Transparency Reforms and Evaluation Support

Specialised Therapeutics Australia (STA) welcomes the opportunity to provide comments on the introduction of new measures to improve TGA transparency. STA was co-founded in 2008, with a commitment to commercialising specialist therapies and technologies that meet the unmet medical needs of all patients in its regions. Underpinning this endeavour is a foundation of innovation, which must be protected by regulatory transparency.

Sarcoma Awareness Month: Karen’s Story

Karen Lurati was in her late forties, juggling a busy career and family when she noticed she was steadily gaining weight. Because she was also experiencing other symptoms like tiredness and hot flushes, she put it

down to menopause. It was only when she felt an increased heaviness, or pressure on her pelvic floor, that she sought further investigation. Doctors discovered a 7.5 kilogram tumour wrapped around her internal organs. Karen had never heard of sarcoma before and was devastated at her cancer diagnosis. Three years later, she remains cancer free and feels ready to share her story, but admits the emotional recovery has taken a lot longer than the physical. To mark Sarcoma Awareness Month 2020, Karen is sharing her story to let others know there is hope.

"I was 48 and had a busy career as a retail consultant and lecturer when I was diagnosed with a retroperitoneal liposarcoma in my abdomen. Doctors thought it had probably been growing for about five years before we found it. By then, it was massive – weighing in at 7.5 kilograms.

Because it grew so slowly, it just felt like weight gain. My tumour was not hard, it was really just fatty tissue, so it was soft and jelly-like and it was all encased. It had wrapped itself around all the spaces in my abdomen and it really did not do anything to me, except make me tired.

It was quite obvious I had a lot of weight in my stomach. But because of my age, I thought it was menopause. I was trying everything to lose weight, but nothing worked. I also had some hot flushes and some ongoing digestive issues, which I thought might be linked to a food intolerance.

I never suspected cancer, because it really did just feel like menopause. The symptoms seemed to make sense and I thought I just had to accept it. The weight seemed to creep up slowly and my tumour did not show up in any general medical tests, like mammograms or colonoscopies. I was oblivious it was there, because it did not grow inside any of my organs, it was just wrapped around the outside.

It was only when I eventually felt a ‘push down’ feeling – like you feel when you are pregnant – that I went and had a pelvic scan. Doctors told me my organs were okay, but they did see a mass that they could not identify.

So, they did a biopsy and realised it was cancer. Then everything happened very quickly. I had radiation prior to surgery to try and stabilise the growth before they could operate.

I had a massive 10-hour operation because they ended up taking out one of my kidneys and a section of my bowel as well. The tumour had started to infiltrate these areas and it was becoming dangerous.

I was really sad about losing a kidney and worried when they started taking organs out. But in hindsight, I was so lucky it was a kidney and not another organ that was impossible to remove.

Thankfully I avoided having to have chemotherapy. My particular sarcoma apparently does not respond well to chemo. After the surgery, doctors felt that they had got it all.

My tumour was apparently so rare and so interesting, that it has now been sent to a research lab in America. It is funny to think a part of me is now there, but I hope the research on this part of me will help other people for years to come.

I will have scans every six months for five years, but so far, so good. It is the fear of a cancer recurrence that I have found overwhelming and difficult to deal with. I do think the mental side of a cancer diagnosis takes longer to recover from. I became really depressed and found it hard to get out of bed. My Mum had died of cancer just before I was diagnosed and also, I think my own diagnosis made me lose trust in my body. Everyone says to me, 'How did you not know, it was the size of two babies!' But cancer has made me realise that none of us has control over anything. You can exercise and eat properly and be a good person and still get cancer. It has really helped me to speak with a psychologist about everything, because it made me realise I was carrying a lot of grief and fear.

On the positive side, I feel very grateful that if I had to experience cancer, it was one that could be treated. You have got to make the most of what you have got while you have got it. I am so thankful for the Peter Mac sarcoma and radiation teams, particularly Professor Michael Henderson and Associate Professor David Gyorki who are leading specialists in the field. My recovery is thanks to them, and also to my beautiful family and strong friendship and community network – they really stepped in and helped me, as well as my family.

I really am one of the lucky ones. Now I want to tell my story to help others who are diagnosed with sarcoma."

To learn more about sarcoma, clinical trials, or to find a sarcoma specialist, please visit www.sarcoma.org.au

*** Karen shared her story in July 2020**

Sarcoma Awareness Month: Dr Susie Bae

Many patients are "scared of being a guinea pig" but the reality is that they're likely to have better outcomes if they choose to take part in a clinical trial.

So says Dr Susie Bae, who specialises in both sarcoma and breast cancers. Her advice to patients is always to participate in a trial if it's offered by clinicians, but admits many people are fearful of what's involved. Susie

shares her insights about her work and her patients to mark Sarcoma Awareness Month, explaining why her work provides a window to some of life's best and worst moments, but is always "a great privilege".

"My work is diverse – I specialise in both sarcoma and breast cancer across three different hospitals and I am also a clinical research fellow with the Australia New Zealand Sarcoma Association (ANZSA).

"Whatever the cancer but especially with sarcoma because it is a rare cancer, I always encourage patients to take part in trials. All the evidence shows that just by taking part, patients involved in studies are actually more likely to do better – no matter what therapy arm of the trial they are assigned to.

Patients say to me, 'I don't want to be a guinea pig'. Many are fearful perhaps because they feel like they are losing a sense of control. Some worry about the unknown element of being part of a trial.

What they need to know however, is that in most cases of sarcoma trials they will get the standard of care, regardless. With any trial, no-one is under-treated. But those who are randomised on a study to receive a new therapy will be exposed to another agent as well, which has already shown promise in pre-clinical studies.

I also want them to know that mostly, people who go on and take part in a trial actually do better. The reasons for this are probably multi-factorial.

Once they get involved in clinical trials, they have a very dedicated trial team. They will be assigned research nurses and they get monitored a lot more closely. There is ongoing blood work and scans. So, I would say there is probably a higher chance that we will know early whether a particular treatment is working or not working. And patients on trials have a higher chance of getting better support.

The only way we will ever advance in terms of being able to treat diseases like sarcoma is by doing trials.

We have come a long way treating sarcoma in the past five to 10 years, because there are improved treatment options and newer therapy algorithms, but there is still a lot of work to be done.

In terms of the next advances for sarcoma, I don't think it will be one major breakthrough that will solve everything, but I think we will see a series of incremental advances that will make an overall difference – things like better supportive care, new molecules and better combination therapies.

It is a great privilege to be a medical oncologist, to work with patients and to go on what can be a really difficult journey with patients and their families.

I do get affected when things don’t go well, despite the very best efforts of the full medical team.

Over time, I have learnt to manage some of the sadness better and have been able to have some level of detachment so I can protect myself. But it is hard.

Like other cancers, those who are diagnosed at early stage with sarcoma tend to have good outcomes.

But there are those who become metastatic or present with metastatic disease and you do know that they have a finite time.

Specialising in sarcoma, you are dealing with a lot of bone sarcoma as well, which means you are dealing frequently with young people.

Emotionally this can be really challenging. These people are meant to be in the prime of their lives, but they are in hospital, enduring hospital stays and treatment. Their families are struggling as well.

I have had many patients who have made an impact on me, both as a person and a clinician. Recently, I had a patient, a beautiful young man who was only in his early 20s. He had a very unusual cancer, a poorly-differentiated soft-tissue sarcoma. It was a big deal for him to come to Peteramcfor treatment. He worked in the family business and he had a partner – there was a lot they wanted to do in life, and they were hoping to have a family.

This man had one last wish – he wanted to die at home. He was in so much pain but in the end, we did make it happen. It was all of us – me and the nursing staff and the palliative care team working together to make it happen.

But he got there. He was at home, with his family when he passed and it was beautiful. It was such a huge privilege to be part of this experience.

I love my work and I can’t imagine doing anything else.”

***July 2020**

Dr Susie Bae is a medical oncologist with subspecialty interests in sarcoma and breast cancer, working at the Peter MacCallum Cancer Centre and Eastern Health. She has also worked as a Clinical Research Fellow for the Australia and New Zealand Sarcoma Association (ANZSA) since 2012. Dr Bae is the national lead in overseeing the Australian Sarcoma Database, which collects comprehensive sarcoma datasets from seven adult sarcoma services around Australia. For more information about sarcoma or to find a clinician, please go to www.sarcoma.org.au.

Sarcoma Awareness Month: Dr Ganessan Kichenadasse

Immunotherapy drugs used as single agent therapies are so far showing little effect in treating sarcomas, according to an Adelaide-

based sarcoma specialist, Dr Ganessan Kichenadasse. He says that while there have been some positive steps forward in treating sarcomas in the past 20 years, there is much more to be achieved. Dr Kichenadasse predicts the next advances will result from combination treatment approaches, combining immunotherapy agents with chemotherapy, as well as employing newer targeted agents. To mark Sarcoma Awareness Month 2020, he shares the following insights.

I am always astounded and humbled by the resilience of my patients facing a cancer diagnosis especially sarcomas due to the complex maze of journey they undertake pre and post diagnosis.

Sarcoma can be a difficult disease to treat and it does require a complex multidisciplinary team involvement.

We really don't know why most sarcomas happen, but we do know of some pre-disposing factors, like familial links, or strong exposure to toxic chemicals or radiation. Often the first sign someone has a sarcoma is when they develop a mass or a lump, usually on their limbs. However, sarcomas can arise anywhere in the body. The symptoms depend on the location when either cause pain, or pressure related symptoms from masses. It may be back pain, or it can present as a blocked kidneys or rarely bowel obstruction. If it is a soft tissue sarcoma in the uterus, the patient may experience pain in the lower abdomen, or pelvis with or without vaginal bleeding.

The outlook for the patient really depends on the type of sarcoma and the stage of diagnosis. The good news is that most patients can be cured if they are diagnosed early. But once the disease has metastasised and spread to another organ – most likely the lung, liver, lymph nodes — the five-year survival outcomes are not so good. Only 10 to 15% of patients live five or more years in the advanced stages of the common varieties of aggressive sarcomas. Sarcomas absolutely remain an area of high unmet need.

In the past two decades, we have definitely seen progress in how sarcomas are managed, and outcomes have also improved – even for those with advanced disease.

Until recently, we had traditional chemotherapy drugs like and doxorubicin and ifosfamide. Since then, there have been three more drugs increasingly used for second line treatment. However, the response rates to these have been around 10%.

The hope moving forward is in combination approaches. Unlike other cancers, sarcomas are not as sensitive to immunotherapy – despite our initial expectations. Some particular types of sarcoma might have a higher response rate – like pleomorphic sarcoma or leiomyosarcoma. To date, we have examined immunotherapy agents as single agent therapies. I believe the next advances in sarcoma treatment will come from using these agents in combination with chemotherapy and oral targeted agents. As a clinician, it is important we work collaboratively with our peers around the country and internationally to continue finding new answers.

What would I say to patients? I would say that there is always hope for improvement in outcomes of patients with sarcomas. Always look for participating in clinical trials when possible.”

To learn more about sarcoma, clinical trials, or to find a sarcoma specialist, please visit www.sarcoma.org.au

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Managing your Diet

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

BEFORE, DURING AND AFTER BREAST CANCER

Good nutrition can impact breast cancer treatment tolerance and recovery,[1] as well as reduce the risk of recurrence[1,2] 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.[3]

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.[4] You need to remember that hormones have been banned in Australian chicken production for decades, and this means chicken is absolutely safe to eat.[5]

Do I need to avoid soy products because of the oestrogen?

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 fatigue! 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 chemotherapyinduced 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[2]. 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.

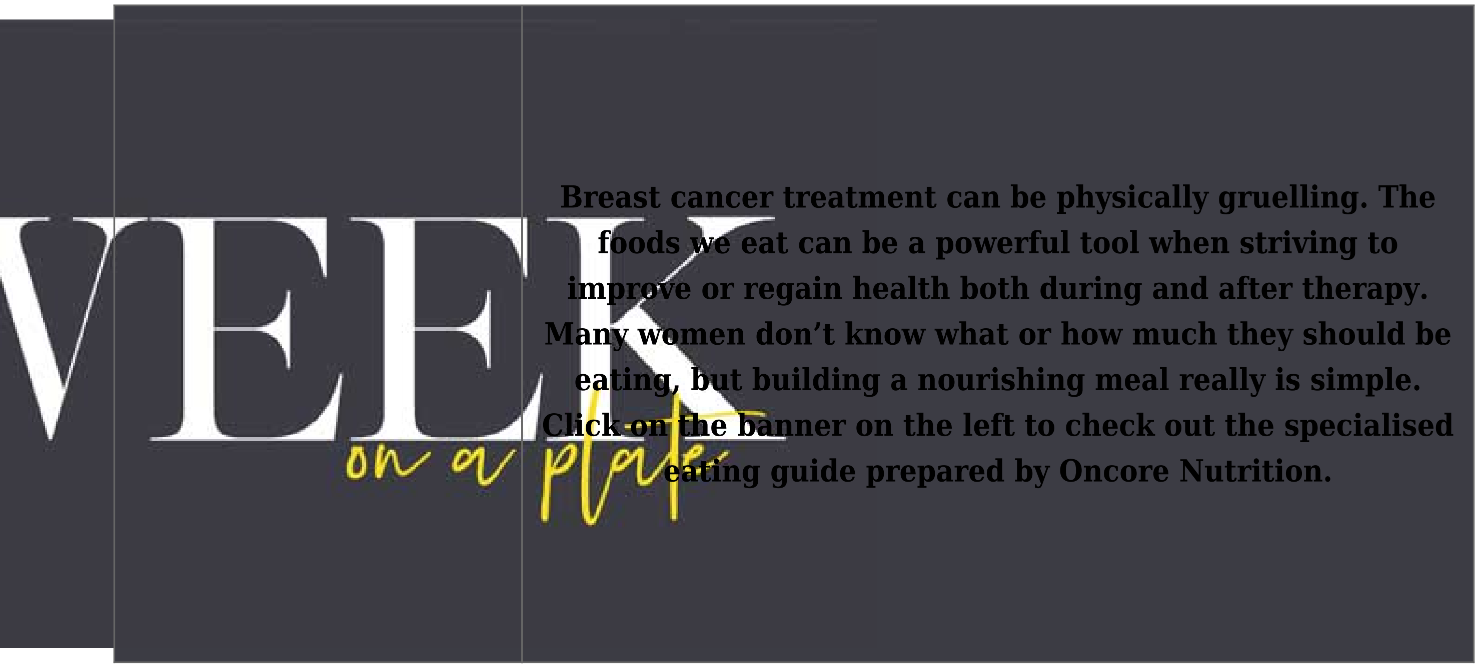
Foods to eat include the flesh of fruits and vegetables, legumes such as lentils and peas (avoid the skins or blend them, e.g. try hummus instead of whole chickpeas), wholemeal bread and cereals, grains such as barley, flaxseed, oatbran, psyllium and soy products.

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

Elise & Lauren



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. Click on the banner on the left to check out the specialised eating guide prepared by Oncore Nutrition.

1. Arends J, Bachmann P, Baracos V et al. ESPEN Guidelines on nutrition in cancer patients. Clinical Nutrition. 2016; 1-38.
2. www.wcrf.org/dietandcancer/cancer-prevention-recommendations
3. Anand P, Kunnumakara AB, Sundaram C et al. Cancer is a Preventable Disease that Requires Major Lifestyle Changes. Pharmaceutical Research. 2008 Sep 9;25(9):2097-2116.
4. Lo JJ, Mark Park YM, Sinha R et al. Association between meat consumption and risk of breast cancer: Findings from the Sister Study. International Journal of Cancer. 2019 Aug 6;146(8):2156-2165.
5. www.foodstandards.gov.au/
6. Chi F, Wu R, Zeng YC et al. Post-diagnosis Soy Food Intake and Breast Cancer Survival: A Meta-analysis of Cohort Studies. Asian Pacific J Cancer Prev. 2013;14(4):2407-2412.
7. www.aicr.org/patients-survivors/healthy-or-harmful/soy.html?utm_campaign=recharge&utm_ medium=email&utm_
8. Pace A, Giannarelli D, Galiè E, et al. Vitamin E neuroprotection for cisplatin neuropathy: a randomized, placebo-controlled trial. Neurology. 2010 Mar 2;74(9):762-6.
9. Brami C, Bao T, Deng G. Natural products and complementary therapies

for chemotherapy-induced peripheral neuropathy: A systematic review. Crit Rev Oncol Hematol. 2016 Feb;98:325-34.

10. www.wcrf.org/dietandcancer/exposures/meat-fish-dairy
11. Redman MG, Ward EJ and Phillips RS. The efficacy and safety of probiotics in people with cancer: a systemic review. Annals of Oncology. 2014 Mar 11; 25:1919-1929
12. Zick SM, Ruffin MT, Lee J, et al. Phase II trial of encapsulated ginger as a treatment for chemotherapyinduced nausea and vomiting. Support Care Cancer. May 2009;17(5):563-572.
13. Levine ME, Gillis MG, Koch SY, et al. Protein and ginger for the treatment of chemotherapy-induced delayed nausea. J Altern Complement Med. Jun 2008;14(5):545-551.
14. Pillai AK, Sharma KK, Gupta YK, et al. Anti-emetic effect of ginger powder versus placebo as an add-on therapy in children and young adults receiving high emetogenic chemotherapy. Pediatr Blood Cancer. Feb 2011;56(2):234-238.
15. Ryan JL, Heckler CE, Roscoe JA, et al. Ginger (Zingiber officinale) reduces acute chemotherapy-induced nausea: a URCC CCOP study of 576 patients. Support Care Cancer. Jul 2012;20(7):1479-1489.
16. Kleinschmidt S, Rump G, Kotter J. [Herbal medications. Possible importance for anaesthesia and intensive care medicine]. Anaesthesist. Dec 2007;56(12):1257-1266.
17. Backon J. Ginger as an antiemetic: possible side effects due to its thromboxane synthetase activity. Anaesthesia. Aug 1991;46(8):705-706.
18. Ojewole JA. Analgesic, antiinflammatory and hypoglycaemic effects of ethanol extract of Zingiber officinale (Roscoe) rhizomes (Zingiberaceae) in mice and rats. Phytother Res. Sep 2006;20(9):764-772.
19. Mary J. Marian. Dietary Supplements Commonly Used by Cancer Survivors: Are There Any Benefits? Nutrition in Clin Practice. 16 August 2017
20. Hauser K, Walsh D, Shrotriya S, et al. Low 25-hydroxyvitamin D levels in people with a solid tumor cancer diagnosis: the tip of the iceberg? Support Care Cancer. Jul 2014;22(7):1931-1939.

Minds Matter

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

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%[1] 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.[2] “Moreover, we see a three-fold reduction in a patient’s ability to adhere to cancer treatment if they are distressed,[2] and research shows us that untreated distress is associated with a 17% higher mortality rate.[3] 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.

“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. [4] 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 printbased 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.”

Dr Lisa Beatty

STRATEGIES

to 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

Affection	Provide frequent hugs & cuddles.
Consistency in caregiver	Have a consistent and trusted caregiver (parent or relative).
Maintain routine	Have your relative or partner maintain your child's routine.
Have regular contact with your child	Even if you are sharing care, ensure that you see your child frequently.
Special treats	Read books together, record lullabies and leave voice-messages for them.
Visits to the hospital	Let your child see where you are receiving treatment.
Provide reassurance	That Mummy or Daddy will be home soon.

3-5 Years

Information	Let your child know you are sick and what that means (tired but not dying).
Daily child care & maintain routine	Have a consistent substitute caregiver.
Address guilt	Tell them cancer is not their fault.
Play & artwork	Use these opportunities with your children to express emotions & provide education.
Question time	Arrange a time each day (e.g. after dinner) when children can ask you questions and share feelings.
Show your emotions	Assure your child that expressing your emotions for brief periods is helpful.
Mentor	Have a relative or friend show a special interest in your child.

6-8 Years

Education	Tell your child you have cancer and explain treatment.
Consistent caregiver & routine	Have a consistent substitute caregiver.
Address guilt	Tell them cancer is not their fault. Offer repeated reassurance.
Inform school & teachers	This will help to ensure that your child will be supported at school.
Question time	Answer your child's questions honestly. Also let them know it's okay if they don't want to talk.
Visits to the hospital	Let your child see where you are receiving treatment and introduce them to your doctor.
Mentor	Have a relative or friend show a special interest in your child.

9-11 Years

Education	Give more detailed information about your cancer and explain treatment.
Family approach	Cancer is stressful for the whole family, but you will manage the uncertainty together.
Address guilt	Tell them cancer is not their fault and it is not contagious.
Inform school & teachers	This will help to ensure that your child will be supported at school.
Question time	Answer your child's questions honestly. Also let them know it's okay if they don't want to talk.
Maintain normality	After-school activities, sports and time with friends are important to maintain.
Reading & Writing about your cancer	Encourage your child to do this if they are interested.

Teens

Education	Give more detailed information about your cancer and explain treatment.
Maintain normality	This is important at home and school. Remind teens it's okay to still have fun with friends.
Encourage emotional expression	Teens may do this by writing or talking (to you or others) about how they feel about your cancer.
Inform school & teachers	This will help to ensure that your child will be supported at school.
Support groups	If your teenager is interested, contact CANteen for support, or investigate other online resources.
Check out your expectations	Don't expect your child to take on caregiving or challenging roles.
Family Time	Try and spend time together as a family.

This table appears on the findingmyway.org.au website. It has been reproduced with permission from Dr Lisa Beatty.

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

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

1. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative care settings: a meta-analysis of 94 interview-based studies. Lancet Oncol. 2011;12(2):160-174.
2. DiMatteo M, Lepper HS, Croghan TW. Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. Arch Intern Med. 2000;160(14):2101-2107.
3. Pinquart M, Duberstein PR. Depression and cancer mortality: a meta-analysis. Psychol Med. 2010;40(11):1797-810.
4. Kissane DW. Marriage Is As Protective As Chemotherapy in Cancer Care. J Clin Oncol. 2013;31(31):3852-3.

Breast Friends & Modern Surgery

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

BREAST Friends & MODERN SURGERY

with Dr Chantel Thornton

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, project-oriented 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.”

Dr. Chantel Thornton

New Small Cell Lung Cancer Drug Accepted for TGA Evaluation Under Project Orbis

Singapore and Melbourne, Australia, 3 June 2020: A NOVEL marine-derived drug to treat Small Cell Lung Cancer (SCLC) has been granted a provisional designation by the Therapeutic Goods Administration (TGA), based on encouraging results from an international trial evaluating its safety and efficacy in several solid tumours, including SCLC.

Data from a key Phase 2 study of the drug Lurbinectedin demonstrated a 35% overall response rate in second-line patients, with a median overall survival of 9.3 months (95% CI 6.3-11.8) which is a clinically meaningful advantage over current standard of care in patients in second-line SCLC therapy.[1]

These results also underpin a decision by the US Food and Drug Administration (FDA) granting Lurbinectedin a priority and accelerated review. Lurbinectedin will now be reviewed concurrently by the FDA and other international regulators, including the TGA, under the ‘Project Orbis’ initiative.

This multi-country collaboration between international regulators is designed to streamline approvals where there is a strong unmet medical need, predominantly in oncology and haematology. This project may enable cancer patients to receive expedited access to new therapies.

In tandem with the provisional designation, lurbinectedin is now being investigated in patients at five cancer centres in Sydney, Melbourne and Queensland. All study subjects are SCLC patients who have relapsed after being treated with standard platinum-based chemotherapy, with or without immunotherapy.

A principal investigator on the new Australian study, Associate Professor Tom John at the Peter MacCallum Cancer Centre, said patients had few treatment options after failure of first-line therapy.

Associate Professor John commented: “The initial Lurbinectedin data are encouraging, and we will be collecting local data to see if it matches that seen in the international study. There is still a significant medical unmet need in Small Cell Lung Cancer. We welcome new treatment options for this difficult to treat patient population.”

Lurbinectedin is being made available in Australia and Singapore by independent pharmaceutical company Specialised Therapeutics Asia (STA) under exclusive license from Spanish biopharmaceutical company PharmaMar.

STA Chief Executive Officer Mr Carlo Montagner described the TGA’s provisional designation for Lurbinectedin and review under the Project Orbis collaboration as “extremely encouraging”.

“We welcome the provisional designation that acknowledges the encouraging data demonstrated to date and the high unmet medical need in patients with refractory SCLC,” he said.

“We look forward to progressing Lurbinectedin through relevant regulatory channels in South East Asia and Australia / New Zealand as expeditiously as possible.”

In the interim, STA will continue to make this compound available to eligible patients under a named co-pay Patient Access Program in our region.”

Up to 1900 Australians[2] and 1100 Singapore residents are diagnosed with SCLC every year, representing approximately 15% of all lung cancers.[3]

Ends.

About Specialised Therapeutics Asia

Headquartered in Singapore, Specialised Therapeutics Asia Pte Ltd (STA) is an international biopharmaceutical company established to commercialise new therapies and technologies throughout South East Asia, as well as in Australia and New Zealand. STA and its regional affiliates collaborate with leading global pharmaceutical and diagnostic companies to bring novel, innovative and life-changing healthcare solutions to patients affected by a range of diseases. Its mission is to provide therapies where there is an unmet need. The company’s broad therapeutic portfolio currently includes novel agents in oncology, haematology, neurology, ophthalmology and supportive care.

Additional information can be found at www.stbiopharma.com

About PharmaMar

Headquartered in Madrid, PharmaMar is a biopharmaceutical company, focused on oncology and committed to research and development which takes its inspiration from the sea to discover molecules with antitumor activity. It is a company that seeks innovative products to provide healthcare professionals with new tools to treat cancer. Its commitment to patients and to research has made it one of the world leaders in the discovery of antitumor drugs of marine origin.

PharmaMar has a pipeline of drug candidates and a robust R&D oncology program. It develops and commercializes Yondelis® in Europe and has other clinical-stage programs under development for several types of solid cancers: Lurbinectedin (PM1183), PM184 and PM14. With subsidiaries in Germany, Italy, France, Switzerland, Belgium, Austria and the United States. PharmaMar wholly owns other companies: GENOMICA, a molecular diagnostics company; Sylentis, dedicated to researching therapeutic applications of gene silencing (RNAi). To learn more about PharmaMar, please visit us at www.pharmamar.com.

About lurbinectedin

Lurbinectedin (PM1183) is a synthetic compound currently under clinical investigation. It is a selective inhibitor of the oncogenic transcription programs on which many tumours are particularly dependent. Together with its effect on cancer cells, Lurbinectedin inhibits oncogenic transcription in tumour-associated macrophages, downregulating the production of cytokines that are essential for the growth of the tumour. Transcriptional addiction is an acknowledged target in those diseases, many of them lacking other actionable targets.

About the Phase 2 basket study

The Phase 2 basket study of Lurbinectedin was a multicentre, single-arm phase II basket trial, designed to evaluate the safety and efficacy of Lurbinectedin in patients across advanced several solid tumours, including SCLC.

Treatment with Lurbinectedin induced a 35.2% overall response rate (ORR), which consisted of all partial responses (PRs) occurring in 37 of 105 patients. An additional 35 patients had stable disease, leading to a disease control rate of 68.6% (95% CI, 58.8%-77.3%).

Overall, 65% of patients had a decrease in tumour size and responses occurred in 5 of 8 patients who had failed prior immunotherapy. Twenty-eight patients (26.7%) had progressive disease and 5 patients were not evaluable.

The median duration of response was 5.3 months (95% CI, 4.1-6.4). The response rate was higher in patients with platinum-sensitive disease, where the ORR was 45% compared with 22.2% in patients with resistant disease.

Overall, the median progression-free survival (PFS) was 3.9 months (95% CI, 2.6-4.6) and the 6-month PFS rate was 33.6% (95% CI, 24.0-43.1). In the sensitive subgroup, the median PFS was 4.6 months (95% CI, 3.0-6.5) and the 6-month PFS rate was 44.6% (95% CI, 31.2-57.9). In the resistant population, the median PFS was 2.6 months (95% CI, 1.3-3.9) and the 6-month PFS rate was 18.8% (95% CI, 6.8-30.9).

At a median follow-up of 17.1 months, the median overall survival (OS) was 9.3 months (95% CI, 6.3-11.8) and the 12-month OS rate was 34.2% (95% CI, 23.2-45.1). The median OS was 11.9 months in sensitive patients versus 5.0 months in resistant patients.

The most common grade 1/2 adverse events (AEs) included fatigue (51.4%), nausea (32.4%), decreased appetite (21.0%), vomiting (18.1%), diarrhea (12.4%), constipation (9.5%), and neutropenia (5.7%). Grade 3/4 AEs included neutropenia (22.9%), anaemia (6.7%), fatigue (6.7%), thrombocytopenia (4.8%), febrile neutropenia (4.8%), pneumonia (1.9%), increased alanine aminotransferase level (1.9%) and skin ulcer (1.0%)

- • TGA has granted provisional designation for new drug Lurbinectedin based on encouraging Phase 2 results and high unmet medical need
- • A marketing application has now been accepted by the TGA under provisional evaluation pathway
- • Lurbinectedin has received priority review under the FDA’s accelerated approval pathway
- • Lurbinectedin to be considered under the ‘Project Orbis’ initiative, which has been designed to allow collaboration between the FDA and select international regulators, including the TGA
- • Lurbinectedin currently available to patients in Australia and Singapore via a named co-pay Patient Access Program

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References

1. Trigo J. et al, Lancet Oncology, 2020, Vol 21 (5), P645-654
2. https://lung-cancer.canceraustralia.gov.au/statistics . Last Accessed May 2020
3. Singapore Cancer Registry 50th anniversary monograph 1968 – 2017

Brain Tumour Awareness Month 2020: Prof Kate Drummond

Neurosurgeon Professor Kate Drummond says all brain cancer patients want more time. “There is always a wedding, a baby, an event or someone that needs to be cared for,” she says. But with the most serious form of brain cancer, glioblastoma multiforme or GBM, time runs out too quickly – despite the greatest efforts of oncologists and highly skilled surgeons. Kate says there are around 1000 Australians diagnosed every year with GBM and most survive an average of just 15 months. “The reality is that for these patients, not much has changed since 2005,” she admits. “My hope is that by 2030, we will have something else. It may not be a magic bullet, but we might have a series of smaller “wins” that when working together in combination may change outcomes. There is so much research going on and patients should have hope that teams are working tirelessly around the world to try and make a difference.”

To mark Brain Tumour Awareness Month 2020, Kate shared some of her thoughts.

“I particularly recall on patient, a really lovely man aged just 60, who was away on the trip of a lifetime with his wife, travelling overseas. He started to feel ‘not quite right’ and was becoming a bit confused. He put it down to stress, but they went off for a CT scan overseas. The results from that prompted them to return home for an MRI scan. It revealed he has a glioblastoma, the most serious form of brain cancer. And in this case, it was not in one just spot. We found he has one of the unusual tumours that has travelled a throughout the brain. We will treat it to hold it off for a while, but because it is not localised, it’s almost untreatable. If he lived more than one year, it would be a miracle.

I am a doctor and yes, this is all part of our work, but I do feel for him, his family and all of my patients who face this diagnosis. Sixty is a time in your life when you should be finally starting to ‘breathe out’ a bit.

Something like this can happen to anyone. Glioblastoma is the most serious form of brain cancer and it is most common in those aged over 45. It can occur in children, but it is not the commonest type of brain tumour in kids.

It is an awful disease that seems to happen when people are in their prime, or have just paid off the house, are moving into retirement or semi-retirement and think they are about to embark on a caravan adventure around Australia, or some other long-held dream.

I also feel so much for a 77-year-old patient with her first ever seizure. When we investigated, we found that her tumour had spread everywhere. Because it is so extensive, this lady will go straight to palliative care.

The data in Australia does suggest GBMs are becoming a bit more common, but people are living longer and are not dying of other diseases. So it’s hard to know if this is a real increase.

Are we doing enough? Yes and no. The reality is that since 2005, not much has changed for brain cancer patients. There have been small wins – surgery is better and safer and we are more aggressive in our management. Our understanding of quality of life is better. But there have been few new treatments made available.

Having said that, there has been explosion of how we understand cancer in general, what causes it and what drives it. That information is critical and for some cancers, like melanoma, it has led to a revolution. Understanding a single gene led to a revolution in haematological cancers. Understanding the B-RAF mutation led to a revolution in melanoma treatment. My hope is that we will see the same sort of breakthrough in brain cancer.

> ***Brain cancer is an under-funded and under-studied cancer. It is rare by cancer standards, although it does disproportionally cause death and disability. Breast cancer is much more common, but fewer people die from the disease.***

We do now know more about where brain cancer grows, why it grows and what the important mutations are, but we have not found that magic bullet yet.

People who are diagnosed should be hopeful that we are making progress, and we are understanding more about how we can do clinical trials better. There are lots of smarter things on the horizon, which make me hopeful.

I am driven by the patients I see every day. People always want more time. There is always a grandchild to be born, or a wedding to go to or a partner to care for. There is always more life. There’s rarely a time when people go, ‘that’s enough’. And that’s why as medical professionals we have to keep finding answers, keep researching and try to give people the ‘more’ that they want.”

For more on what drives Professor Drummond, please click here.

May 2020.

Brain Tumour Awareness Month 2020: Introducing Vanessa

In Brain Tumour Awareness Month, we are recognising passionate people who are making a difference in brain cancer. Vanessa van den Berg is a senior ST brand manager, responsible for marketing several products in oncology and haematology. But, she has a very personal reason for making a difference in brain cancer.

“I’m a strong believer that our life-experiences prepare us for a greater plan. When we face challenges, we do not always see the bigger picture, but it always become apparent – almost like ‘joining the dots’.

In 1982 my mum was diagnosed with a brain tumour at the age of 38, raising 4 children and living a full life. As I was only 12 years old, this period had a lasting impact on my outlook on life.

Mum had her first surgery to remove the brain tumour and came out of the operation fairly well. Unfortunately, the tumour grew back within three months and when it did, it spread into an eloquent area of her brain and she went to hospital for further surgery.

The second surgery was more challenging, and we waited anxiously for over 20 hours. When we were allowed to see her, she could only say a few words and couldn’t remember or pronounce our names.

Our first language as a family is Afrikaans, however mum’s mother tongue was English. When she started speaking again a day or two later, she could only speak English and had to learn to speak Afrikaans again.


BRAIN TUMOUR
AWARENESS
MONTH 2020

She had to undergo extensive whole brain radiation, which was still very much the treatment of choice in the early 1980’s, however luckily no chemotherapy was required.

> *While she did recover, her speech was permanently affected and she couldn’t express herself, especially if we teased her and made her angry. You never forget the shock of seeing your mother unable to speak, tears running down her cheek, as she tries to communicate.*

Mum survived another eight years, when she died very suddenly of a brain aneurysm. The post-mortem showed that she had an aggressive leukaemia, which was most likely the underlying cause of this haemorrhage.

It was 12 years after Mum’s death that I lost my Dad to mesothelioma as well, which ignited my passion even more to make a difference in the lives of cancer patients.

It is ironic that my professional life in the pharmaceutical industry has led me to work with oncology and haematology products – “joining the dots” of my life story.

When I work now, I think of the extra time new therapies can give patients, even if it is only a small amount of time. Time to walk down the aisle at a child's wedding, going on a last family holiday, getting married. I am passionate about extending life. I am passionate about the role I can play in offering patients hope.

From personal experience I can tell you, those few months can mean so much. Mum was there to raise us. I would do anything to have that time again. I would have done anything to have my mother at my wedding ten years later. My experiences have created my passion to help other people and their families.

During Brain Tumour Awareness Month, I would love to honour the health care professionals who make this possible and the patients living with brain cancer."

Vanessa shared her story in May 2020.