Cancer Council Queensland

cancerqld.org.au

Disclaimer

This video should not be used as a substitute for medical, legal or financial advice. To read Cancer Council Queensland's full health disclaimer, please click here.

Webinar: Fear of cancer recurrence in breast cancer survivors

Tuesday, April 30, 2019

Presenter: Professor Jane Turner

ANNA GORDON:
Good morning everyone and welcome to Cancer Council Queensland's health professional webinar on the topic of Fear of cancer recurrence in breast cancer survivors. My name is Anna Gordon and I'm Advisor for Cancer Information and Education here at Cancer Council Queensland. We have participants from all over the state this morning and I would like to particularly welcome those from regional rural and remote areas. Before we begin, I'd like to acknowledge the Traditional Owners of the land on which we work and live and also pay my respects to Elders past, present and emerging. Just a bit of housekeeping at the start.

This webinar will run for one hour. Professor Jane Turner who is our guest today will speak for about 45 minutes and we'll have some time for questions at the end. Please feel free to ask questions during the webinar. Just type in your questions into the chat box on the bottom left corner of your screen and press enter and we'll read out the questions at the end of the presentation. This session is being recorded and will be available on our website. And once the recording is online, all the participants who have registered will get a notification. So, you'll be able to go and re-watch it or share it with your colleagues who couldn't make it.

OK, now I'd like to introduce our guest presenter Professor Jane Turner. Professor Jane Turner is a Psychiatrist at the University of Queensland Faculty of Medicine and she brings a wealth of experience to today's session. She has worked for over 20 years in the field of psycho-oncology providing treatment to patients with cancer and their families. Professor Turner also has extensive research experience focused on clinical interventions and sustainable models of service delivery. And Professor Turner will share some of her knowledge with us this morning. So, I'd like to welcome Jane and hand it over to you now.

JANE TURNER:
I'm delighted to be here and welcome to everyone who's joined us. So, I've been asked to talk about fear of cancer recurrence today. This is a really big topic in oncology. So, how do we define that? Well, fear of cancer recurrence is the fear, concern or worry that cancer could return or progress. Now that's a really important point because for many of us, we may think that this is something that's confined to people who've got early stage disease. However, even people with metastatic or advanced cancer worry about further disease progression. And I think that that's an important point to bear in mind. Now this is actually quite a big problem and I think it's important for us to think about that.

So, this is a big study. It was a population based sample created from two state based cancer registries. And the thing that was really compelling about this study was that they had survivors not just from breast cancer but prostate, lung, colorectal and melanoma and they assessed their unmet needs with a 34-item Supportive Care Needs Survey. And 37% of survivors said that they had moderate or high levels of unmet need in relation to one or more items. And right up at the top, number two, is fears about the cancer spreading.

So, this is actually a problem that affects a number of people across diagnoses and until fairly recently, we really had been not able to offer very good evidence-based interventions to help these people. So, we also know that when people have high fear of cancer recurrence, that actually affects their healthcare behaviour and I think that there are major implications also for cost.

So, Belinda Fuse has done a lot of work in this area and her survey of women with early stage breast cancer showed 70% had high levels of fear of cancer recurrence. And what tended to happen is that people who've had higher fear of cancer recurrence went to their GP more often. They had higher frequency of breast examination.

Conversely, this is a really important point, they were sometimes avoiding having mammograms or ultrasounds. They had more use of complementary and alternative medicine and more use of counselling and support groups. And I'll bring that back to discussion later when people actually have unscheduled visits particularly to their GP, when they call the cancer help line and are thinking, Maybe I should have some extra tests. Doing extra tests does not reassure these people. In fact, it may actually make their anxiety worse.

So, hang on to that thought. We will come back to that. We're also now recognising that fear of recurrence is an issue in caregivers. We know that carers, that's a funny word, isn't it? Carers. But anyway, carers, partners, family members of people affected by cancer do have high levels of distress and we know that their fear of cancer recurrence is as high or higher than patients. And this is an important thing to identify because this might actually drive the fear in some people.

So, if you've got a caregiver or partner who's saying, Well, are you sure about that? Oh, I think you should go and get that checked out love. I think you should have another test." So, what we think is that, you know, we've got to think about the people who present to us and see them in their social context. So, it seems that the fear of recurrence bounces around between the person with cancer and with their carer. But also caregivers who feel that they don't have enough information or where they have blocking discussions. Sharon Manne talks about mutual buffering. And in my experience, that is really not at all uncommon.

So, the person with cancer doesn't really talk about it with their family members because they want to protect them from being upset. The person's family members don't talk about it because they don't want to upset the patient. And so there's all of this background tension and anxiety that's never resolved or discussed. If you've already got family stress and illness, that's a big issue and of course if you've got recurrent or metastatic disease. So, what I'm suggesting so far is that the fear of recurrence is a high concern. It's common. People who have this seek more help and that actually might be part of the problem, and they're in a social context where that fear may be driven or certainly increased by the attitudes and behaviour of people around them.

So, what are the consequences? This is not a trivial thing. People who have high fear of recurrence have worse quality of life, greater distress and anxiety, intrusive preoccupation with cancer. If we think about breast cancer, it's a very commonly depicted cancer in the media. In October, everything is pink. We've got breast cancer awareness month. People who've been affected by breast cancer really will find that there are very few opportunities for them to be completely free of thoughts and reminders about that. And of course they often seek out information as well looking at Google.

People who have a high fear of cancer recurrence sometimes struggle to establish future goals and plans. And you know, I can think of someone who said to me, Well, I don't see any point in addressing my smoking because I'm gonna die from cancer anyway." So, people can feel that they're stuck in a corner. Fear of cancer recurrence is

also associated with over-checking and monitoring, high frequency of breast self-examination and as I've said avoidance and not having mammograms or ultrasounds.

Now I said right at the outset that until fairly recently we really haven't had good evidence-based interventions to help people with high fear of cancer recurrence. Most of you would be very, very familiar and confident with the concepts underpinning cognitive behaviour therapy. So, in cognitive behaviour therapy, which is very commonly used for distress and marked levels of depression, we help the person identify their unhelpful thoughts and behaviours. So, if we think about the example of a simple phobia. Someone says, "I can't go into that room. There could be a spider in there." You would actually help them in CBT to say, Well, what's the chance of a spider being in there? What would be the worst thing that would happen if there is a spider in there? All of those sorts of things. And you would help the person develop skills to challenge their cognitive distortions.

Now the problem with applying fear of cancer recurrence and CBT together in a treatment modality is that the fear of recurrence is actually reasonable. Even if you have early breast cancer and you have a 97% chance of surviving long term, but what about those 3%? We can't promise necessarily. We can't guarantee. So, there is always uncertainty about prognosis. The other thing about CBT is that it's very focused on the here and now.

So, it's actually developing very practical strategies to help the person cope with their unhelpful thoughts. It doesn't actually give the person a narrative or a framework for understanding the origin of their problems. And in working with people with high fear of cancer recurrence, I actually think it is an important thing for people to understand how this has evolved because it actually reduces their level of distress and blame and self-doubt and actually helps them feel more optimistic about dealing with it. The other thing about CBT is that it doesn't really identify the existential challenges. And we all know that if you've been diagnosed with cancer, you have to confront your own mortality.

Now someone said to me once, Well, when I had cancer, it was like the mirror was held up to me and I had to look at who I really was. And I didn't like all of those parts." So, CBT doesn't focus on those whereas in fear of cancer recurrence, my experience is that inevitably, those existential personal and background factors are important.

So, I'm going to talk about the model that we've developed and that we have examined in a randomised controlled trial. And so there are several theoretical considerations at

the outset. The first is that this is a rational fear. So, compared with CBT where we're looking at unhelpful thoughts or irrational thoughts, this is a rational fear. We're saying CBT really has major limitations. And our model draws on self-regulation of executive function, and I'll explain what that is, and acceptance and commitment therapy and relational frame therapy. And I'll work through these in turn.

So, self-regulation of executive function some of you may have heard of this, some of you may not. This is a technique developed by Adrian Wells in the UK and it's a trans-diagnostic model of emotional problems. And really it's about metacognitions. So, it's not actually about saying that thought is unhelpful or that thought is unreasonable. It's actually thinking about how you then deal with the thought. So, it's about self-regulation of thoughts and emotions. And I'll go through that in more detail.

So, what Adrian Wells and other people are saying and what we're saying in this intervention is the thoughts are reasonable. The thoughts are OK. Trying to get rid of those is not going to work. It's how you help someone respond to those and deal with them. That's the essence of this intervention. Now this is actually, this slide is unfortunately already covering up the core issues that should be here. So, it's not actually displaying as it should. But I'll work you through I'll walk you through these things. So, right at the top of this slide sort of towards the middle, we've got our understanding of risk factors. So, what our model is saying is that there are some people who are actually vulnerable to having high fear of cancer recurrence because of things that have happened in their life.

If you were nine when your mother died from breast cancer and your father re-partnered very quickly and then they had three more children and you felt marginalised, you would actually spend your adult life in most likelihood thinking that, a, cancer kills people and b, if it does kill people, life is dreadful. So, you get that same woman who comes to a diagnosis of breast cancer say in her early 50s, she's got children who are in their 20s, she becomes very anxious because she needs to be there for her children. She's worried about what would happen and she's thinking about her own experiences. So, that's just one example.

Now the next thing that we think is actually really important is the cancer experience. We all know people who've had a diagnosis of cancer and who have sailed through treatment and so they're riding the high seas in the height of luxury on the QE2. You know, nothing seems to be a drama. And yet there are other people you think about another example say someone who's had a normal mammogram and then she presents with an interval cancer.

So, she presents with a lump say 12 months later told Well, we don't think it's cancer but we'll just check." Another example might be a young woman who's been told she's too young to have cancer. Then she has further assessment. She has a fine needle biopsy. Oh, it takes ages to get the results back because the laboratory staff are on holidays. There are public holidays. And then she comes to the clinic and the result's out there. She eventually gets the results. The surgeon she wants to go to is on leave. The surgeon actually tells her about the surgical options and then she decides to seek a second opinion. She gets a very different opinion. She has surgery, she has chemotherapy. Well, she has multiple admissions with neutropenic sepsis. She has terrible reaction and she gets terrible nausea and vomiting. She gets peripheral neuropathy. She has dreadful reaction from radiotherapy.

This woman is obviously going to start to think, "Well, everything that's possible that can go wrong will go wrong with me." Why should she be confident about the future? Everything's gone wrong. The next part of our intervention talks about values clarification. At the outset I said that one of the things that happens is when someone is diagnosed with cancer, they actually have a challenge with their sense of self and their existential self. And a lot of people start to either feel, Well, what was my life worth? What should I do?" or feel stuck. They think, "Well, why can I make choices? What can I do about it? Because nothing is going to work." And so part of our intervention is talking about values clarification.

One of the other really important part of our intervention is helping people learn to live with stress. A lot of people worry about stress. A lot of people think that stress could cause cancer. Stress may play a role say in developing a cold. You're more likely to develop a cold if you're really busy and stressed. Stress could play a small role in the development of cancer theoretically. But if it does, it's a very, very small role. And yet people worry about stress and they try to eliminate it from their lives and that of course causes them more stress.

Now if we move to the right side of this diagram, challenging beliefs about worry, this is actually a really cool part of the intervention that we've developed and it goes back to what I'm calling metacognitive skills. So, what we know is that there are people who are roughly divided into two camps. There are people who think, This worry is gonna make me sick. I've got to stop worrying because it's gonna make the cancer come back." Alternatively, there are people who tend to think, I've got to be on my guard. I've got to be focused because that will protect me." But that actually keeps people locked into their worry and stress. And if we move follow that blue arrow up and then we look at cognitive skills, this is actually where we help people understand that what they're

doing is continuing to reinforce the problem. And they talk about what they call cognitive attentional syndrome.

So, this is actually not a syndrome as such although that's the way it's described. It's really about people developing antennae for the diagnosis. You know, if you get a red car, suddenly you notice all these red cars on the street. It's just amazing. And so what we find is that say women diagnosed with breast cancer will suddenly find all this information. Everyone they've heard of has had breast cancer. So, they actually have antennae. They seek out the information and they ruminate about it. And that sort of fuels the fire. And then of course we come further up and people have this high recurrence. So, we've got all of these things that are fed into it. And of course the other problem is education.

So, a lot of people don't actually understand the information they're given. I was just looking at some resources last night for another study I'm working on. And one of the quotes from the women was saying I didn't understand what he, the doctor, was saying and he didn't understand that I didn't understand." And I think that that is actually not a rare thing. So, we often think that we give people good information about something but they may not have the information. They may misinterpret that. And so that's an important part of our intervention as well. So, the study I'm talking about is called 'Conquer Fear'. We've published this study. It was a very effective intervention to treat people who had high fear of cancer recurrence. And I'll walk you through more details of the study and how that worked. So, we conducted this across Australia. I think we had 17 participating centres and we trained therapists from all of those centres.

So, we invited 987 people to take part. So, the people we chose, we ended up mainly with women with breast cancer, but we did have some people with colorectal cancer and some people with melanoma. Now we invited people to take part, a number of those people weren't eligible. So, we're really aiming to have people right at the outset who had early stage disease not because we think that this may not be helpful for people with advanced disease. But when you're conducting a trial, the more homogeneous or the more similar your research population is, the better it is in terms of interpreting your results. OK, so we randomised 222 of those people and then we looked at the follow up data.

So, what were the characteristics of the people in this study? So, the average age was 53. The majority were women. No surprise there. Majority had tertiary education. And we think that that fits in with what we see about people who participate in research. More than half were partnered. Two years since diagnosis. So, here we are, 89% had

breast cancer and the majority had stage zero to one. And most of them had had a combination of treatments.

So, if we look at our primary outcomes. So, we actually in a randomised trial, you're comparing people's response to either a placebo or a comparable intervention. If we compared our intervention 'Conquer Fear' with nothing, that's actually a bit cheeky because in fact nothing wouldn't improve anyone. So, it would be better than nothing. So, we developed a control arm that we called 'Taking it Easy'. And 'Taking it Easy' was relaxation sessions. And I can walk you through those. So, if you look at this slide, the pink... Sorry, I couldn't resist it, pink for breast cancer. There we go.

So, we've got a reduction in those measures. So, if you look at a drop, the measure we're looking at is FCRI Fear of Cancer Recurrence Inventory. So, that is a structured validated measure for fear of cancer recurrence. And looking at the beginning, the levels of distress or fear of recurrence were similar in both groups. Now they did drop in both. This is a very interesting thing. So, we had five sessions. The 'Taking it Easy' with structured relaxation. Those people improved. They liked it. But look at how big the difference is between the pink and the blue arms.

So, the people who had the 'Conquer Fear' intervention had a big drop in their fear of recurrence after the intervention. But look, three months and six months later, that has continued to drop further. And I think the reason for that is because the intervention has given people skills that they are continuing to apply. It's not giving people a drug, and that's the end of it. You're not taking the drug. They're actually continuing to apply the techniques that we've told them about. Now one of the subscales of the fear of cancer recurrence inventory is the severity and again reduction is greater than the control arm of 'Taking it Easy'.

We also looked at secondary stress. Some of you might be aware that we're increasingly recognising that being diagnosed with cancer is highly traumatic for many people. And we looked at post-traumatic stress and anxiety. Again that dropped for both. So, a drop is a better outcome. But the drop was greater for those who had the 'Conquer Fear' intervention. And quality of life. Now this is the opposite. So, the higher the score, the better. So again, you can see at the beginning these people's scores were very similar. The people who got 'Taking it Easy' had a gradual increase in their quality of life, but we had a huge jump after treatment in quality of life for the people who had the intervention. So, what we found was that participants in both groups improved in all outcomes.

Now what are the key practice points here? So, I've said that fear of recurrence is a rational fear. Reassuring people does not make it better. Additional tests don't provide reassurance. Being urged to be positive does not make it better and in fact I think it's probably going to make it worse. So, we're part of a society where people wanna be brave, they wanna be positive. And if you google breast cancer, you will get within a second, a million quotes. You know, "When life gives you lemons, make lemonade" and all of those sorts of rubbishy things. So, the problem is that what we know is being able to talk about anxiety, being able to talk about fears, being able to talk about even unpleasant thoughts actually helps adjustment.

So, when someone says they're frightened of their cancer coming back, rather than saying, "Look, you'll be fine." what we should be saying is, "Tell me about that." We should also recognise that this doesn't magically go away. So, if you're taking a call from someone who's three months down the track, don't say to them oh, well, in 12 months' time, this will be different." Because it doesn't seem to dissipate over time. So, helping the person understand the origins of the concern appears to be very helpful. Helping people understand that this is the new normal. So, taking pressure away from that person to get back to what they were before. Resisting the impulse to do additional tests beyond the normal scheduling. Listening to their distress. I think it's very important to understand the circumstances of the diagnosis. So, every patient I see, it doesn't matter what their cancer is, I ask about their diagnosis. Now if you see people with head and neck cancer, for example, and I see a lot of those people, it is very common for those people to have been treated with two or even three courses of antibiotics for a sore throat before someone says, "Well, let's go and refer you to an ENT surgeon." Now that is entirely reasonable first management. However, you can understand then the person thinks, Well, they missed that. They didn't get that right. How can I be sure that everything else is going right?" So, feeling that the person's diagnosis hasn't been made well or that things have been missed or there's been a delay. It is not helpful to criticise the doctors or the breast screening staff. What is helpful is to acknowledge the person's feelings around that. So, saying you feel that this has actually made a difference to your situation now. That is a difficult situation to feel. So, specific issues the slide, this is Slide 24, fear of cancer recurrence specific issues. Understanding their objective risk of recurrence is important and also the content and frequency of thoughts about this. So, you're really wanting to have a sense of how much this is troubling someone. Is this something that's an occasional thought or is this something that's stopping people going out? Is this stopping people actually relating to other people? And you want to find out what are the triggers? So, if someone says that every time they go on to Google, they start to get anxious. Well, maybe they shouldn't be looking at Google so often. OK, the

slide I'm talking to now is Slide 25, meaning and consequences. So, you want to know what is the impact of fear of cancer recurrence? So, that is emotional. It might be physical self-examination. Financial, what about people who have unplanned or unscheduled medical appointments or investigation? And it might be interpersonal. So, I can think of a woman who became very fearful that she would die from her cancer, although she had a good prognosis. And she was very, very worried that she wouldn't achieve everything that she wanted to in her professional role. So, she started working extra hard, extra long. She started micromanaging other staff at work. I think that they actually got a bit jack of her behaviour to be perfectly honest. And she became absolutely exhausted, angry and resentful. And helping her think about her life goals and future planning actually helped her take a step back and slow down. OK, so Leone, we're on meaning and consequences. That's the right slide. OK, perfect. OK, excellent 'cause she's got meaning and consequences. So, we're on track. Thank you. So, the other issue to think about is what would recurrence mean for this person and those they love? So, someone who is in their 40s and who has young children, it's very obvious to think well, if they had a recurrence, that would be devastating for their children. But let's take that a step further. What if this person has been sexually abused as a child? What of those who've experienced domestic violence or trauma? What if they've never disclosed that to their partner and they see that they have to be the one who protects their children? So, a recurrence becomes even more terrifying because they feel that they're the only one able to keep their children safe. This slide is not a clean slate, OK? So, a few people come to a diagnosis without past experiences or loss or adversity. And for a lot of people that shape their worldview. You know, there are people who come to this diagnosis who say, Well, everything bad that can happen, will happen to me." The problem is too that when these people are reassured or told that they should be positive, they feel guilty or ashamed. And then of course that causes them further stress. So, a formulation basically this is a psychiatric term. It's actually if you like the narrative. It's actually explaining who this person is, who they are, what are their vulnerabilities, why have they come to this situation? And helping the person understand, if you like, how all these holes have lined up in the Swiss cheese can be incredibly affirming for people. The person who actually can say, Well, it's not my fault that my mum died. It's not my fault that my father then abused alcohol. I can see now that that shook my confidence. Then when I felt I didn't have a doctor who listened to me, that then made me more anxious. I'm not weak or stupid. It's the fact that all of these things were lining up to make it hard for me."

So, the next slide is making sense of it. And this is actually a sort of fairly dense slide but I think it's an important thing to illustrate how we're using metaphor in this study. So,

we've used quite a bit of acceptance and commitment therapy. Acceptance and commitment therapy is about the person helping to think about what in their life they can change and what they can't. And we also use a lot of metaphors. So, here's an example, Francesca. She was pretty wild during her teenage years. She had after an experience of abuse, she always felt guilty didn't disclose that to her husband. And then when she got cancer of the cervix, she thought that was her fault because she'd had multiple partners felt too guilty to talk about it. Very protective of her daughters.

Now let's actually just take a step sideways and you never thought that you'd be hearing about children's fairy stories at this hour on a Tuesday morning. But I'm going to remind you about 'Sleeping Beauty'. So, in 'Sleeping Beauty', the King and the Queen upset the bad fairy. She takes some breach by not being invited to the christening and casts a spell and says that the Princess will prick her finger on a needle and she will fall asleep for 100 years. And in fact that's exactly what happens. The King and Queen banish all needles from the kingdom. The girl goes up to a little tyrant, sees this woman spinning in fact who's the bad fairy, and she reaches down and says, "What's that?" And she pricks her finger on a needle and falls asleep.

Now in using a story like this, you could say to Francesca, those parents thought that they were protecting her. They tried to do everything to make her safe. Is another possibility to actually educate that daughter about the danger of needles? Is another possibility to actually talk with your children about risk and vulnerability, to talk about cyber abuse, to talk about not putting photos of themselves naked online? So, that's an example of the sort of therapy that we might be doing.

So, this slide is key points. The aim of the intervention is not to get rid of worries about the cancer completely. That is unlikely to be possible. It's to help the person focus less on them, give them less importance and develop goals for the future which give their life purpose, direction and meaning. So, the specific techniques I've already talked about acceptance and commitment. I had a patient who had a very complicated relationship with her mother and she continued to visit her mother despite the fact that her mother was really quite cruel to her. And one day she said to me, You know, I've actually looked at the fact that I visit my mother every week in the nursing home.

It makes me upset, sad and angry for several days afterwards. And it doesn't matter what I do, I've never changed that relationship. Maybe I need to actually stand back and say, Is this helpful for me, and what do I do instead?" And she actually then made a decision she would visit her mother once a month. And that created a dramatic improvement in her wellbeing. The metacognitive approaches, some of you will be

aware of these. Attention training is something that's been pioneered by Adrian Wells. If you go online you'll find out more about it. Detached mindfulness is an important part.

So, you've all heard of mindfulness. It's the new black. Detached mindfulness is different from mindfulness and you do not need to practice or rehearse it. Detached mindfulness is actually seeing the thought and choosing not to engage with it. So, an example I give to people is you wake up one morning and there's a red car parked outside your house. And I say, "Well, what do you do?" And people shrug and say, "Well, nothing." I say, "Do you get in the car and go for a drive?" No. Do you pump up the tyres? No. Do you fill it with petrol? No. Do you take it for a cut and polish? And they start to get a bit frustrated by this point. They say, "No, the car's got nothing to do with me." And I say, "Well, there you go. It's exactly like a thought."

Just because the thought is there, it does not mean you have to interact with it. Just because the thought is there, Oh, I could die from cancer, doesn't mean you have to do anything about it. You can observe the thought the way you'd observe a passing cloud. Another example might be waiting for a bus. You're waiting for a bus and a bus comes, but it's not going where you want to go. Just because the bus is there doesn't mean you get into it. You wait for the bus that is appropriate for you. We talk about attention to threat monitoring.

So, we talk about what are the things that pose people stress and how they deal with that. We give people information. You know, a lot of people think that if they've had breast cancer, if they pick up a recurrence very early, that will influence the outcome. And in fact that is actually not borne out by the literature. And people are aware of that. Establishing agreed behaviours are also important. So, sometimes making a contact. Is it helpful for you to look at Google 15 times a day? Well, you need to think about whether that's going to be something that you're going to continue to do or whether you're going to change it. Are you able to agree to examine your breasts once a day instead of 30 times a day?

So, establishing agreed behaviours. I think the whole living versus surviving is really important. And so it's about helping the person think what can be changed and what cannot. I don't know why I've got the 'e' missing out of me but it's about what matters. What do I want for my future? How do I achieve my goals? And I think, you know, I often say to people who've been affected by breast cancer, This is a lousy script but you're in the director's seat. So, you make a call about how you want to live your life. This is the chance for you to ditch things in your life that are dragging you down and for

you to make plans for the future." The card sort exercise, I don't think I've got time to go through that in detail now. But if you go online and just click card sort exercise, that will come up.

Essentially what we did in the study was the card sort exercise gives you a number of topics you know, things like being healthy, having a spiritual relationship, protecting my friends and family. And we asked people to sort them into three parts. So, one is things that are really, really important, another part is things that aren't important at all, and then in the middle, mm, not so sure. What is interesting is that when you ask people then to look at the pile they've made of things that aren't very important to them, they will often say that in fact they spend a lot of time on those things. Like the woman who was visiting her mother every week even though that was causing her grief and the mother manifestly wasn't grateful, she realised that in fact she was better just doing things that did matter.

People who say, "I wanna be close to my family and friends," and then say, "Well, I haven't got time to take my children to sport on the weekend." Maybe you need to think about those sorts of things. So, here are some examples of the sort of things that come up in the card sort exercise. Engaging in sport, being curious, managing things, having a life filled with novelty, those sorts of thing. So, it's very helpful to allow people to actually reflect on that because I think often people who've had cancer feel stuck. They feel powerless. And this is about helping people move forward and choosing things that they want to do.

The metacognitive therapy I've already mentioned is about thoughts about thoughts. And in this intervention, we're helping people to learn the techniques I've talked about detached mindfulness but also challenging the value of worry. Helping people see that worry will not protect them. A certain amount of worry is OK, but beyond that, that is not helpful. And helping people be able to turn their focus away from cancer related stimuli and onto things that are more meaningful in their life. Some examples we might give to challenge this is how do you know that your worry is harmful? How long have you been worrying about it? Have you developed one yet? What's the mechanism by which worrying could cause cancer recurrence?

I'm not going to go through attention training in detail. This is actually a specialised technique. But basically it involves helping the person learn to have better control of where their thoughts are focused. We've all been in a situation, and I have this fairly frequently, you're in a meeting and your thoughts drift off. You think, "Oh, did I take those lamb chops out of the freezer? Oh, I've forgotten to look for dinner." And

someone says, "Oh, Jane what do you think about that?" And I think, "Oh, I have no idea what you've been talking about." And so that's an example of where our attention has moved away from the task.

So, that demonstrates that we are all capable of shifting our attention. And giving that example to people, people who say, "I can't stop myself thinking about the cancer." You might say, "Well, do you think about it when you're asleep? Do you think about it when you're reading a story to your children? Do you think about it when you're focusing on a task?" No. It is possible to have control over those things. I've already talked about detached mindfulness. And threat monitoring is really about helping the person identify what is dangerous and what's not. So, the person who's had breast cancer has a sore back. Oh my God the cancer is in my back. I'm going to die from it." Helping the person have an internal dialogue and say, Well, have you ever had a sore back before? Yes. Is there an explanation for that? Well, I was in the garden yesterday." Helping the person understand that if it's cancer, it'll be either severe or it'll persist or there'll be other symptoms.

So, it is OK to wait a few days before you seek attention if none of those things apply. Seeking attention immediately locks you into that cycle of Oh, it's bad, it's bad. I've got to be worried." Information and misperceptions is really important. Helping people understand that a healthy lifestyle, having physical activity may actually reduce the risk of them getting heart disease, maintain bone health and maybe even reduce the risk of cancer recurrence. And I famously tell people that you can't get rid of stress. The only thing compatible with no stress is death. Stress is part of life. Stress gets us to things on time. Stress stops us from actually running out of toilet paper or getting speeding tickets.

So, allowing people to see that stress is part of life. And I give people the example going to have your next scan. Yes, you will be stressed. It's like an international trip in coach class. It's horrible and you just put up with it and it will finish. Establishing agreed behaviours is another part of our intervention. So, giving people ideas about lifestyle and how they would review new symptoms.

So, the clinical assessment the questions to ask is Do you worry about it coming back? How often do you think about it? How much does it affect your quality of life? And would you like help to deal with your concerns about it? And this is the subscale. I don't know that you would actually be wanting to use that necessarily. So, at that point I will stop and I might open for questions if there are any.

JANE TURNER:
Well...

JANE TURNER:
Yeah, yeah. So, if people have got questions there is no dumb question as I famously tell my medical students. I would say that any clinical psychologist who is clinically experienced would have the tools to be able to provide these sorts of therapies. So, clinical psychologists are trained in acceptance and commitment therapy, mindfulness and those sorts of things. So, if you've got someone you're concerned about, I think it's very reasonable to ask them to see their GP and get a mental healthcare plan and see a psychologist.

ANNA GORDON:
There's a question there.

JANE TURNER:
OK, do you see carers who have not had a diagnosis but are fearful? Oh, absolutely, absolutely. So, Amy's question is about carers who've not had a diagnosis. So, in fact, I think carers are the big untapped source of distress that we need to be thinking about and they can often fuel the fire. So, I think when you see people who are worried about fear about recurrence of cancer asking them about the people in their life and what they say to them because they may actually need specific help particularly if someone is depressed. The question I always ask people about their support you know, it's easy to make assumptions.

If someone's married or whatever to assume that they've got good support. And the question I ask people is, Do you get the support that you feel you need?" And so that allows the person to say, Oh look, he's fantastic but he's got no idea about what I need here." And so that actually allows you to drill down further about that. But I agree, Amy, I think it's fairly important to actually explore the issues with the carers.

Yep. So, Jane's got a question. How do you confront people who've got a different outlook to their partner? For example, a patient has high fear of cancer recurrence and partner doesn't seem concerned and that it was affecting the relationship. Well, I can tell you a funny story about that. So, years ago before we did this study, I had a woman had early breast cancer who was very anxious about the recurrence. And we talked about it and she just said her husband acted as if she’s had an ingrown toe nail.

Anyway, I asked him to come to my office and he turned up and he was an absolute bloke in his Stubbies and his Jackie Howe singlet and you know he really sort of a tough

fella. And we had a bit of a chat and then I said to him, Have you ever thought even fleetingly that your wife could die from this?" And he said, "Oh shit, yeah." And she burst into tears and she thought, That's the nicest thing you've ever said to me." You know, we all laughed about it but the reality is people are different. And I suspect the way I frame it is to try to give people the benefit of the doubt. And I wonder if I would be saying to this person is sometimes when people love us very much, but are very fearful about the future, they behave in ways that seem as though they don't care or aren't interested. But I think that that's often because they love us or because they're frightened.

So, that's another way around this is to say you know, your partner I suspect relies on you and is very frightened about what they would do if you weren't here. But that's a very hard thing for them to say. So, if you can try to have a middle ground where you can frame that difference in terms of a misguided demonstration of affection, it's not always that of course, but that actually allows a face-saving way in I think. Any thoughts on group programs?

So, Robbie Zacharias in Denmark is running a group program. I haven't seen the data from that. Some of the stuff I think is very amenable to group work particularly the metacognitive, the detached mindfulness. I think that that whole initial formulation why did this happen? How did the holes in the Swiss cheese line up? I actually personally think that that is a really, really important part of the intervention. I don't have data to back that up but that's my clinical experience and I think that you can't do that in a group. Some of this is deeply personal and you get things that people have never disclosed.

So, I think that there are people who are thinking about maybe melded groups some online sorry someone group and some individual. There are people who are looking at online applications of this as well and I think that that's a real possibility.

So, the questions about the context of the relaxation control. So, 'Conquer Fear' was a therapist delivered intervention. It occurred over five sessions. And in the relaxation control arm, we worked through say the participants were blind to the intervention. So, we said we're doing a study to see if we can help people with high fear of cancer recurrence. So, the people in the relaxation arm didn't know that that wasn't the intervention. We took their history as well and got their formulation and their narrative and then we worked through a series of relaxation strategies.

So, one session we use guided imagery, we used progressive muscle relaxation in another session, in another we used quick relaxation and it was all manualized and in a structured format. And those people did improve and they did like it. So, in the absence of anything else, relaxation may be helpful. Is 'Conquer Fear' implemented or are there any plans to implement it? We've actually had a lot of discussion about this. Phyllis Butow and Louise Sharpe and I have been running workshops about this at the International Psycho-oncology Society.

We have looked at a broader rollout of this and we've given a lot of presentations about it. I guess it's a matter of watch this space. It's proving incredibly complicated to think about how we might do that. But at the outset I would say that all clinical psychologists have the rudimentary skills to be able to deliver at least parts of this technique even if it's not seen as part of that package.

ANNA GORDON:
There are no more questions. OK, if there are no more questions, I think we can wrap it up for today. I'd like to thank Professor Jane Turner so much for the great presentation. It was certainly very interesting and very valuable information. I'd also like to thank all the participants who joined us today. As I mentioned, this webinar was recorded and it will be uploaded to our website. I know some people had some issues with slides being too fast or too slow. But once the webinar is uploaded on our website, you can re-watch it again and it should be all in sync there.

Shortly after this webinar, you'll receive evaluation forms in your email. We would really appreciate if you could complete those as your answers will help us plan future programs and improve what we're doing. We have a few other health professional sessions like this coming up. If you go to our website under “health professional education”, all the details will be there and you can register and attend those.

I'd also like to encourage you to join our Health Professional Cancer Network. If you haven't already registered, again you can do it on our website under “health professionals” tab. And everyone who registers, receives updates on services, upcoming information sessions, networking opportunities and things like that. OK, that brings us to the end of our webinar. And thank you so much for attending and thank you Jane once again. And have a great day.