



## Reflecting on the different shades of pink

It was hard to miss Breast Cancer Awareness Month in October. There was pink everywhere. We heard a lot about those who have had a 'brush' with cancer, those who have 'won the battle' and those who have 'lost the battle'.

Yet often forgotten during October are the thousands of Australian women living with secondary breast cancer. These women are living with a progressive illness and are in a steady state of decline. I am one of those women.

Unlike the Hollywood movies, having this illness does not mean that life suddenly becomes one of living it up, finishing your bucket list or travelling the world. Mortgages still have to be paid, food still has to be put on the table, children still have to be nurtured. Life goes on as it always has.

So now we all learn to live with a new 'normal', trying to juggle our lives to fit everything in, including endless trips to and from various doctors and hospitals who try their best to keep us out of pain and as well as possible for as long as possible.

A decreased state of health forces most women to lessen their work hours or stop



*Jane with her family*

working altogether. This leads to a reduced income, which, together with increased medical expenses, cause an extra burden that is not catered for by our social system.

Pain and fatigue do not get you a disabled or 'babies with prams' spot close to the entrance of shops, and standing in a queue at the checkout next to someone who is sneezing and coughing can be a death sentence as your immune system struggles to cope.

Our partners and families live with someone who is often ill or in hospital for one reason or another. We love them for their care, understanding and

help but live in guilt of how this illness has also disrupted their lives. We feel guilty about no longer being able to be the best mother or the best partner we can be. We feel guilty because the bulk of the family budget is spent on special diets, vitamins and medicines.

Decisions become even more complicated than before – can we take advantage of the 'early bird' rates on a family holiday or will we be too ill by then to go? Should we change jobs, or stick to the one we are not so happy with so we can use our accumulated sick leave? There is now no such thing as a five-year plan.

In contrast though, I love every extra day I have with my family and friends who have become even more precious. Time has more value, unexpectedly I can now feel the breeze dancing around me on a hot day, and realisation dawns that a messy house is not the end of the world and a broken nail will grow. Now free from the frivolous, I can stop chasing the unattainable or unlikely. I am also lucky to have faith that my days have been written in the book of life and that I will only meet my maker in His perfect timing.

So the month of October is still pink – yet some of us live in a darker shade of pink.

*Jane, QLD*



# Managing mouth care with Afinitor

Earlier this year, Afinitor (everolimus) was listed on the PBS for the treatment of hormone receptor positive secondary breast cancer that has become resistant to hormone therapy treatment alone.

While clinical trials found that Afinitor provides better quality of life than alternative IV chemotherapy treatments, like all treatments Afinitor has some side effects. In particular, some women develop a condition called stomatitis (inflammation of the mucous membranes in the mouth). This can cause sores in the mouth or mouth ulcers, or cold sores if you are prone to them.

Stomatitis can be managed, especially if it is treated early,

and usually gets better over time.

If stomatitis is going to occur, it is usually within the first few weeks of treatment. It is important therefore to look after your mouth well, especially in the first two months of treatment.

To help reduce the impact of stomatitis, it is recommended that you:

- use a soft toothbrush and mild tasting toothpaste
- allow your toothbrush to air dry, and replace it regularly
- frequently rinse your mouth with a bland mouthwash such as sterile water, normal saline or sodium bicarbonate solution
- floss your teeth daily

- avoid products containing alcohol, hydrogen peroxide, iodine and thyme
- drink plenty of water
- use an oral moisturiser (such as Biotene) and keep your lips moisturised
- take your Afinitor at the same time every day, and take it either with or without food, but the same way each day (i.e. always with food or always without food).

You should also avoid hard, crunchy, spicy and hot foods, as these may cause small injuries in your mouth and increase the risk of mouth sores.

Your medical oncologist should see you two weeks after you start treatment with Afinitor.

At this appointment, be sure to let him or her know if you are having any issues with your mouth. If you develop a sore mouth between appointments, contact your specialist to discuss what you should do. There are medications you can be prescribed.

If you do develop a sore mouth, try avoiding very cold and very hot foods, and drinks containing caffeine and alcohol. It can also be helpful to drink through a straw to help keep liquid away from sore areas in your mouth.

If you have any concerns about your treatment with Afinitor, please talk to your medical oncologist.

# Metastases in non-common sites

Secondary breast cancer most commonly occurs in the bones, lungs and liver. Sometimes, it will also affect the brain. BCNA's *Hope & Hurdles* has information that specifically addresses metastases in these sites.

There are also other places where secondary breast cancer more rarely appears. These include:

- Eyes
- Spleen
- Abdomen

- Kidneys
- Peritoneum
- Stomach lining
- Ovaries
- Pituitary gland
- Skin
- Bowel
- Gallbladder.

As these sites are not so common, there is little specific information available for women whose breast cancer spreads to these places. It can be helpful

to know that treatment for secondary breast cancer in these sites is very similar, if not identical, to treatment for metastases in the more common sites: chemotherapy, hormone therapy and radiotherapy as required.

Most women who develop secondary breast cancer in an uncommon site will also have it in one or more of the more common sites. The general information available, such as

that in *Hope & Hurdles*, should give you a good basis for understanding secondary breast cancer in any site.

If you need more information about secondary breast cancer and treatment, you may like to ask your medical oncologist to take the time to explain things to you. It is important that you feel well informed and confident about the treatment and care you receive.

# Raising awareness of secondary breast cancer

During October – Breast Cancer Awareness Month – BCNA highlighted the unique needs and challenges faced by women and men living with secondary breast cancer through media and our social network outlets. We are aware that some people living with secondary disease find the focus on survivorship during October challenging. Women have told us they feel the community doesn't understand what secondary breast cancer is or what a diagnosis means.

Our secondary breast cancer campaign was designed to educate the public and improve understanding of the disease. For the first time in Australia, we formally acknowledged Secondary Breast Cancer Awareness Day on Monday 13 October.

To help inform our approach, we conducted a survey of more than 580 Australians living with secondary breast cancer and held a focus group in Melbourne with 11 women.

During October, we encouraged our members to raise awareness of secondary breast cancer through their local media, and we asked them to share our messages on Facebook and our online network. A special poster and fact sheet were developed for people to download, print and display. All our media activities in October promoted *Hope & Hurdles* for women with secondary breast cancer.

We were delighted to receive coverage on secondary breast cancer and our survey outcomes from a number of media outlets, including television, radio and print. There were also many 'likes' and 'shares' through our social networks.

## BCNA's survey outcomes

The secondary breast cancer survey was designed to help us better understand the needs and challenges faced by those living with this disease.

We had a wonderful response from our members, with 582 women and three men living

with secondary breast cancer participating. Sixty-six per cent were aged between 50 and 69. However, almost one-quarter (24 per cent) were under the age of 50.

Seventy-seven per cent of respondents had been diagnosed with secondary breast cancer within the last five years. Survey participants were from all states and territories, with 59 per cent living in a metropolitan area, and 41 per cent in a regional, rural or remote area of Australia.

Through the survey we found that 65 per cent of respondents face financial difficulties as a result of their secondary breast cancer diagnosis and treatment. Out-of-pocket costs and loss of income are the key causes of these difficulties.

Drugs that are not currently listed on the Pharmaceutical Benefits Scheme (PBS), surgery and radiotherapy are the treatment areas with the highest out-of-pocket costs.

It is important to note that, despite these financial



challenges, women tell us they want to know about all treatment options regardless of cost.

We also found that 21 per cent of women with secondary breast cancer had a GP Management Plan, and only 14 per cent had a GP Mental Health Care Plan. These plans can assist women to manage the ongoing side effects of their diagnosis and treatment, through referral to allied health professionals such as physiotherapists and dietitians or, in the case of mental health plans, counsellors and psychologists. For more information on these plans, read the 'Help from your GP' article on page iv.

BCNA will continue to analyse the results of the survey and will use them to raise awareness among health professionals, government, the general public and all those with an interest in breast cancer about the particular issues facing women with a secondary breast cancer diagnosis.

# Halaven (eribulin) listed on PBS

Women living with secondary breast cancer now have access through the Pharmaceutical Benefits Scheme (PBS) to a new chemotherapy treatment option following the listing of Halaven (eribulin) on the PBS from October.

Clinical trials have shown Halaven can extend the time before the breast cancer

progresses, as well as extend life. They also found Halaven was well tolerated in terms of side effects, allowing women receiving it to maintain good quality of life. Common side effects are similar to those of other chemotherapies, including low blood counts, fatigue, nausea, joint or muscle pain and hair loss.

Halaven is administered by an intravenous infusion, which only takes between two and five minutes. This means it is a quick treatment to receive, and doesn't involve a lengthy admission to an oncology clinic.

In October 2013, BCNA provided a submission to

the Pharmaceutical Benefits Advisory Committee in support of the application to list Halaven on the PBS.

If you are interested in learning more about Halaven, you may like to talk to your medical oncologist.

# A letter to Simone

Dear Simone

Firstly, thank you for your letter in *The Inside Story* (June 2014). It touched me profoundly. Let me give you a little of my background – I am a registered nurse and have worked in oncology for many years and more recently in community palliative care. I also worked for some time as a breast care nurse and have had breast cancer myself.

I have no wise words to offer you, no uplifting motivational quotes – I only have compassion. I have no idea really what it must be like to walk in your shoes day after day. I have no idea what it must be like to face challenge after challenge. Nor how you manage a 'normal' life alongside managing all that cancer entails. Breast cancer can have positives in that there is a range of treatments to trial when the

disease relapses or a treatment ceases to work, but conversely, as you so beautifully describe, women get tired. It has nothing to do with 'giving up' or 'stopping the fight' – your body just gets tired and getting up time and time again after being knocked down just seems too hard. Women are so good at putting on the 'face' that makes others close feel that everything is okay but often it's not – it's a struggle.

The reason I work in palliative care is because I am humbled and overwhelmed that amid the incredible hardships that women endure they somehow keep putting one step in front of another. This is true resilience. I believe it is okay to say it how it is – to share your vulnerabilities and struggles as it gives others (even others with seemingly trivial challenges in life) permission to



Jeanette

have a voice. There must be room for this alongside the positivity and well-intentioned care and passion of all those who walk alongside us through the breast cancer experience.

In my work too, words like yours give permission to others to say what they want and what is

important to them as their life nears its end, because sometimes the 'cancer fight' is so intense that there is no time given to stopping and considering death – and having time is so important (or at least having a choice as to how you wish to spend the time). Those answers as to what do you want now, what do you want your life to look like now, what do you wish to do with your 'time' – that's who you are – the you who had a life before cancer, during cancer and now. Thank you Simone on behalf of myself and the women I look after. Thank you for your honesty. Thank you for your resilience to keep getting up time and time again. Thank you for your life as it has been and as it is. Thank you from the bottom of my heart.

Jeanette, VIC

# Help from your GP

A recent survey by BCNA into the needs of women living with secondary breast cancer found that only 21 per cent of respondents had a GP Management Plan. These Medicare funded plans are drawn up by your GP, in consultation with you. They set out your individual health and care needs, what you can do to help manage your health, and what services will be provided by your GP. Sometimes other health professionals may be needed

to help with your health care, for example a physiotherapist, dietitian or podiatrist. If you need to see one or more of these health professionals, your GP can put a Team Care Arrangement in place. These plans provide you with a Medicare rebate for up to five visits per calendar year to the health professionals identified in your Team Care Arrangement. If you feel you could benefit from emotional support through a counsellor, your GP can also draw up a GP Mental Health

Plan. These plans offer up to 10 subsidised visits with a mental health professional such as a counsellor, psychologist or specially trained social worker.

Our survey found only 14 per cent of women with secondary breast cancer have a GP Mental Health Plan in place.

If your GP has not offered you a GP Management Plan, Team Care Arrangement or GP Mental Health Plan, you may like to discuss this at your next visit.

If your GP bulk-bills you, there will be no charge for these plans. You may like to ask about any charges when you make your appointment.

For more information about these plans, visit the financial and practical assistance page in the secondary breast cancer section of the BCNA website, [www.bcna.org.au](http://www.bcna.org.au).

*The Inside Story* is a supplement to Breast Cancer Network Australia's *The Beacon* magazine.

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