

Your Money and Breast Cancer



The following article features in Issue One of the ST BREAST magazine.

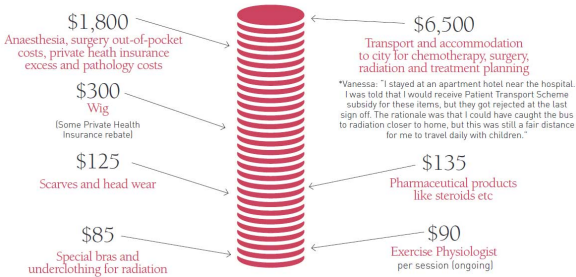
Vanessa was 43 years old and a single mum to two children aged five and three when she was diagnosed with breast cancer in 2016. She had a mortgage and took eight months off work, using all her accrued annual leave and sick leave and then taking leave without pay. Because she had private health insurance, 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:



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.

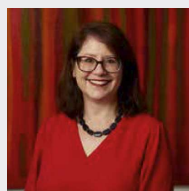
A 2016 Breast Cancer Network Australia report noted that a woman with private health insurance will typically pay around double the out of pocket costs of a public patient. This higher financial burden for private health insurance holders results from expenses incurred during surgeries, chemotherapy, 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

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Start Moving

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.

An Early Breast Cancer Diagnosis

The following article features in Issue One of the ST BREAST magazine.



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 Plaister

Storytelling for Business



Wellbeing newsletter prompts “outstanding” employee response

A strong focus on wellbeing has provided a safe space for employees to share personal stories at Specialised Therapeutics Australia (STA), which has today been named an employer of choice in the Australian Business Awards.

STA launched a light-hearted, monthly wellbeing newsletter prior to COVID-19, but made it a weekly event during the pandemic, after human resources manager Kate De Carolis “kickstarted” the inclusion of personal stories.

“It’s been outstanding, the amount that people are willing to share in those personal stories, and I think COVID has really enabled that to happen,” she says.

“People are constantly looking for that connection.”

De Carolis says employees now feel comfortable to contribute to the newsletter with their own stories – sometimes deeply personal and vulnerable – creating a virtual support network for employees.

While the newsletter is a standout feature that De Carolis says has made a difference during COVID-19, she notes that STA offers employees a range of benefits that boost its employer value proposition, including a full health insurance allowance for employees and their immediate family members;

company days off between Christmas and New Year in addition to annual leave; birthday leave; and a new program called “WEAK” (Weekend Afternoon Kickstart), allowing employees to finish work early on one Friday each month.

“All those little things we provide... really builds up to an environment where people enjoy coming to work,” De Carolis says.

STA Named Employer of Choice in 2020 ABA Business Awards



Melbourne, Australia, 8 October 2020: Independent pharmaceutical company Specialised Therapeutics Australia (STA) has been recognised as an Employer of Choice in The Australian Business Awards 2020.

The prestigious awards recognize organisations demonstrating business innovation, product innovation, technological achievement and employee engagement via a set of comprehensive award categories.

The Employer of Choice (EOC) accolade in particular, recognises workplaces that help employees reach their full potential, via the introduction of policies and

practices encouraging recruitment, engagement and retention.

STA Chief Executive Officer and co-founder Mr Carlo Montagner said STA had a long-standing commitment to recruiting and retaining outstanding employees, and further building and maintain a company culture consistent with its core values of Passion, Integrity, Teamwork, Courage and Humanity, or 'PITCH'.

"Since Bozena and I established STA 12 years ago, we have remained determined to embed these core values into all facets of our business," Mr Montagner said.

"We are an independent, family-owned pharmaceutical company that has grown from two employees in 2008 to more than 35 currently, commercialising our portfolio of specialist medicines in Australia, Singapore, Malaysia and New Zealand.

"Our independence sets us apart, not only in terms of our family values, but in how we nurture and build our workforce. We have introduced a range of initiatives to attract and retain a top-quality team who bring extensive experience in global pharma. STA is proud to be recognised by the ABA and will continue striving to remain an Employer of Choice in the Australian pharma industry."

Some of the workplace initiatives introduced by STA to encourage recruitment, engagement and retention of high calibre employees include flexible work arrangements, additional leave, Weekend Arvo Kick Start or 'WEAKS' leave, over-and-above the legally required employer superannuation contributions, outstanding health insurance benefits and ongoing training and development.

Mr Montagner added: "Workplace flexibility has been a pillar of our business to date, and will remain so moving forward. Currently, a majority of our employees are women. While we have not hired based on gender but on capability, we understand that female employees are frequently balancing work and life requirements. We have worked hard to achieve an inclusive and accommodating environment at STA that helps all team members fulfill their obligations outside work as well as enjoy career success."

ABA Program Director Ms Tara Johnston said: "Fifty-four organisations have been selected in this year's ABA Employer of Choice Awards. These organisations have demonstrated adaptability in the workplace by utilising flexible and new ways of working and learning.

“The landscape of the workplace environment has changed rapidly, as technology has gained momentum, coinciding with businesses navigating a broad range of interrelated issues from the impact of the current challenges facing the global economy. The ability to work from anywhere, combined with the advances in connectivity tools makes us geographically neutral.

“Leading organisations have begun to implement an entirely new working environment that break down communication barriers, positioning organisations to harness the talent within their organisation, transform the employee experience and position businesses to be more resilient.”

Entrant organisations are required to demonstrate achievements across the key areas of Organisational Culture; Leadership & Strategy; Employee Education, Training & Development; Employee Health, Safety & Satisfaction; Performance Management; Recognition & Remuneration.

Organisational participation includes private companies, public companies, multinational subsidiaries, non-government organisations, educational institutions, government departments, government agencies, local government and statutory bodies operating in Australia.

For more information visit <https://employerofchoiceawards.com.au/eoc-winners-2020/specialised-therapeutics-2020-eoc/>



ST wins Prime Healthcare Award

We are so proud, that in an exceptional field of finalists (including some of the world's biggest pharma companies) it was our breast cancer patient support program that took out top prize. Special thanks to our program collaborators Pharmacy Phusion for their support and assistance overseeing this tremendous effort.

ST named as PRIME Awards finalist

At ST, we pride ourselves on customer service. We deal with healthcare professionals every day to discuss our portfolio of specialist therapies and the patients who might benefit, and we never forget that there is a person and a family at the heart of every discussion.

Sarcoma Awareness Month: A/Prof Jayesh Desai



Australians who are diagnosed with sarcoma have around a 70% chance of complete cure if they are diagnosed early, according to one of the country's leading sarcoma experts. Associate Professor Jayesh Desai says making a correct diagnosis at early stage - before the cancer has spread to other organs - is crucial to helping patients make a complete recovery. To mark Sarcoma Awareness Month, he shares some of his insights.

"Sarcoma represents only 1% of all cancers. Although they are rare, with many patients never having heard of them before they are suddenly given this diagnosis, expert care is well set up in Australia with specialty centres in each of the capital cities. They can strike people at any age, but if a young person is diagnosed with cancer, in a significant number of cases it will be a sarcoma.

We know sarcoma is not just one disease; there are around 100 different sub-types. Sarcomas can be found in the soft-tissues or in the bone. Some rare sarcomas have known causes, but in the vast majority of cases, the cause is unknown. About 20% of soft tissue sarcomas are called leiomyosarcomas and between 30 and 40% are liposarcomas. So, in the world that I live in, these soft-tissue sarcomas are very common. And the people diagnosed with these types of sarcoma tend to be what I call 'young middle aged'.

What would I say to someone diagnosed today? I would say that it is critically important you get expert help early. Outcomes are so much better when patients are referred to a specialist multidisciplinary unit early.

Sometimes this is hard, because sarcoma symptoms can be vague. But generally speaking, if someone has a lump that is larger than the size of a golf ball and it is located within a muscle or deep within a system, it should be investigated

immediately and considered malignant until proven otherwise. That person should be referred to a sarcoma specialist for an immediate biopsy to make sure the right treatment path is adopted for that patient.

Sarcomas do vary in how fast they grow. Some can be slow-growing and others can be very aggressive. But if a sarcoma is caught early, most patients can be cured with a combination of surgery and radiotherapy. Patients with metastatic disease are occasionally still curable, but in many cases, they are not.

One of the important things I would say to patients is to make sure you have a really high-quality multi-disciplinary care team that is working together making decisions.

Research is unbelievably important, and will lead to better treatments. I think international collaboration in this area is vital. The sarcoma population in Australia for example, may be too small to gather the relevant data if we worked in isolation. But the international sarcoma community, who we work very collaboratively with, has a much broader pool of patients and therefore the ability to conduct international randomised studies with hundreds of patients; so we can confirm whether a particular treatment is effective or not. Patients should know that taking part in clinical trials remains critical for us to make a difference, and it won't necessarily mean they won't receive the best standard of care.

Looking further ahead, I think more unique treatment approaches will come from using combining existing therapies, or even newer approaches like epigenetic therapies. This will involve us potentially being able to switch genes on or off to treat particular cancers.

I have been a practising medical oncologist for about 15 years now and I was fortunate early in my career to work alongside one of the world's global sarcoma gurus at the Dana Farber Centre in Boston. I felt a real responsibility to bring this work back to Australia.

Many, many patients I have treated have left an impression on me. I can recall a patient a number of years ago with a very rare sarcoma subtype, with was challenging to diagnose. He was only in his early to mid-twenties. That patient went on to receive immune therapy as part of a clinical trial, based on some emerging data from colleagues overseas. He has done remarkably well. That was largely because of the effort that went into his diagnosis, and international

collaboration to share learnings on promising approaches. He had an atypical soft tissue sarcoma, and his treatment was “tailored” to his individual cancer. I guess the take home message here is that putting the effort into getting the right diagnosis and tailoring therapies can make a really big difference.

One of the most difficult things about my job is that often we are seeing young people with a disease that can be very difficult to treat. There is naturally a high level of anxiety with these patients and their families, something our team is particularly focused in how we support them.

But working toward a cure for those patients who are diagnosed early is very rewarding.

What is also pleasing is that our community works together very well. Not just the medical professionals and researchers, but also patients and their families, to try and come up with better treatments. Industry also plays a part in this – pharma companies are making a difference by providing new therapies and making them accessible here in Australia for our sarcoma patients, which is particularly gratifying.

There is always more work to be done but we have come a long way.”

*** Associate Professor Jayesh Desai is a Medical Oncologist at the Peter MacCallum Cancer Centre and is also a founding member and current board member of the Australia New Zealand Sarcoma Association (ANZSA). To learn more about sarcoma, clinical trials, or to find a sarcoma specialist, please visit www.sarcoma.org.au.**

RxPONDER: Medical Oncologist Dr Richard de Boer



Medical oncologist Dr Richard de Boer discusses interim results from the Oncotype DX RxPONDER study, presented at the 2020 San Antonio Breast Cancer Symposium. Click on the video banner above to watch the video.

RxPONDER: Professor Arlene Chan



Professor Arlene Chan discusses interim results from the Oncotype DX RxPONDER study, presented at the 2020 San Antonio Breast Cancer Symposium. Click on the video banner above to watch the video.