Summary of questions from the audience answered by Dr Richard de Boer, Medical Oncologist at the Royal Melbourne Hospital and Epworth Hospital

1. ***What advice do you give women who are taking long haul flights, to avoid deep vein thrombosis (DVT)?***

The risk of DVT is higher if you are being treated with tamoxifen than if you are being treated with an aromatase inhibitor.

My advice is to continue taking tamoxifen for the flight – don't stop taking it – particularly if you do the following to reduce your risk of DVT:

- wear flight compression stockings
- do plenty of walking and stretches
- drink plenty of water.

The question of whether you should take aspirin during a long haul flight is often raised. There is some evidence that it may help to reduce the risk of DVT. Aspirin assists clotting in arteries more than it does in the veins, so it's beneficial for people who have had a stroke or heart attack. Even if you haven't had a stroke or heart attack, it may still possibly be of benefit if you're perhaps a bit older and have more difficulty getting up and moving around the plane.

If you have had DVT in the past, you are at a higher risk of developing DVT again. In this case, it's a good idea to ask for advice from a blood/clotting expert (haematologist).

2. ***My breast cancer was initially diagnosed as hormone receptor-negative and HER2-positive, however, after further testing they found that I actually had triple negative breast cancer. I have completed surgery and chemotherapy. Are there any other treatments for triple negative breast cancer?***

When core biopsies are analysed, the pathologists will often perform an initial analysis of the tumour HER2 status, but this is not the definitive result, and must be confirmed by testing on the full breast specimen. The result from the full specimen is the more accurate and is the final result.

While there is no additional treatment (after chemotherapy) for women with triple negative breast cancer, the follow-up procedure is exactly the same for you as it is for women with other subtypes of early breast cancer.

3. ***Do you think it's safe for women with oestrogen receptor-positive breast cancer to use topical oestrogen creams?***

This is an excellent question with different opinions on the answer. Unfortunately, there is little data to help guide our opinion/answers. In my view, if a woman is being treated with tamoxifen, I think that using topical oestrogen creams are reasonable because tamoxifen blocks oestrogen from working in the body, regardless of where the oestrogen comes from.

Aromatase inhibitors are quite different. They block oestrogen that is produced by your body, but they don't block oestrogen absorbed into your body from topical oestrogen cream. There is a real lack of data about how much oestrogen is absorbed by the body from these creams, and hence we don't know if this is safe.

A researcher I previously worked with tested the levels of oestrogen absorbed by seven women who used topical oestrogen cream and the results were varied. At least one woman absorbed a high amount of oestrogen while some of the other women did not.

I tend to recommend that women try a topical oestrogen cream for two or three months, and then stop so to assess how they're doing. If it makes a large difference to their quality of life, the woman is then in a position to make the choice between stopping or continuing to use the cream

4. ***For post-menopausal women who were diagnosed with hormone-positive breast cancer, is a complete hysterectomy an option to reduce the level of oestrogen in the body?***

Women have two ovaries, two fallopian tubes, and a uterus. During a hysterectomy, the uterus is removed. However, the uterus is not involved in the production of oestrogen, and so doesn't have a specific role in breast cancer, so does not routinely need to be removed in ladies diagnosed with breast cancer.

The ovaries are different – they do produce oestrogen, therefore they are related to breast cancer, and blocking oestrogen, or oestrogen production, is an important part of treatment for hormone-positive breast cancer.

In post-menopausal women, the ovaries no longer function and do not produce oestrogen, so there's no particular reason to remove them as part of standard treatment.

Some women who carry a BRCA gene mutation choose to have their ovaries and fallopian tubes removed to reduce their risk of developing ovarian cancer. Often the uterus is removed also, despite the fact that it doesn't produce oestrogen, because it is in the same area as the ovaries and fallopian tubes.

Some women experience complications from their uterus while on treatment with tamoxifen eg bleeding, polyps. Removing the uterus is an option for these women.

The situation is different for pre-menopausal women. Some women's periods stop after chemotherapy treatment, and restart months later. This can cause concern for women because oestrogen is again being produced by the body, and they are concerned it may increase their risk of recurrence. The medical field is still not clear on what to do in this situation (ie remove/turn the ovaries off, or leave them functioning), and so it tends to come down to the preferences of the woman. An important trial (the SOFT trial) has been performed to answer this question.

1. ***Is it safe to stop tamoxifen treatment in order to have children?***

This is a complex issue, but I think that having children after breast cancer is a viable option, and for some women this will mean stopping, or pausing, tamoxifen earlier than planned.

Observational studies have shown that having a child after breast cancer appears not to be detrimental to the woman's health or chance of disease recurrence.

No one really knows at what point it is safe for a woman to stop tamoxifen treatment in order to have children. A lot of health professionals say women should complete at

least two years of tamoxifen before pausing treatment. This is not medically determined; it's really based on the fact that women tend to feel better after two years. They have usually recovered from active treatment (surgery and/or chemotherapy and/or radiotherapy) and are generally in a better frame of mind.

Some women are really keen to complete five years of tamoxifen before considering trying to become pregnant, but this often means they're quite a bit older by the time they try to become pregnant and their natural fertility is lowered.

If women choose to stop taking tamoxifen before they have completed five years of treatment, I tend to suggest that they resume treatment after they have their baby, so to complete the full five years of treatment.

2. ***Could you talk about the use of tamoxifen to reduce the risk of developing breast cancer in young women with a strong family history?***

Large clinical trials have shown that tamoxifen treatment reduces the risk of developing breast cancer in women at high risk.

The uptake of tamoxifen as a risk reducing treatment is very low in Australian. According to a recent paper, only around three per cent of women at high risk of developing breast cancer in Australia currently take tamoxifen.

This is due to a number of factors including the fact that tamoxifen is not subsidised for women at high risk of developing breast cancer, and also that women tend to be concerned of the side effects.

Summary of questions from the audience answered by Jane Fletcher, Health Psychologist and Director of the Melbourne Psycho-oncology Service.

1. ***This is more of a statement. You spoke before about making informed decisions. However, often women have surgery days after being diagnosed, and they simply don't have the time to look at good quality information.***

I absolutely agree. Also, some women are often given too much information and experience 'information overload'.

If you are experiencing anxiety about a particular issue, getting good quality information is going to drop that level of anxiety.

Don't hesitate to ask your health professionals questions. When you are in a medical appointment, that is your time and you can use it to ask questions. I encourage you to take a list of questions to your medical appointments, and you can even ask your doctor to write down answers for you, so that you can go home and do some research.

The internet is a great resource but it's also a very dangerous place. I would strongly suggest that you don't search 'breast cancer' on the internet and read anything that comes up.

It's best to stick to reputable websites that provide good quality evidence-based information, such as Breast Cancer Network Australia (www.bcna.org.au), Cancer Council Victoria (www.cancervic.org.au) and BreaCan (www.breacan.org.au).

2. ***I have experienced insomnia for some months now, and often find myself reading blogs on BCNA's online network in the middle of the night. I have been prescribed sleeping tablets, but I'm a bit fearful of taking them. Is it ok to take sleeping tablets to break a cycle of insomnia?***

It's absolutely fine to take sleeping tablets to break a cycle of insomnia. Taking them for a few days to break a cycle of insomnia isn't going to create dependency.

There are a few strategies that you can try to help you sleep:

- Try writing down everything before you go to bed.
- Try going to bed at around 10–10.30pm when you get a hit of melatonin.
- Try to avoid doing anything stimulating before you go to bed. For example, don't read, watch the TV or use a computer, tablet or phone in the bedroom. These things stimulate your brain, and the light that they create also tells your brain that it's time to be awake.

Try some sort of meditation or sleep CD to distract you from your thoughts and help you get to sleep. Avoid listening to the radio and music as these engage the brain.

3. What advice can you give about talking with children?

The Cancer Council has a wonderful information resource called *Talking to kids about cancer* (http://www.cancervic.org.au/about-cancer/cancer-and-children/what_to_tell_your_child) which explains in detail how to speak with children of certain age groups.

It's really important not to keep secrets from your children. Being open and honest with children, using appropriate words for their age, reduces their anxiety.

If you have hushed, secretive conversations around them, your children are going to think that there is an issue with them because they are very egocentric. This issue can even arise with teenagers who are still quite egocentric.

By talking openly with children, you reinforce to them that illness is a normal part of life that can be discussed openly.

Avoid saying to children that everything is going to be ok, because this can sometimes set them up for a fall later on.

If children ask if you're going to die, I suggest you say something like 'well, I'm not dying right now, because I'm here with you'. You're not saying that you are never going to die, but you are reinforcing to the child that you are fine in that moment.

4. ***(male partner) I want to provide my wife with the best support I can. I always provide a positive response to her questions. However, I feel that sometimes there's a need for me to 'say it how it is' but I'm not sure when that's appropriate. Do you have any strategies to help with this?***

One of the most important things you can do for your partner is to listen to her. Even if what she tells you strikes a fear response in you and is quite upsetting, just listening will help her, without trying to 'fix' the situation. Trust that your partner will tell you if she needs you to do something.