone treatment for their breast cancer."

#### Relationships

Dr Kiely admits that some relationships won't and don't endure a breast cancer diagnosis and treatment.

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with Dr Belinda Kiely

"Most partners are great and are very supportive, but they struggle too and are often unsure what best to do and say. Others, sadly don't want to stick around, but sometimes this happens because things weren't that great to begin with. Some women believe their partners would be better off finding someone more attractive and whole. Interestingly, when you actually speak to their partners, this thought has never entered their minds.

"Often it's about how a woman feels about her body. I had a woman recently who was in tears because she could not even look at herself in the mirror after her mastectomy. She is really struggling with being flat-chested and does not feel like a woman anymore.

"A cancer diagnosis changes so many things for people but put simply, it takes away selfconfidence. Unfortunately, it takes time for that confidence to be regained. "People often forget to be kind to themselves and give themselves a break. Open communication with their partner is a great first step."

#### Loss of Libido

Dr Kiely says loss of libido or interest in sex can be very difficult to treat and is usually caused by many factors including low oestrogen, fatigue, pain from surgery, fear of cancer recurrence and poor body image.

"It is particularly a problem when a woman's partner wants more sex. Sometimes partners also experience loss of libido because they are worried about the cancer.

"I want women to know that all of this is very normal. Communication is really important. A loss of libido is a normal reaction to the treatments you have had, the changes to your body, and the stress of having cancer. "I have had patients who have had breast cancer treatment and who have gone on to continue fulfilling sex lives, but it does take time and effort. And some of them have seen psychologists or counsellors to help them. It probably takes longer to be aroused and they have to concentrate on other things, like kissing, going on dates, nice lingerie, massage, touch, and foreplay – these thing all become more important.

"We tend to think sex is just penetrative, penis in vagina sex, but there are a lot more ways of being intimate."

#### Communication is vital

Dr Kiely says communication is vital and women should talk not only to their partners, but feel comfortable asking for help from members of their treating team. Doctors, nurses, psychologists, counsellors and social workers can all help with problems related to sex and relationships.

"Unfortunately, bringing up the topic of sex with their doctor can be difficult for women. I try and normalise it by explaining the common problems experienced by other women with breast cancer and then ask if they are experiencing similar problems. I don't always have a solution, but I try and help by suggesting useful resources or arranging a referral to someone I think can help.

"Women need to know it may not be like this forever. For most, it does turn around, but it will be different. For some women, their sex life may never be the same as it was but with good support and advice and a lot of patience and even a sense of humour, this can be turned around and it can still be fulfilling."

#### Useful resources

- Breast Cancer Network
   Australia (bcna.org.au) Breast
   cancer and sexual wellbeing
   booklet
- Cancer Council (cancer.org.
   au) Sexuality, intimacy and cancer booklet
- 3. Australasian Menopause Society (menopause.org.au)
- 4. Society of Australian
  Sexologists
  (societyaustraliansexologists.
  org.au)
- 5. Relationships Australia (relationships.org.au)
- 6. Australian Psychological Society (psychology.org.au)
- 7. National Cancer Institute (cancer.gov) Self-image and sexuality





# Henopouse Senopouse CANCER

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MENOPAUSE can be difficult when a woman is well, but when it's part of breast cancer treatment, symptoms like hot flushes and vaginal dryness can be particularly debilitating. But Associate Professor John Eden from Sydney's Prince of Wales Hospital, says women should know that there is much that can be done to manage menopause both during and after breast cancer therapy.

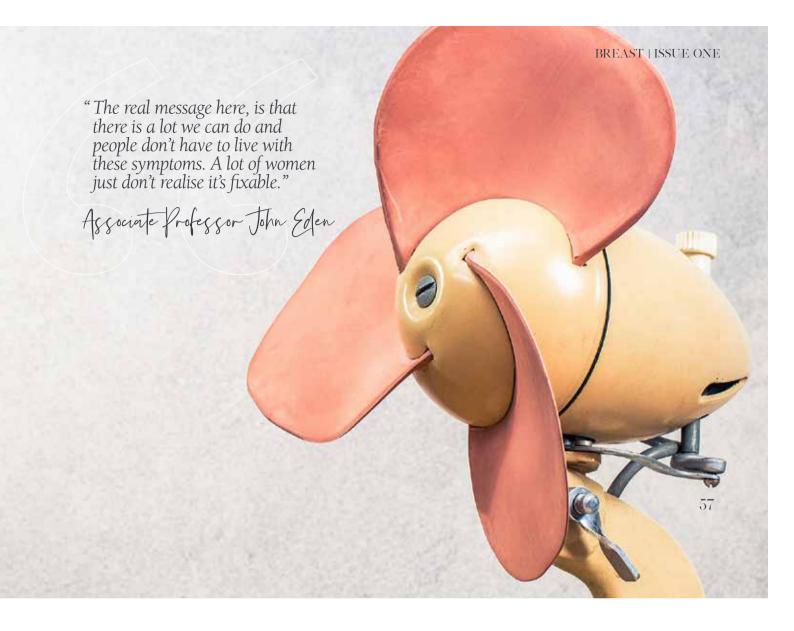
Not that he is downplaying the distress these symptoms cause some of his patients.

"The big problems are severe flushing and severe vaginal dryness. These can be terrible problems for women, and I have women who come to me crying they are so distressed – just the lack of sleep from the hot flushes can be awful.

"It can be 5-10 flushes per hour day and night, waking every 30 minutes. People don't really realise how bad it can be. For these women who have had treatment for breast cancer and are put into menopause very suddenly, it can be very debilitating."

Associate Professor Eden says menopause may be the result of commonly-used chemotherapy agents, which can damage eggs and deplete what is a finite egg reserve.

"The younger you are, the less likely you are to go through menopause," he says. "It is much more common in older women. We typically see it by the second month of treatment. They get severe sweats and flushes because of the suddenness of it. We see the same problem with someone who has had surgery and had their ovaries removed."



Associate Professor Eden says chemotherapy-induced menopause is usually permanent, however there are exceptions.

"Some young women have their ovaries stunned and then their cycle returns, but for the vast majority, it is permanent. If you go into menopause and you are over 40, it is likely to be permanent. Even those women who do get their ovarian function back will go into menopause a lot earlier than anyone else."

Associate Professor Eden says women whose cancers are hormone-sensitive may also be prescribed drugs to block ovarian function. "This is often combined"

with another endocrine therapy and again, the body will be put into menopause. In these cases, the menopause is reversible, although women will still have menopausal symptoms while ovarian function is blocked."

#### Managing Hot Flushes

Associate Professor Eden says the good news is that there are a number of therapies available to manage hot flushes.

He says lifestyle strategies can be largely ineffective, so his first option is a complementary therapy known as Remifemin Plus, which includes an extract of black cohosh and St John's Wort. "This has been shown in numerous clinical trials to be equivalent to low-dose hormone therapy, which is pretty impressive for the relief of hot flushes.

"It has also been shown in the laboratory to inhibit oestrogen-receptor-positive and breast cancer cells. Just about every other herbal extract women try for menopause contains plant oestrogens and certainly women with breast cancer should stay away from those."

Associate Professor Eden says there are a number of other treatment options to help manage hot flushes.

#### Managing Vaginal Dryness

Another common menopause symptom that breast cancer patients frequently need help with is vaginal dryness.

"It can be so severe they can't have intercourse at all, and even walking is uncomfortable," Associate Professor Eden says.

"We are using a lot more aromatase inhibitors these days and they seem to completely oestrogen-deplete a woman, so the vaginal dryness problem is particularly common now and particularly severe."

He said there are a number of treatments that will provide relief, but the first thing he advises is to "get rid of soap".

"Australian women don't want to use soap on their face because they are worried about drying their skin out, but they seem to think it's fine to wash their bottom and vulva with soap. They should stop this and use a gentle wash, like Cetaphil or QV – things that are often used for eczema.

"They can also try a vaginal moisturising product or use basic coconut oil or olive oil lubricants. There is also a good natural product called Sylk. A lot of these remedies make everything much better, although you are left with a small group – about 1 in 5 – who have a major problem."

Associate Professor Eden says those who continue to suffer may want to try  $\mathrm{CO}_2$  laser therapy to regenerate vaginal walls.

"Basically, it has been used in dermatology for decades and it thickens vaginal and vulval skin. It helps an awful lot of patients. For the 1% who say nothing works, we do sometimes use low-dose hormone treatment.

"The real message here, is that there is a lot we can do and people don't have to live with these symptoms. A lot of women just don't realise it's fixable."

Associate Professor John Eden Associate Professor John Eden is a gynaecologist and reproductive endocrinologist (a specialist in women's hormones). He has had a 30-year research interest in how women can maintain quality of life after breast cancer and is currently part of the multi-disciplinary breast cancer group at the Prince of Wales Hospital in Sydney.



# How can A Chemotherapy?

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Not every woman diagnosed with breast cancer will need chemotherapy Many in fact, can be safely treated with hormone therapy alone.

Associate Professor Nicole McCarthy from the ICON Cancer Centre in Brisbane says cutting-edge genomic tests like the Oncotype DX breast cancer assay can now provide women and their doctors with extra information about their breast cancer, as well as the likely benefit of chemotherapy.

"There is great relief when a woman is told she can be treated with hormone therapy alone," Associate Professor McCarthy says.

"If you don't need chemotherapy, it is a huge bonus. Women can keep working and living their lives, and not worry about the side effects associated with chemotherapy.

"Chemotherapy can impact cognitive function and general energy levels.

"Younger women may become menopausal quite abruptly as a result of chemotherapy. The side effects of this can be significant and debilitating. If it is safe to avoid chemotherapy, then that is far preferable."

Associate Professor McCarthy admits many Australian women have probably been unnecessarily treated with chemotherapy as a safeguard to reduce their risk of breast cancer recurrence, in the absence of this specific information

"Without the specific information provided by genomic tests, many clinicians will err on the side of caution," she says.

"In Australia it is a cost issue. In many other developed countries, genomic testing is part of the standard of care and is used to help guide treatment decisions. Here, women can pay thousands of dollars for a test and for many, this cost is not manageable.

"I always tell eligible women about the availability of genomic testing, because some women will lose that amount in lost income just by missing work for treatment."

#### We asked Associate Professor McCarthy to explain genomic testing – how it works and who is eligible.

#### What is genomic testing?

"A genomic test involves taking a sample of a patient's breast tumour and screening it for the presence of specific genes, providing information about the likelihood of how that breast cancer is going to grow and spread.

## Should all breast cancer patients have a genomic test?

Genomic tests are most useful for patients whose cancers are hormone-receptor positive (HR+) and HER2-negative and whose cancer has not spread to lymph nodes, or involves only 1-3 nodes. For clinicians, it provides extra information and may be particularly beneficial for those patients who we think have an intermediate risk of recurrence, based on standard pathology tests. In these cases, a genomic test can help to confirm a decision on whether chemotherapy is necessary.

If we are sitting on the fence in terms of a decision regarding chemotherapy and a test comes back that puts the cancer in a low risk category, you feel much more comfortable with the decision to

#### Is it really safe to avoid chemotherapy?

There is lots of clinical trial data that suggests that low-grade, node-negative, strongly hormone responsive cancers have a very good prognosis and that hormone therapy alone is enough.

Having used these tests for 7-8 years now, I have a growing confidence, because I have long-term follow up with some of my patients who have not had chemotherapy based on the advice of genomic tests, and who have done well.

While no test is perfect, genomic testing does provide us with additional information above and beyond what the standard pathology report tells us. There are a number of genomic tests available, but the strongest clinical data is with the Oncotype DX breast cancer assay.

## What's the case for avoiding chemotherapy?

There are all the usual reasons, including the physical side effects and the impact on family life.

While many women will still work when they are having chemotherapy, most women will not be able to maintain the same level of work during treatment. In fact, many women will not be able to maintain their level of function after chemotherapy, or it can take many months to recover. Many women never go back to the work they were doing before chemotherapy

# Do some women doubt the accuracy of genomic testing and decide to pursue chemotherapy anyway?

I have only had one woman who has not followed the result recommendations.

I tell women, 'Don't do the test i you are not going to be confiden in the results. You don't want to spend thousands of dollars on a test if you aren't going to follow its recommendation.

If a woman is particularly anxious and could not possibly forego chemotherapy because she wants to throw every treatment possible at her cancer, then I would say don't 'do the test'. A woman must be comfortable following the

I know of one woman who was desperate to avoid chemotherapy and had the test done. It came back and showed that she had a high risk of recurrence. She is now having chemotherapy and is very accepting of her treatment, because she recognises it was the right way to proceed."

Associate Professor Nicole McCarthy

# Ceeping your RER

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"Trust in your people. Your people will stay and love the business and the brand they work for if you look after them."

Nina Bosco

Managing professional and career commitments can be difficult after a breast cancer diagnosis, but some Australian employers are recognising that they need to support staff during periods of chronic illness.

We spoke with Tim Naim, Head of Health, Safety & Wellbeing at the National Australia Bank about how one of Australia's biggest employers can assist its people.

# What policies and procedures does NAB have in place to assist employees through both work and non-work related injury and illness?

All NAB employees are entitled to 12 days paid sick leave accrued progressively throughout each calendar year (pro-rata for part time employees).

NAB is committed to supporting its people through injury and illness, as well as in their successful return to work where necessary. NAB has a strong early intervention focus to injury and illness management, and has an internal Health Management and Rehabilitation Team (made up of allied health professionals) who provide support to employees and their business units.

Those experiencing psychological illness can also access counselling services through our Employee Assistance Program (EAP) program.

## How important are flexible work practices during times of illness?

At NAB, we understand that supporting people to achieve work/life balance is imperative to ensuring they can contribute productively in their role. This is why we are committed to providing flexible working policies (including flexible work arrangements, breaks from work and support in special circumstances) to help employees balance life priorities with work and manage their careers.

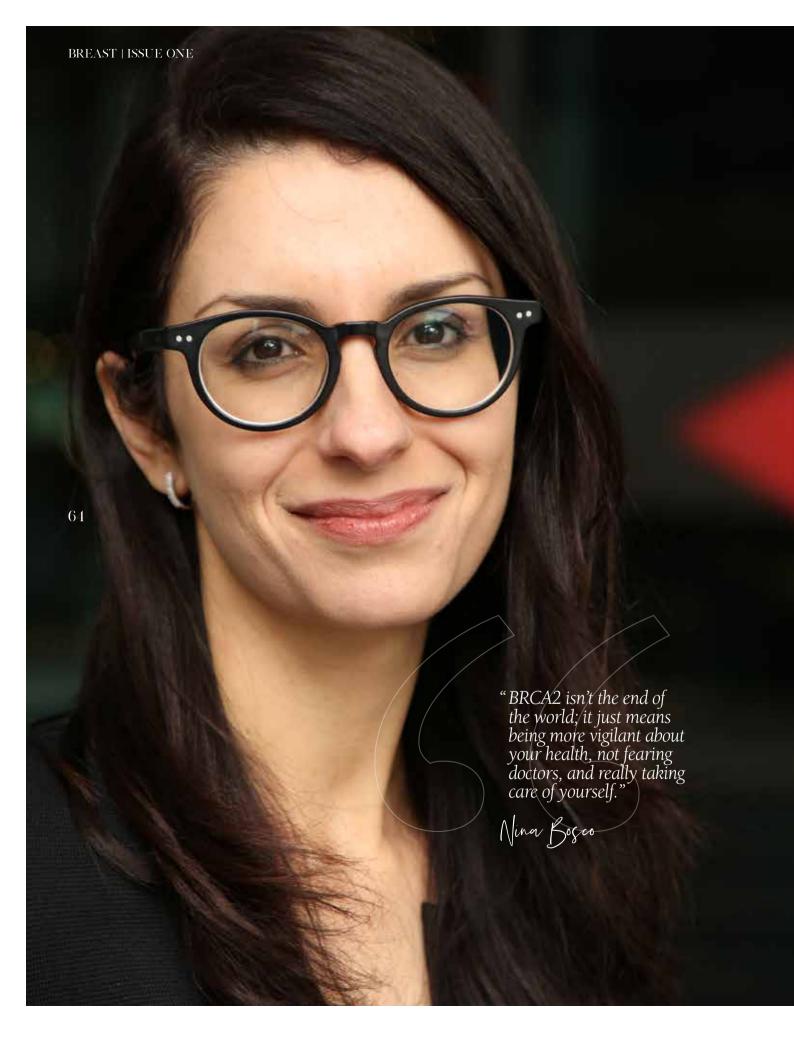
We know that during illness, there are additional pressures and concerns and we encourage our People Leaders to work with their staff members to create a flexible working arrangement that best works for the person experiencing illness, their team and the business. This allows people to focus on managing their treatment and recovery, instead of being uncertain about work.

We want people to get well, return to work and continue to meet their personal and professional needs.

# Is there a particular sick leave policy for a chronic illness like breast cancer?

Our people can also access Prolonged Sick Leave, which is paid leave that may be made available to an employee when they:

- Have a prolonged personal illness or injury;
- Have exhausted their accrued sick leave; and
- Are not in receipt of workers compensation or temporary disability payments.



#### NINA BOSCO'S STORY

After her Mum was diagnosed with ovarian cancer in early 2019, 35-year-old communications executive and mother of three Nina Bosco underwent genetic testing. Similar to her mum, her test came back positive for the BRCA 2 gene, dramatically increasing her own risk of developing breast or ovarian cancer. For Nina, it was a 'nobrainer' to undergo a double mastectomy as an initial step to mitigate the risk of developing cancer due to the BRCA2 gene mutation. In a few years, she will also have her ovaries removed.

She says in the months leading up to her surgery and throughout her long recovery, her employer – the National Australia Bank – was "fantastic", allowing her to work flexibly as required.

"I have always been loyal to my employer and the NAB brand, but it has definitely gone up another level after this arduous experience and the wonderful support I received from my colleagues and senior executives within the bank.

This all started in December last year. We went out to lunch and my Mum could not finish her food. She felt full really quickly and she was bloated. The bloating specifically had been going on for a little while, but she had put it down to menopause. I pushed her for a pelvic ultrasound, which is when we made the unlikely discovery.

One of her ovarian tumours was 23-centimetres—it was enormous! A second tumour was six centimetres. She has had chemotherapy—a combination of intra-peritoneal and intravenous—and has no disease any more. She is continuing on therapy for the next few years to try and keep her cancer in remission. She has been an absolute hero. Even her team of oncologists think she is such a trooper.





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Genetic testing was recommended for my Mum straight away - the day after surgery in fact, when they removed all of the visible cancer. The alarm bells went off because Mum's aunt in Greece has ovarian cancer, another aunt had developed and died of breast cancer in 1983, my grandmother had colon cancer and Mum's brother had prostate cancer. So four out of four siblings, with three exhibiting the "typical" pathway of a BRCA2 mutation – breast, ovary and prostate for men.

Even before I knew I carried the BRCA2 gene, I had always been very vigilant with my breasts. My GP would call it hyper-vigilant. Not only regular breast ultrasounds, but six-monthly clinical examinations and also a mammogram for the first time at 34. I always had this deep feeling. While breastfeeding

my son Lucas almost 9 years ago, I even met my now amazing breast surgeon Elaine – she assured me the lumpiness while feeding was completely normal.

Once I was tested and the result was positive it really was a nobrainer. I just thought, 'they are definitely coming out'.

For me, my breasts have done an amazing job feeding three wonderful children, including twins. I was fortunate that my husband and I completed our family in our twenties.

Mum feels awful, but truly she has saved me. For ovarian cancer management, the best way to mitigate risk is to remove the ovaries and fallopian tubes. For BRCA2 this should occur well before the age of 50 when the risk escalates dramatically; for me,

this will happen by age 45. Until

I have to stay on the contraceptive pill to suppress ovulation, because halting that process every month is protective.

#### Work

My Mum and Dad do a lot of caring for my three sons alongside my in-laws, so life became a bit chaotic juggling work and kids after she was diagnosed.

I'm very lucky to live super close to my parents and next door to my parents-in-law, so we worked out a new rhythm with the diagnosis.

My employer, the National Australia Bank, has been fantastic. I've worked at NAB for 12 years, and they've seen me through a wedding, and three babies – including a tough twin pregnancy!





Since everything happened, I have worked flexibly and worked a lot from home. It is fantastic that in this day and age you can manage to keep working through these sorts of life events. It keeps your mind off the hard stuff and keeps you mentally busy.

And at the end of the day, we are all adults and there are so many ways to work remotely and stay on top of things. So long as the work gets done, that is what counts.

It might be different if I worked for a small company but NAB is a big employer and they have progressive and innovative workplace policies that are really designed to look after their people. This sort of flexibility is not just for health matters; it's time to look after elderly parents or even taking time for mental health. It's just nice to know they have your back during the tough times.

#### The Future

As for my three boys - Lucas, Christian and Alexander - they will be tested for the BRCA2 gene at 18, when they are old enough to deal with what it means for them. They have a 50:50 chance of carrying the gene, so it's essentially like flipping a coin.

Should they test positive for BRCA2, they are at an increased risk of male breast cancer, prostate cancer as well as melanoma and pancreatic cancer (which is similar for women who carry the gene). I know there will be more screening and trials and ways to look after people like us, particularly when it comes to pancreatic cancer, so I try not to dwell on that too much as the research is still so new.

It's actually quite comforting having a gene that has been so extensively researched and continues to be. So many people have strong family histories of cancer, and their gene mutation has still not been discovered

BRCA2 isn't the end of the world; it just means being more vigilant about your health, not fearing doctors, and really taking care of yourself."

Mina

\*Nina has since had a successful prophylactic double mastectomy with reconstruction, and all breast tissue was deemed benign. She is now recovering at home after the six-hour surgery, and looks forward to returning to NAB in full health later this year.



#### These are her words.

"It all started back in 2018. We had sold our eyewear business and we were working with the new business owners, travelling in Europe doing the trade fair. I lifted a suitcase into the car and felt a pain in my side. I went to see a doctor who thought I had fractured a rib. They gave me a bunch of painkillers and expected it would repair itself.

When it was not getting better my husband and son took me to a physiotherapist who thought she could get me walking without pain in two weeks. But a week later I developed a weakness in my leg, where my leg sort of dropped,

I did 10 rounds of radiation on my back, to mop up any cells left after surgery. Then I started on a new medication, a cutting-edge therapy that is an amazing drug to basically seek out cancer cells in my body to destroy them. I am also on oestrogen-suppressing medication. I do get exhausted. You learn to go with the flow on the down days, don't feel guilty and give your body a chance to rest and catch up. Then on the good days you have energy to be with people that mean a lot to you and have a good laugh at life. It's the only way for me.

When you have early breast cancer there are all the outward signs. You

I do think about my own mortality. I would love to see Teiger get married to his beautiful partner. I get wistful looking at him, and it breaks my heart to see him have to cope with all of this. But I am confident he is going to have an amazing life.

What would I tell that innocent little girl in the picture that upset me? I would tell her it is going to be okay. I would say, 'You are in safe hands and you will have an amazing life with the most incredible experiences and fantastic friends. The husband you meet at a party in Bali at 23 will be as funny and crazy as you, and you will have a beautiful boy at 25. You will create



and I was sent for an MRI. It was so painful laying down I had to be sedated. I thought I had a herniated disc, but the doctor came in and said he had found an egg-sized tumour on my spine.

That was the Monday, and I was operated on that afternoon to remove the tumour. By the Friday I heard the word cancer, which was shocking. Further tests revealed it had started in my breast and spread to my spine. I was never aware of the hazelnut-sized lump in my breast, which had not even been picked up by mammogram. I also had some spots on my lung.

One thing I have learned with metastatic cancer, is that they take the treatment a lot slower. I had always said that if I got breast cancer, I would just chop my bosoms off and get rid of the cancer. But my doctors told me this was unnecessary.

go for chemotherapy and everyone knows. But I feel fine and I look pretty much the same. It is surreal.

My husband Jono and my son Teiger (who is now 23) have been amazing. Jono has been incredibly supportive and kind in every way and Teiger slept in a chair by my hospital bed every night for a week. We have always been close. He has been to see a psychologist to help him process everything and it has been helpful for him. I said to him the other day, 'You could look at this as one of the best things that's happened to me, because it puts everything into perspective'. I used to worry about everything, but this has freed me. I have travelled, but it was always about work. Now I want to go to America and I want to go to Japan - it's about creating memories and doing what I love.

an incredible friendship – I met my dear friend Jane Ferguson when I first moved to Sydney, and she has been 'my person' through life and all of this. I call her 'Fierce Jane'. We rent houses together in the UK (where we are both originally from) and get our whole families together for a mad week of dancing, eating and playing silly games. It's these things that are important.

Yesterday, I got the results of a PET scan and they were very positive. There are little spots left on my spine and lung, but they are very small. When you have this incurable cancer and they say it's shrinking, it's special. Who knows for how long? We take it scan by scan."

Louise Scents

# YOUR Breast Cancer

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Vanessa was 43 years old and a single mum to two children aged five and three when she was diagnosed with breast cancer in 2016. She had a mortgage and took eight months off work, using all her accrued annual leave and sick leave and then taking leave without pay. Because she had private health insurance, her surgery was done in a private hospital, but her chemotherapy and radiotherapy treatments were in the public system. Three years post-diagnosis, she has tallied up the bills and now estimates she is already more than \$25,000 out-of-pocket - and this is not counting intangibles, like not being considered for promotion at work or other forms of professional development.

Vanessa says now, "Transport and accommodation expenses were my biggest spend. If I had known that the Patient Transport Subsidy scheme would not be applied in my case, I would have gone private for adjuvant therapies as well, and gone to a private oncology centre closer to home, allowing us to stay in familiar surrounds for the treatment period.

"Overall, I would say that we were fortunate, because I had critical illness insurance, and this paid out a lump sum soon after diagnosis.

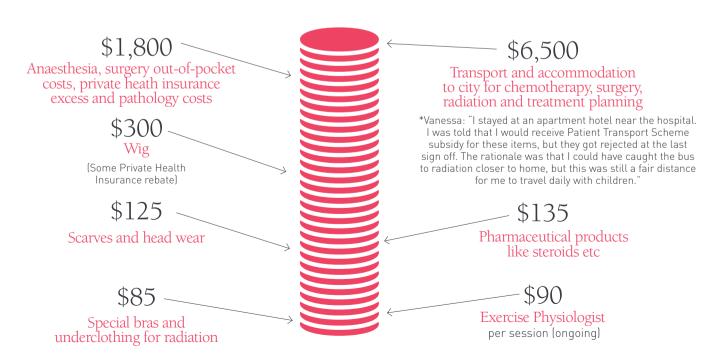
"I really recommend that people get this now. It meant that I could meet immediate expenses without stress and also, I didn't have to worry about things like mortgage payments, while in the gap between salary continuance and no pay.

"I wanted as little disruption as possible to the children so keeping them with me and acting like we were on a bit of a city holiday was really important and I am fortunate I was able to do this because of my financial situation.

"The most surprising expenses have been the ongoing costs — even now, three years post active treatment. Because of treatment side effects, I am paying for orthotics for my feet and having eyebrow tattoos because mine never properly returned. I am also having counselling for anxiety and am taking other ongoing medication. Even travel insurance is more expensive now. Yes, a breast cancer diagnosis is expensive."



#### Some of Vanessa's costs:



### WITH ANNE GRAHAM STORY WEALTH CEO

The out of pocket costs described by Vanessa on the previous page might seem hefty, but they're all too familiar when it comes to breast cancer, according to senior financial planner Anne Graham.

The Melbourne-based CEO of Story Wealth Management says a cancer diagnosis can be financially crippling to young and growing families, particularly when women are still working, raising children, contributing to mortgages and other household expenses, as well as managing busy lives.

She says breast cancer is expensive, with a Deloitte report recognising that the average patient pays around \$36,000 over a lifetime in out of pocket expenses – with most incurred in the first few years post-diagnosis.

"Obviously the out of pocket medical costs will vary patient to patient, depending on the treatment they have and whether they have private health insurance, Anne says.

"As a starting point, I would tell women to contact their private health insurance provider at the earliest opportunity after diagnosis and establish exactly what they are entitled to.

"I would then look at whether some of the treatments required might be able to be covered as a public patient, even for a patient who has private health cover." It makes sense to get as much information as possible to enable you to make an informed decision.

A 2016 Breast Cancer Network Australia report noted that a woman with private health insurance will typically pay around double the out of pocket costs of a public patient.

This higher financial burden for private health insurance holders results from expenses incurred during surgeries, chemotherapy, radiotherapy, breast MRI scans and other diagnostic tests, as well as specialist consultations.

"But the other things that go under the radar and can be crippling to families are loss of expected income, for both patients and carers, as well as additional costs of 'buying in' help with household tasks and childcare," Anne says.

"These are costs that are not actually related to medical expenses, but are part of the cost of cancer."

And it might be all the 'little things' that really add up. A study by Cancer Council Victoria in 2016 estimated that the average cancer patient in Victoria would spend \$1,128 on parking alone in their first year after a cancer diagnosis. Then there are costs of complementary therapies, wigs and turbans.

Anne also warns that reconstructive surgery might be classed as elective if it is 'after the fact' and again, costs can blow out. "I would always advise women to do their homework and really investigate what they are going to be billed for.

"It's also really helpful if they have another set of ears when this information is provided because there is so much that they are trying to process."







Anne says there are a number of questions she would ask a woman upfront who had just been diagnosed with breast cancer in order to make a financial plan. These include:

### How much do you have in the bank? Have you got access to money immediately?

Everyone should have a nest egg for situations like these. We typically say three months income or \$10,000. But everyone's expenses are different. It just provides you with an immediate buffer

#### How much have you got in superannuation?

A woman who has been diagnosed with terminal disease and has a life expectancy of less than two years is able to get early access to their lumpsum benefits from their super fund, tax free. To do this, two medical practitioners must fill in documents noting that your life expectancy is less than two years. If you live longer, you are not obliged to repay the money and there is no penalty.

When breast cancer is not considered terminal, it is quite difficult to access superannuation early - and when we say early, we mean before age 55 at the earliest. You can access super these days for various treatments, but getting early release of super because you have breast cancer and need the money can be tricky. You need to demonstrate real financial hardship, but to do this you need to have been receiving an eligible Centrelink income support benefit for 26 continuous weeks to qualify.

A woman may be able to access her super under special provisions for a mortgage under difficult circumstances - when there is going to be a house foreclosure for example, but you can't access it to pay rent. That's just the way the rules are. If a woman is seeking access to super to pay for medical treatment, it needs to be signed off by a specialist, so it is quite a process.

And in the big picture, it is sometimes not the best thing to access super early. Depending on the prognosis, these funds might be better used later on.

## Have you got sick leave or annual leave accrued? Are you entitled to any time off work?

Even if a woman is planning to continue working through treatment there are going to be days that she will need to take off work, for treatment and/ or the effects of treatment. It is important employers are flexible and patients are realistic about what they can achieve and manage. Having a frank conversation with an employer from the outset is important, so both parties are comfortable with how things are going to be managed. We find that even patients with resources behind them are reluctant to not work. But I would also tell women to think about going part-time even in the short term, if it is not a financial necessity.

### Can your partner afford to take time off work?

Women often need support at medical appointments and when they are recovering from the effects of treatment. If there is no other family support, a partner may need to take time off work to step in and help. We find women rely on family and friends a lot, through school communities and the kindergarten mums, things like that. The best of people comes through in times like this.

### Can you approach your lender to ask for a freeze on payments for three months?

If you think you are going to be in real strife, you are better off being proactive. Sometimes lenders will allow a temporary freeze on mortgage payments and this might give you a bit of breathing space when some of the costs are rolling in. It's always worth asking the question sooner than later, and before things get out of hand.

#### Are you covered by insurance?

I think trauma insurance is right up there with income protection insurance – everyone should have it. How much it costs depends on age, gender and even whether you are a smoker.

But the reality is that most women don't have this kind of insurance in place, and don't even know about it. People tend to begrudge paying for insurance, because they don't see a return on investment. But there is very little to help women other than insurance when they face a breast cancer diagnosis.

Income protection insurance might cover you if you can't work. A total and permanent disability insurance might be paid out if you can't work again, but trauma cover has no relationship to your ability to work. What it is related to, is a diagnosis of a specified illness or injury. And the big ones that are typically covered under a trauma policy are heart attacks, stroke and cancer, It is a lump sum payment that is paid out on diagnosis. The beauty of a trauma insurance policy is that you get that paid

provided the illness meets the definition in your policy. The lump sum payment can pay for treatment, or fill in the gaps when you have leave without pay, or your partner takes carer's leave. It is money that can replace income or be used for treatment or even a holiday. It really can see people through some very tough times.

Anne Graham

\* For more information about Story Wealth Management or to speak with a financial advisor, please go to www. storywealth.com.au or phone 03 8560 3188

This information is of a general nature only and has been provided without taking account of your objectives, financial situation or needs. Because of this, we recommend you consider, with or without the assistance of a financial adviser, whether the information is appropriate in light of your particular needs and circumstances.



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# DRA Abreos

Belonging to Dragons
Abreast Australia is
not just about being a
member of a sports group.
It's about unconditional
support, friendship and
regaining the confidence to
be a strong woman who is
able to rebuild a fantastic,
full life after the trauma of
a breast cancer diagnosis
and its treatment."

Caren

DAA Member &

Breast Cancer Survivo













Dragons Abreast Australia (DAA) is a national dragon-boating association bringing together breast cancer survivors and their supporters. Membership is diverse, with people from a wide range of ages, backgrounds, athletic abilities and interests.

DAA began in Australia in 1998, following the release of ground-breaking Canadian research highlighting the physical benefits of dragon-boating following breast cancer treatment. Since then, it has been further revealed that paddling can assist in the breast cancer treatment recovery process, specifically assisting with complications from lymphoedema.

More than 30 paddling groups have now been founded across Australia. The youngest member is 27 and the oldest is 94! Whatever the age, all involved say participating in this sport has helped them to regain a sense of control over their lives after the tailspin of breast cancer, along with optimism for their futures.

DAA members are vital proof that there can be a fantastic life after a breast cancer diagnosis - one involving sport, competition, fun, fitness and travel.

Every DAA paddler had to take that first step into a boat full of welcoming smiles and encouraging words. If you, or someone you know would like to experience the fun, friendship and fitness that comes with dragon-boating, why not join us for a paddle?

For more information visit our website <a href="www.dragonsabreast.com.au">www.dragonsabreast.com.au</a> and find a group near where you live. No group in your area?

Contact us at: <a href="mailto:office@dragonsabreast.org.au">office@dragonsabreast.org.au</a> and find out how you can start your own group and take charge of your life.

Ne look forward to meeting you.

# after breast cancer

#### 78 RACHAEL LONERGAN'S STORY

It was a few weeks before Christmas in 2008, when Rachael Lonergan found a lump sitting in the crease under her right breast. She wasn't checking for anything in particular, just scratching an itchy spot. But that itch has saved her life.

After further investigation, Rachael was diagnosed with stage 2B triple negative breast cancer and underwent surgery, chemotherapy and radiotherapy over the following year.

At the same time, her sister Katherine was also undergoing cancer treatment. Katherine had been diagnosed more than 10 years earlier but had experienced an aggressive recurrence of synovial sarcoma.

The family's attention was focused on helping Katherine and her children manage their day-to-day life. While there was no shortage of people willing to help Rachael as well, she found taking people up on their offers of assistance difficult to accept.

"But then I had a lightbulb moment when, soon after a friend had gone home from a visit, I wanted to change my sheets," Rachael recalls. "But I couldn't lift my arms and I realised that had I asked her to help, she would have. It's awkward to admit you need help. I started thinking that there has to be a better way to connect people who want to help, with the tasks people need help with."

So the advertising executive approached the conundrum as a strategist – clearly defining the problem before working through to a solution.

The result was CanDo, a software tool launched in early 2018. It is basically an app, which is free for patients to download and use. It's functionality is broad. Inside the app, you can build a team, set and allocate tasks, diarise appointments and events, and update your personal 'team' on how you're feeling and what you need from them.

"I wanted to make it okay to ask for help, but also wanted to provide a tool to manage all those offers of help that can otherwise feel a bit burdensome because now you have to give people a job to do," Rachael says.



"Currently we have more than 3000 users and we grow by around 50 users every week. I get letters and emails from people from all walks of life and from all over the world, telling me they love the app or have recommended it to a friend.

"Lots of doctors have recommended it to their patients and I'm very grateful to say that CanDo is recommended by most patient support programs in the cancer sector."

Rachael is working on a new offering from the CanDo platform, where organisations will be able to own a branded and customised care environment.

"It's an exciting opportunity to bring CanDo to even more people and deliver more care. We see people getting all sorts of help from walking the dog, to making a meal, to helping with financial paperwork. And it's all powered by the people who already know and love you, so it's a fantastic validation of relationships. It's a truly win-win proposition for patients, their carers and their medical teams."

Dachael

The CanDo app is available to download from both the Apple Appstore and Google Play.







# KEE-Snacks

Alexandra Stewart had forged a professional career as an orthoptist and was studying forensic science at university when she was diagnosed with breast cancer – just nine weeks before her wedding. She endured a double mastectomy, surgery, chemotherapy and early menopause. The side effects of her treatment were horrendous. She clearly remembers the nausea and metallic taste in her mouth, as well as the mouth ulcers and malnutrition.

She also remembers the "jelly and custard" hospital food she was served because she could not keep anything else down and the weight loss she suffered because she was so depleted.

It was only when her treatment was all over and she'd come out the other side of breast cancer that she found her new purpose – an online food business for cancer patients called "Kee-moh Snacks", featuring recipes she designed and trialled herself with the help of nutritionists.

This business also spawned her first book, 'Festive Fare', which is a collection of Christmas-inspired recipes tailored to people undergoing cancer treatment. Now a second publication, 'Jelly is Not Food' has just been launched.

From here, Alyx dreams of Kee-moh Snacks becoming a global enterprise, informing hospitals around the world that cancer patients need foods that are nourishing, palatable and delicious.

#### This is her story.

"In my early thirties, I found a tiny speck of a lump in my right breast and I mentioned it to a doctor who told me it was probably just hormonal

But 18 months later, it felt like the lump had suddenly grown exponentially overnight and it had become painful. I went to my regular GP and the rest, as they say, is history.

It was such a whirlwind. The following week I was into surgery. This was exactly a week after diagnosis.

I had a single mastectomy initially and then I had the other breast off a year later because there were signs of pre-cancer in my other breast. Because of my age, the surgeons said to get it done.

The side-effects of chemotherapy were brutal and took an inordinate toll on my body. The biggest issue was nutrition and actually being able to get food in (and stay in). Side-effects had made it so difficult to eat that I had developed disease-related malnutrition. It's very common in the cancer world but not widely dealt with. My entire diet for months (when I could eat) consisted of lamb, garlic, the freshest white bread with the crusts removed and strawberry jam. I was so malnourished that I lost about 10 kilograms. For the duration of chemotherapy, I was also on other hormone-suppressing medication which put me into early menopause. I had hideous hot flushes. At the peak, I was having a hot flush every minute and a half. That was the most distressing thing. I had to sleep on towels on the bed because I was soaked through.

#### Fertility

Egg freezing was provided as an option to me early on, but we opted against it because we wanted to do everything in the shortest possible time that we could. My cancer was so hormone-positive that a pregnancy would have tipped me over the edge. I would have been putting more hormones into my body to feed that cancer. I had not found anybody I wanted to have kids with until I met James. so it was a whole new area for me anyway. I thought he was good breeding stock! It's more these days that I think about not having children. Sometimes I wonder which one of my nieces and my nephews I will be able to rely on and if I will be lonely when I am older. I find that not having the opportunity to have children plays more on my mind now.

#### Work and Friends

I went back to work too soon after my chemotherapy, way too soon. It was only a couple of weeks after finishing chemotherapy. It was a ridiculous move in hindsight, but I just wanted to be out of the house. Cancer can really be a lonely and isolating experience. I lost a lot of friends because I think they didn't know what to say; it scared them. Nobody wants to hear the truth; they want everything to be rosy for them and for you.

#### Kee-moh Snacks

A few years ago, I realised I had to find my new purpose. Cancer had changed me. I had learnt so much from my cancer experience and I realised there was something else I needed to be doing. I started listening to people with different ears. I had always enjoyed cooking, but I have found I am really good at improvising and making up recipes! I realised I wanted to give people the tools they needed to prepare nutritious and comforting food while going through cancer. That was really how Kee-moh Snacks began and the cookbooks are an extension of that

#### Fear of Recurrence and the Future

It's 13 years now since my experience and I am doing well. I am fit and healthy but the fear of cancer returning is always there. I call it the 'black shadow' and it comes in waves. I don't know how I get out of it; I just need to let it run its course. I think it is becoming more prevalent now because I realise I have so much more to do. For me, it is about leaving a legacy and what if I don't get the time to do that?

If I was diagnosed with secondaries tomorrow, I think I would be in a heap. I want the time to do what I need to do.

For now, I am exactly where I am meant to be. I have never had a real feeling of purpose until now. I will never be grateful for having had cancer, but I am grateful for what it has given me."

Alyx

For more on Kee-moh Snacks or to order a cookbook, please go to https://kee-mohsnacks.com.au/





# Having

HOPE Cancer Care is the brainchild of sisters and pharmacists, Joanna Klopper and Naomi van Hagen.

Joanna is a rural community pharmacist and Naomi a hospital pharmacist specialising in oncology.

Despite their extensive medical backgrounds, it was not until Naomi was diagnosed with metastatic breast cancer in 2015 that the sisters realised how difficult it was for patients to find and choose over-the-counter products that helped to manage the side effects of various cancers and associated cancer treatments.

"Even with my own medical background and my connections – my husband is a medical oncologist – I found it difficult to locate some of these supportive care products," Naomi says.

"I wanted to make sure other patients could find what they were looking for without any trouble. Hopefully HOPE will now do this for other patients." After many months researching and seeking advice from various specialists, the sisters launched HOPE - an acronym for Helping Oncology Patient Experiences.

"Our aim is to provide the very best products and specialist pharmacist advice to help manage the side effects of various cancers treatments," Naomi says.

"We have a team of specialist advisors who have helped us enormously, identifying and sourcing products that might be useful. These specialists include medical oncologists, haematologists, nurses, gynaecologists and radiation oncologists.

"There are products for mouth care, skin and hair care, digestive health, aches and pains, nose care, nail care, eye care, hair care and sexual health. We have tried really hard to provide a comprehensive range that covers all elements of a patient's holistic care. This is really about providing products that support quality of life."

Joanna & Naromi

For more information please go to www.hopecancercare.com.au





#### YOUR ONCOLOGY NURSE PRACTITIONER

WITH GILL KRUSS,
MELBOURNE CANCER CARE

Oncology nurse practitioner Gill Kruss first worked on a cancer ward as a graduate nurse in the 1990s and it was there she discovered her own natural affinity for oncology nursing and supportive care. After 20 years as an oncology nurse, a chemotherapy nurse, a breast care nurse and an oncology research nurse, she is now an oncology nurse practitioner with Melbourne Cancer Care, predominantly looking after patients with breast and gynaecological cancers. Oncology nurse practitioners are specialist nurses who provide vital support to cancer patients, by "filling the gaps" in cancer care and helping patients cope with their diagnosis and treatments. Here, Gill outlines how an oncology nurse practitioner can assist breast cancer patients and why she is so passionate about her job.

"The role of an oncology nurse practitioner in breast cancer is so broad, and so varied. We are there to provide all kinds of support to patients – whether it is physical, psychological, spiritual, social or practical. As nurse practitioners, we can work both collaboratively and independently and are empowered to take the initiative and make decisions.

It's not uncommon for us to devote up to an hour to an individual patient, assisting them with whatever it is they need help with. On any given day, this could be counselling patients, educating those women who want more information about their disease and treatments to help them make informed choices, administering injectable anti-cancer therapies, or providing practical support, such as helping complete paperwork required to access their superannuation or life insurance.

Clinically, as a nurse practitioner, I am trained to have a more advanced scope of nursing practice. My work consistently involves assessing and monitoring cancer patients who may have side effects from their anticancer treatments, or symptoms of their disease. I can determine if there is a need for more medication or dosing changes. I can prescribe a variety of medications and order some diagnostic tests. I can also make referrals to other health care professionals, services and community resources. I also work very collaboratively with the oncologists at Melbourne Cancer Care and with the breast care nurses at the hospital. We communicate well and keep each other well informed about the condition of our patients and any significant changes to their management plans. We have many people on oral anticancer therapies these days who need that advanced monitoring and management.



"It's not always an easy job and there can be some sad days, but you get a lot of satisfaction when you see the impact your care can have."

Gill Kryss

As an oncology nurse practitioner, I have the scope to make decisions on whether a patient needs dosing changes, or whether other medications need to be prescribed to help manage any side effects. I am also a point of contact for outpatients via phone and email, so I can answer any queries and provide advice over the phone or decide whether the best place to manage their symptoms is in the hospital, or by the GP, or whether they need to come in to the private consulting rooms to be assessed by myself or one of the oncologists at Melbourne Cancer Care. Working with patients and being able to support them is a real passion. You develop a rapport over time with many patients, particularly with the metastatic breast cancer patients. Because our treatments can be a lot more effective these days, those women with stage IV breast cancer are often living for longer.

I think most breast cancer patients will experience some anxiety. Those with early breast cancer worry about how they will cope with the variety of treatments they may need and many fear a relapse of their cancer. Those with metastatic disease have more complex supportive care needs associated with the uncertainty of having a life-limiting illness, and many worry about those close to them or want information on how to stay well for as long as possible. Their symptom management needs will vary depending on where their metastases are and what treatments they are on. The goal for these women is to prolong their life, but also to preserve their quality of life for as long as possible. And there is so much we can do these days to help women manage disease or treatment symptoms.

I also support those patients who are approaching the end of their life by having the necessary discussions with them and their families to help them prepare better for what is ahead and ensuring they are linked into the palliative care and supportive services that they may need.

It's not always an easy job and there can be some sad days, but you get a lot of satisfaction when you see the impact your care can have. You know that you are making a difference when you can help women cope better with their disease and their treatments."

Gill Kryss



West Australian mum Leah Stupar was only 32 years old and breastfeeding her second child when she first noticed lumps in her breast. While she was initially diagnosed with mastitis, she sought a second opinion and was diagnosed with breast cancer. A surgeon advised that her chances of surviving for five years were "thirty percent at best". Now 12 years cancer-free, she is telling her story to give other women hope. The baby daughter she was breastfeeding when diagnosed is now 14 years old. This is Leah's story, in her own words.

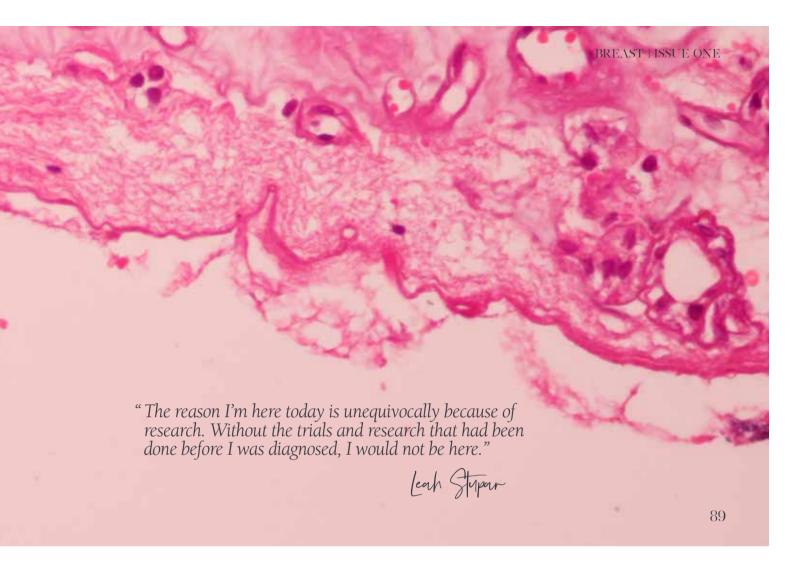
"My cancer journey began when I developed mastitis while breastfeeding my second child. A while after I finished feeding, I noticed some lumps. A doctor felt comfortable they were part of mastitis and didn't do a biopsy. But a few months later, one of my breasts felt bigger and it also dimpled when I squeezed it gently, though it wasn't painful. Around the same time, Kylie Minoque was diagnosed with breast cancer and I realised that no one is immune from breast disease. I sought a second opinion. A biopsy revealed I had a 5.5cm grade 2, stage 3, oestrogen-positive invasive lobular carcinoma.

I saw a surgeon who told me rather abruptly that my chances of surviving the next five years were 30% at best and that I should "go home, eat chocolate, drink red wine and make the most of my children". I was only 32 years old. My husband and I drove home in shock, not knowing where to turn.

Then I met a lady at the Cancer Council who gave me hope. She had a very similar story to mine. She was also diagnosed at 32, but was still going strong in her sixties. I decided that I needed to find the best oncologist and get this thing sorted. Enter Professor Arlene Chan from the Breast Cancer Research Centre in Western Australia.

After my surgery, I went to Arlene's office full of anxiety, but she quickly put me at ease.

Professor Chan told me she had evidence of women in the same situation as me, who were still going strong after ten years. She asked me if I was prepared to fight. I explained I was young and fit.



Arlene said she'd be hitting me hard with treatment, to give me the best possible chance.

Four years after my diagnosis, I no longer felt under threat. Had I been diagnosed five years earlier, the outcome would not have been good. A few people had survived - like the lady I met at the Cancer Council - but most didn't. The reason I'm here today is unequivocally because of research. Without the trials and research that had been done before I was diagnosed, I would not be here. I'm now twelve years cancerfree. I have an 18 year old son, a 14 year old daughter and a gorgeous husband by my side.

Please support Breast Cancer Research Centre-WA; the work they do saves lives. I'm living proof."



LEAH STUPAR (right)
AND HER DAUGHTER (left)



PROFESSOR ARLENE CHAN

Leah Stupar

#### Joe's 5-minute Tuscan Kale and Eggplant Prawn Stir Fry

#### **Ingredients**

1 tbsp rice bran oil
1 cup kale, chopped
1/2 eggplant, sliced into sticks
1 clove garlic, crushed
4 prawn cutlets
1/2 tsp fish sauce
1 tbsp soy sauce
1 tbsp oyster sauce

#### **Directions**

- 1. Heat 1/2 tbsp oil in wok until super hot then add kale and eggplant. Stir fry for 2 mins, adding a little water to soften the eggplant.
- 2. Heat the other 1/2 tbsp oil in another small frypan and fry prawns, 1 minute each side.
- 3. Add the sauces to the veggies in stir fry until the prawns are cooked. Add prawns to wok, stir through and serve!

#### Thank You, Dahl

#### Ingredients

1 cup green or yellow split peas 1 cup dried lentils 1 onion, chopped 200 g diced tomatoes (tin or fresh) 1 tsp ginger, minced 2 tsp garlic, minced 2 tsp ground cumin seeds 2 tsp ground turmeric 10 curry leaves (tempting to skip if you don't have them, but please don't! they make the dish. freeze what you don't use in a zip lock for next time!) 700 ml vegetable stock 1 tsp chilli 1 tsp peanut or sunflower oil

#### **Directions**

- Place all ingredients in slow cooker. Add extra water to ensure everything is well and truly covered (those legumes are going to suck up a lot).
- 2. Cook on high for 3-4 hrs, stirring occasionally (twice throughout is plenty), adding water as required. That's literally it!

Serve with a side of greens or on a bed of cauliflower rice.

#### Lentil Bolognese

#### **Ingredients**

1 tin of lentils
1 tin of reduced salt
diced tomatoes
3 tbsp extra virgin olive oil
3 tsp minced garlic
200 g mushrooms
150 g spinach
1 pinch of salt
1 tsp pepper
200 g pasta of choice
(we used edamame pasta)
1 bunch of basil
1 brown onion
sprinkle of cheese of choice
(we used goats cheese)

#### **Directions**

- 1. Pre-heat the extra virgin olive oil in a pan.
- 2. Add the onion and garlic and cook until brown.
- 3. Add the mushrooms and cook for 5 minutes or until they soften
- 4. Add the tin of rinsed lentils and diced tomatoes.
- 5. Add a pinch of salt and teaspoon of pepper.
- 6. Stir well and allow the sauce to simmer for 10 minutes.
- 7. Whilst the sauce is simmering cook the pasta as per the instructions on the packet. Once the pasta and lentil bolognese has cooked, divide into 4 servings and top with your cheese of choice and some fresh basil.





#### Cauli-Power Soup

#### **Ingredients**

1 head of cauliflower, chopped into small pieces

1 brown onion

1 tsp garlic, finely chopped or minced

1 tsp butter

1 tsp extra virgin olive oil

1 ½ cups good quality chicken stock

½ cup milk

½ cup cream (optional) 50 g grated parmesan (2tbsp)

1 tsp dijon mustard

#### **Directions**

- Cook onion, garlic and cauliflower in a saucepan over medium to high heat with extra virgin olive oil and butter. Cook, stirring, until cauliflower is soft and translucent.
- 2. Add stock to the saucepan and simmer over for 20mins.

Add milk, parmesan, dijon mustard and cream if using. Blend with a stick blender until smooth. Serve hot with a smile on a chilly winter's day or night!

#### Banana, Blueberry and Walnut 'Nice-Cream'

#### **Ingredients**

1 ½ banana, peeled and frozen overnight

1/2 cup frozen berries (we used blueberries but you choose!) handful of walnuts

#### **Directions**

- 3. Peel + slice bananas, place in container and freeze overnight
- Add banana, frozen blueberries and walnuts to a food processor. Blend until ice-cream like consistency.
- \*Note if your blender isn't powerful enough to blend the frozen blueberries and bananas, let them sit at room temp for 4-5 minutes and then blend.

#### Choc Orange Balls

#### **Ingredients**

50 g pitted dates 20 g natural cashews 15 g desiccated coconut 15 g lsa (linseed, sunflower seed, almond blend) 1 tbsp cacao powder juice and zest from 1 orange

#### **Directions**

- Add all ingredients to a food processor and blend until a wet, sticky consistency forms.
- Roll into balls and store in an airtight container in the fridge.
- 3. Don't (we repeat do not!) eat them all at once!

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# The gift of THE GIFT STATES SPACE SPACE THE GIFT STATES THE GIFT STAT

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Anyone with a breast cancer diagnosis is eligible for a stay at an OTIS property. Guests are matched with available accommodation retreats suitable to their needs.

To enquire about a stay, contact the OTIS Foundation bookings team on (03) 5444 1184, or email bookings@otisfoundation.org.au



#### Do you need a break?

The OTIS Foundation is a nationwide charity gifting retreat accommodation to women dealing with breast cancer and their families.

This amazing organisation is the legacy of Judy Burley, a young woman who lived with breast cancer for seven years until she passed away at 36.

Her husband Andrew Barling established OTIS in her honour, building two purpose-built retreats in 2002 on a site close to the home the couple shared in country Victoria. These retreats welcomed their first guests in late 2002 and the Foundation has grown from there.

Now there are around 30 retreats in Victoria, New South Wales, South Australia, Northern Territory, Western Australia and Queensland, providing close to 3,500 nights accommodation every year to OTIS guests, accompanied by family and friends.

These properties offer time out to relax, reconnect and regroup for those dealing with the challenges of breast cancer.

This organisation is one of a kind. OTIS Chief Executive Officer Claire Culley says it is the only national charity providing retreat accommodation at no cost to people experiencing breast cancer, accompanied by their loved ones.

"Our aim is to provide the gift of time and space in an environment that allows guests to relax, reconnect and take a break away with loved ones in the hope it will reduce some of the psychological impacts of the disease," she says.

And Debbie, a breast cancer patient who stayed as an OTIS guest in 2019 said: "When you need to get away, but have no energy or time or money to make it happen ... OTIS comes to the rescue.

"We stayed at Alyonah in Daylesford which was incredible. I rarely relax or take a break, but this place took a weight off that I hadn't realised I was carrying."



#### McGRATH BREAST CARE NURSES

To find a McGrath Breast Care Nurse, visit mcgrathfoundation.com.au/FindANurse

McGrath Breast Care Nurses are free - and can be accessed without a referral



McGrath Breast Care Nurses provide personalised care to individuals and families experiencing breast cancer. They can provide a single point of contact through the breast cancer experience, helping you to navigate what can often be a complicated process.

#### How can a McGrath Breast Care Nurse help?



#### **Coordinate Treatment**

McGrath Breast Care Nurses work with you, your family and your physicians to help you make the right decisions surrounding your care.



#### Clinical Care

McGrath Breast Care Nurses can support with care after surgery, chemo or radiation therapies.



#### **Emotional Support**

McGrath Breast Care Nurses are available to provide a source of emotional support and answering questions you or your family might have been afraid to ask.



"The help with the physical and emotional impact of treatment was amazing, but by far the most valuable was her understanding of how this would impact the whole family"

– Emily Jarvis, patient.

For more information, visit www.mcgrathfoundation.com.au



