

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: Coping with the emotional impacts of breast and gynaecological cancer

Wednesday, May 15, 2019

Presenters: Dr Keely Gordon-King, Margaret Nugent

ANNA GORDON:

Good morning everyone, and welcome to Cancer Council Queensland's Community Webinar on the topic of Coping with the emotional impacts of breast and gynaecological cancer. My name is Anna Gordon, and I'll be your host this morning. We have participants from all over the state, and I would particularly like to welcome people from regional and remote, and rural areas who have joined us. Before we begin, I'd like to acknowledge the Traditional Owners of the land on which we work and live, and I would also like to pay my respects to the Elders, past, present, and emerging. So just a little bit of housekeeping before we start. This webinar will run for approximately an hour and 15 minutes. And Dr Keely Gordon-King will speak for about 45 minutes, on the impacts of being diagnosed with breast or gynaecological cancer.

And then Margaret Nugent will talk about the different support services that are available through Cancer Council Queensland. Please feel free to ask questions at any time by writing them in your chat on the right side. And we'll have some time for questions at the end of each presentation. I'm aware that there are some health professionals who have joined us this morning, and we welcome you as well. I just wanted to note that the content of this session is aimed at people affected by cancer and their families. This session's being recorded, and the recording will later be available on our website, so for everyone who's registered, we'll send you an email notification once the recording is available. So you'll be able to go and watch it or share it with your families and so on.

OK, so I'd like to now introduce our first speaker, and that's Keely Gordon-King. Keely is a psychologist working here at Cancer Council Queensland, Cancer Counselling Service. And through her work, Keely has developed particular interest in working with women who have been diagnosed with breast and gynaecological cancers. Her work focuses on adjusting to change and supporting women to move towards meaningful values driven lives. So I'll just hand it over to Keely now, and let her do her presentation.

KEELY GORDON-KING:

OK, thank you very much, Anna, for that really lovely introduction. So hello everybody and welcome. It's a real pleasure to be able to be here today, and to use amazing new technologies to connect over such a distance and enable us all to come together. So I'm really glad to be able to be here today and have the chance to talk a bit about what I think is a really important topic, which is the emotional impacts of breast and gynaecological cancers.

So, I've kind of divided today into three different sections. Firstly around, coping with uncertainty, and the impact that cancer can really have on the sense of stability in your life, and particularly in terms of fear of cancer recurrence. And then I thought we could talk a bit about the impact of breast and gynaecological cancers on relationships and belonging, sense of connection with others. And finally, on the impact of cancer on your sense of self, your sense of values, and principles, and how you can kind of cope with these three different kinds of challenging areas. So as Anna mentioned, please feel free to put any questions or comments through in the chat function, and if I'm competent enough to use the technology, I will definitely have a look at it, and hopefully we can make it a bit more of an interactive experience.


So, I guess I wanted to talk first of all about, the depth of impact that cancer can have from an emotional standpoint. Cause I think we often can get caught in focusing in on the physical and the medical impacts, and the emotional impacts can kind of fall to the side sometimes out of necessity, because there's so much importance around focusing on getting to appointments and getting through treatment. But I think that the reason that cancer has such a fundamental impact on emotional wellbeing, is that it's really a threat to our assumptive world. So I think that most of us kind of go through life walking along, kind of assuming that the future is gonna be roughly the same as the past. So we have a sense of controllability, a sense that if we take Action A, Consequence B is gonna result. And I think that what cancer does, is that it kind of just comes in and just rips out the rug, completely from under that. And suddenly the world doesn't feel so safe anymore. It doesn't feel predictable. And there's not that same sense of control. So,

because of that fundamental disruption to our assumptive world, it affects your sense of the future, it can affect relationships, and even more deeply than that, it can affect your very sense of self. And so, I wanted to talk a bit, first of all-around coping with uncertainty.

And in particular, the impact of cancer in terms of fear of recurrence. Fear of recurrence, basically I think is probably almost a universal experience for anyone who's been diagnosed with cancer, and family members as well. It's those thoughts that come into the back of your head, often quite unbidden, and quite suddenly. Like, "What if the cancer comes back?", or "What if the cancer progresses, the treatment no longer works?" So intrusive thoughts that come up. And I think the stats are, that something like over 95% of people who experience a fear of cancer recurrence at some point. So it is a really understandable and normal reaction to a really uncertain and difficult and anxiety-producing situation.

And most commonly, fear of cancer recurrence will take the form of intrusive thoughts. So those are really difficult, unpleasant thoughts that kind of arise spontaneously, or they might be triggered off, and you might be watching TV, and suddenly completely unbidden into your daily soap opera comes in, a storyline about cancer, and then that's incredibly triggering. And all of a sudden, the thoughts are there, and they're feeling really overwhelming about whether the cancer's gonna come back, and the fear that comes along with that. But intrusive thoughts, I guess, the first thing I wanted to say about them, is that they are part of our normal mental process to try and understand what's happening in a really difficult situation. So, when your mind encounters something that feels really huge, and feels really complicated, intrusive thoughts are kind of the mind's attempt to process that, to understand it, and to try and find a way forward in terms of finding a way to think about it, or a way to problem solve it. So it's kind of your mind's attempt to be helpful. But of course, in this situation, it's really not so helpful.

So, how do we suggest in terms of how to cope with intrusive thoughts? Because I think that they are really common, and they're also really, really difficult to cope with. And I'd say that most commonly, what I see with my clients at least, and I don't know if this has been your experience, but what I kind of find is that people instinctively can have this reaction of struggle with intrusive thoughts, where intrusive thoughts can pop in, and straight away there can be this sense of panic, of just, "Oh my gosh, this is too much, this is overwhelming." There's that thought again, I'm supposed be positive," what am I going to do with this. And there can be this sense of almost trying to get rid of the



thought, deny it, push it down. Almost like sort of, getting a beach ball in the ocean and trying to shove it underwater. But the problem that kind of comes along with that kind of panic, and that struggle against the thoughts, is that even though it's a totally understandable reaction, 'cause the thoughts are so difficult to have, when you're kind of resisting and pushing back against thoughts, that's still feeding energy into the thoughts. So even though it's trying to get rid of them, it's still conversely turning towards them, in a way. And so it kind of ends up being the case of, trying to get rid of them, panicking, shoving that beach ball under the water, but of course, that's really effortful. You can't do that forever. And eventually when you have to let go of the beach ball, it kind of bounces straight back up, and sometimes it can end up hitting you in the face. So that can often be what happens with intrusive thoughts when it goes to that extreme of having that panicked reaction.


But on the other hand as well, you also don't want to go into the other extreme, which would be, you're sitting, you're watching your show, a cancer trigger comes up and a thought comes in. And you just completely fall into the thought, and really end up going down a spiral, and before you know it, you're thinking, Yeah, I definitely am gonna have that recurrence." It is gonna happen for me. How am I gonna cope? What am I gonna do to make sure that the kids are taken care of?" And before you know it, your mind can be kind of three years ahead into the future. And obviously, when that happens, that's also anxiety-provoking, and it just means that you're not sort of being able to live in the present and being able to live your life.

So, I think that taking either extreme in terms of an approach to thoughts, both end up feeding into the thoughts, and can make things worse. So, what I've found at least, can kind of be helpful with coping with intrusive thoughts about cancer, is to try and aim for a bit of a balanced approach. So, when the thought comes in, you want to aim not to panic about it. So not to go to that extreme of panicking and trying to shove it under the surface, but rather than panicking, you can recognise that the thoughts' arrived, and say, Yep, here's a thought about the future. There's that familiar guest in my mind that I know tends to crop up," especially when I'm going through triggering times," like waiting for a scan result. But rather than falling into the thought, you then acknowledge the thought, but redirect your attention back to the present moment. So, you're kind of getting a bit of a balance between, not panicking, acknowledging the thought, but then coming back to something that you can actually control and focus in on. And sometimes taking that more balanced approach, it doesn't get rid of the thought, but it can help it a little bit, to shift more into the background, so that you're a little bit more in control of your day.

And in terms of how to come back to the present moment, I think picking something really simple to focus on, that's on the outside of your mind, is usually I found kind of the most helpful thing. So you might choose to focus in on your breathing, or you might choose to focus in on a task that you're doing, if you feel up to it with your energy, getting up and doing something small around the house, like the dishes, and focusing in on the water on your hands, the sensations there, or if your energy isn't up to doing something in the house, sometimes even just changing your environment, when you're stepping outside for a few moments, taking in the sounds that are around you, if there's any plants, noticing the details of nature around you. It doesn't really matter what anchor you pick, but the most important thing is that you pick something that's outside of that thought bubble, because you can't necessarily control what thoughts pop in initially, but what you can do something about, is your response to the thoughts. So you can't control the initial intrusive thought, but you can do something about whether you kind of follow it down a spiral, if that makes sense.

And the other thing I wanted to chat a bit about, around thinking with breast and gynecological cancer, is that I think that a lot of women can find that culturally there can be a huge pressure around needing to stay positive. So, I think we hear it all the time. You probably hear it from friends, maybe even from family that, "Oh, you're such a strong person, you just got to stay positive." "You just got to stick with it. And it can be a real sense of pressure there, that almost can turn into this extreme of feeling like you're not allowed to have difficult thoughts, or you're not allowed to have anxiety, or you're not allowed to feel down. And of course, ultimately, the problem with that is that expecting yourself to be positive all the time means kind of jettisoning off or cutting off half the spectrum of all human emotion. And that's hugely draining, hugely effortful. And I think it kind of has consequences down the line in terms of feeling burnt out, and when you realise that it's not possible, and the difficult thoughts and feelings come in anyway, it can end up making you feel really down on yourself, and feel like it's a failure, where it's really, it was just an impossible task to start with. So I don't know if that's been any of your experiences.

Feel free to put in the chat, if there's, if you've ever felt that kind of pressure to stay positive all the time. And I think sometimes positive thinking can be a bit of a thing that people can get stuck with, because it's that sense of, "Well what's the alternative? Cause I just don't wanna give into the fearful thoughts. So what am I supposed to do?" And I think that there is actually a potential alternative to staying positive all the time, which is to try and work through helpful thinking. So, helpful thinking is about being optimistic



and hopeful. It's about focusing on the positives. But it's also about being balanced. So you want to be realistic, acknowledge the reality of the situation, but actually coach yourself through it, and encourage yourself through it. And if I think you take that more balanced approach, it's sort of a lot more sustainable than just trying to be positive all the time. So developing helpful thinking, or even doing anything with intrusive thoughts, can be really challenging, and sometimes I think it can be easiest to start with, starting at a time that you feel a little bit calmer. So not a time that you're feeling super distressed. Maybe even sitting down with a pen and paper, and just having a look at some of the thoughts that are distressing you at the moment, and I think the first step in this is to try and step back and get a bit of sense of distance from the thoughts. So sometimes it can be helpful to go through a series of questions, in terms of looking at, are there any errors I could be making here? Is there details that I'm missing? Am I ignoring or missing a part of the picture? Maybe I've got a bit of a negative bias here, and I'm just focusing on all the difficult aspects of the situation.

There might be other aspects, that create more of a sense of nuance and balance that I might have a sense of gratitude about. And is it helping me to think in this way? Is this something that is progressing me forward, and helping me to develop more of a sense of control over things, or is this sort of taking me down a path of feeling really hopeless? And another nice one is, is this how I speak to a loved one? If I had someone really close to me, what would I say to them to try and help them through this? And then the final step is to sort of look at, well, is there an alternative way that I can sort of approach this situation? So you're getting a bit of distance from thoughts, recognising that for the same situation there can be hundreds of different ways of looking at it, and the way that you look at a situation can affect how you feel. And sometimes it can be helpful to develop an alternative view point, even if you don't quite believe it. It can still be a helpful starting point, to just open yourself up to different perspectives. So with helpful thinking, you want it to be in your own words, you want it to be realistic but also helpful, so it doesn't have to be positive, but it needs to be balanced, and it needs to take a standpoint of encouraging and coaching yourself.

So, I've got here just a couple of examples of, probably some of the most common thoughts that people come to us with at the counselling service, that they're struggling with. And some examples of how you could sort of work towards a helpful viewpoint of each of those. So for example, really common to have thoughts around self-blame and guilt, like, "I'm stupid", and "I'm hopeless", "I'm feeling upset". I shouldn't be feeling this way, I should just get on with, get back to normal. And rather than trying to just be positive, which might look like, Well, I just shouldn't feel those things, I just got to focus

on being happy," I just got to focus on being grateful, I just got to focus on being optimistic." And more kind of balanced and helpful way of looking at it, is to say, "Well it's actually normal to feel upset. It's not a sign of weakness. It's part of a normal reaction to a stressful situation." And what are my feelings telling me that I need at the moment," in terms of how I can take care of myself?"

Another common one is scare tactics, and all those what-if thoughts. Right now I've finished treatment, I know the cancers may come back, what am I gonna do if it comes back? And rather than saying to yourself, Nope, I'm just not gonna go there. That's not gonna happen, everything's gonna be good." It can be more balanced to just focus in on the positives, and say, Well, it is a possibility, but I'm not gonna worry about something" that hasn't happened yet. I feel well right now, I'm gonna take it one day at a time, and I'm gonna focus" on the things that I can actually control and do something about." And then of course I think something that we all do a little bit of, catastrophizing and jumping to the worst-case scenario. I don't know if that's just me, it's certainly something that I do. So thinking that everything's gonna fall apart, and it's gonna be awful if I can't do everything in the house that I used to be able to do. And rather than saying, Look, I'm just gonna push through it. I've got to get there, I've got to stay positive."

Sometimes it's helpful to take a more balanced view in saying, Well, yeah. I can't do everything that I used to do." And being able to unable to do some things while I recover" is frustrating, but I can cope with that frustration." I can cope if the dishes, aren't completely done by the end of the day." So hopefully that kind of shows you some of the differences between helpful and unhelpful thinking, and helpful thinking versus, trying to stay positive all the time. And I think we've already chatted a bit around trying to ground back in the present. So if you find that the thoughts are getting really overwhelming, it's feeling really messy in your head, that's not the time to try and argue yourself into feeling positive or feeling like you're using helpful thinking. If it gets too much, you're feeling too worked up, the best thing usually is to try and just take a break from your head. So trying to come back to the present moment, to take some breaths, to tune in to what's actually happening outside of your mind. To let all of that sense of overwhelm settle, and then once it's settled, then you can go and look at it a little bit more objectively and look at how you want to kind of work through that.

Yeah so, anyone again feel free to put any comments or questions in the chat function. Keeping an eye on it the best of my ability, which is probably quite limited. But yeah, I think thoughts are probably one of the biggest struggles that people bring up. And then

I'd say, probably the second biggest one that I see at least in my work, is around the impact of breast and gynaecological cancers on relationships and belonging. And it's not just the impacts of treatment. But because these cancers can fundamentally alter your body, they can alter the way that you see yourself, they can have a really big impact on your social circle, and partner relationships as well.

Alright, so some of the common impacts of cancer in relationships, that I see for people with breast and gynaecological cancers kind of coming through, include people withdrawing, and unfortunately it seems that quite a common story that I hear over and over, that it can be people that you previously felt really close to, that you thought you had a good connection, that you thought were really a part of your life, who suddenly after you're diagnosed, disappear, or maybe they're there at the start, but over time as you're going through multiple treatments which is really common, especially with gynaecological cancers, if you're having recurrences and going through treatment experiences, people can start to withdraw over time, and there can be that loss of support. There's also of course, always at least one person around who thinks they need to give their two cents about what their cousin tried that was helpful, or what they think that you should be doing.


And on the other end of spectrum from withdrawal, it can also be quite common for people to feel quite overwhelmed by contact. So family members who may be overseas, and not in regular contact usually, who suddenly are calling every day, suddenly you're feeling that pressure to tell your story to every single person, relive all of the medical appointments, give all of that information. And it can even be just random people, acquaintances at the supermarket, who feel quite able to come up and ask you lots of questions about what's going on for you, which can be really overwhelming. So, I think with all of that complications, that can lead to a real sense of guilt and self-blame. A sense of isolation, or loneliness. Anger and hurt. And overwhelm as well and struggling to cope. So, if that's you and if that's what you're kind of feeling, I'd just say first of all that you're definitely not alone. It's one of the most common things that people bring up when they come to counselling, is how to kind of negotiate, how complex relationships can get when you're facing cancer.

So, I've just got a slide here, and there's no, one or right or wrong way to manage relationships. And each relationship is different. But, I wanted to kind of throw out there, some of the most, some of the strategies that some of my clients have found the most helpful, in kind of managing this stuff. So the first one is just around trying to maintain an openness to change. So just going in with the awareness that, through this

experience, even though it's painful, some connections may change, and some people may end up withdrawing, while some may actually unexpectedly grow, and often, especially when there's someone who's been really close to you that suddenly withdraws, because it's so painful, and because it's such a loss, it's easy for all of our energy to start to be directed towards that loss. And there can be lots of thoughts there around, how could this happen? Why is this person doing this? Don't they care? And all of that is energy flowing into a relationship that is no longer kind of giving you a return on your investment. And I think that when you're living with cancer, when you're going through treatment, your resources and your energy are so precious, and so limited, that you want as much as you can to be directing that towards the people who are there.

The ones who have been there, and there may even be people who, maybe previously were just a work colleague, but they've got their own experience with cancer, and suddenly they show up in a way that you may not have expected. And they're there for you, in a way that some of your other friends may not have been. Also sometimes it can be helpful to think about it in terms of different people, being kind of specialists, in terms of the strengths that they can bring, and the kind of support that they can give. So, I don't know if you've found this, but personally I find that having, it can be quite rare to find someone who has a real strength around just listening. So being able to just be there, hear what's going on without having to give their two cents, to give advice or to try and fix things. So if you've got a couple of friends there, or your partner who has a strength in being able to listen and be there, that's really, really valuable. But equally, many people may not have that skill. So for some people, the contribution that they may have to bring may be around other forms of support. So they might be able to bring their own personal experience to bare, or they might not be so good at talking about emotional stuff, but they might be really good problem solvers. They might be really good at giving practical help, and giving you a lift to treatment, even if when you're trying to talk to them about how you're going, they kind of freeze up or they change the subject. Or there might be some friends who may be totally rubbish at listening, and they not even be that practical, but who give you a lot, or have value in terms of being able to have fun together, and give a bit of distraction, or a bit of humour so you can take a break from the situation, take a break from having to process things.

So sometimes it can help if you're struggling to cope with the changes, to think about it in terms of people having a skills deficit, rather than not wanting to help. And of course if you're finding that your family is coming in and calling you every single day, or your friends are asking you lots of questions in the supermarket when you're feeling really tired, and you just want to get in and out, I'd also throw out there, it's absolutely fine to



put up some boundaries when you need to. That might look like, sending out a bit of a group message and saying, "Hey everyone, look I really appreciate all the messages, and all the support." I'm really fatigued at the moment, and I'm just not gonna be able" to get back to everybody but wanted to let you know that I really appreciate it," and we're gonna send out a once weekly email to let everyone" know what's going on. And so, it can be helpful to send out a group message every now and then, so that you don't feel like you have to get back to every call straight away, or you can appoint a point person. So you can say, "Look, please direct all questions to my lovely sister." Or someone else that you trust. They'll be able to handle it, they know what's going on," and I just don't have the capacity at the moment to reply to messages." And if people are coming up to you, a return to work, or in the shops, and asking questions, or at church, and you just don't feel like you're up for answering them, it's absolutely fine, and I've found that people are really OK with it if you say, Look, I'm actually just trying to have a cancer-free day for today." I'm just trying to take a day where I can just not think" about it and just be me. And usually people are pretty responsive to that.

Yeah and then, finally it can be helpful to, if you've got someone who you think kind of wants to be there, but there's a bit of a mismatch between what they're doing and what you're really needing, it never hurts to kind of be specific in terms of what you ask for with your needs. So if you've got a partner who's a great problem solver, and is trying their best to problem solve their way out of the situation, but that's really not what you're needing, it's absolutely, it can be really helpful, and it's absolutely fine to sit down and have a talk about that, and say, Look, I know that you're trying to help, and I really appreciate it," but actually I don't expect you to have a solution, or to fix anything." All I need you to do, is just sit there and be able to listen while I can vent" and talk about what's going on for me. And often in my experience working with family members, that can actually be a massive relief to hear that, 'cause it takes the pressure off trying to fix anything, and it means that they can just focus on being there, and it gives a sense of clarity around, they know what you want, they know what you're sort of needing. OK.

And then finally, I wanted to talk a little bit about the impact of breast and gyne cancers on identity. Cause I think that all cancers have impacts on your sense of self, but breast and gynaecological cancers in particular, can have really significant, tangible and intangible changes to your sense of self, because the treatments can be so invasive, and at times there can be surgery and treatments that change your body in a way that may not align with your sense of yourself as a woman, or as a person. And that can be really, really confronting, and difficult to approach and cope with. So there can be tangible

changes in terms of the cancer with your body, there can be intangible changes in terms of your sense of femininity, your sense of self, your priorities, what you feel is important in life. So, these are just a couple of quotes from people talking about their experience with cancer, saying, "I don't know who I am anymore. What I thought was important, I don't really care about now." "I feel so lost, and alone all the time. And I think this can be a really deep issue. It sometimes can be missed. Sometimes we're looking more at surface stuff like managing symptoms, and getting back to a routine, and I think we don't always create a space for people to be actually able to explore what's happened for them internally in terms of their sense of self, and what matters to them in their lives.

So, of course this is something that is really, really deeply personal to your sense of yourself, your sense of womanhood at times, and so there's no right or wrong way to negotiate that process. But I think that, what I would say is that, what I've kind of found in talking to people is that, it helps to bring to that process, a sense of intentionality. So rather than just having this sense of, "Well everything's changed, and I don't really know what to do with it." However you choose to process it, I think it helps if you go into it with an awareness that there will be changes, and awareness that those changes can be really difficult, and just an openness to actually exploring aspects that you might've lost, and aspects that you might've gained. So, doesn't matter exactly how you do it, but I think it does matter to bring a sense of intentionality to it, and to create space for that exploration within yourself.

So having said that there's no right or wrong way to progress with any of this, I thought that just in case it would be helpful, or in case it helps to have a little bit of structure, I just mentioned a couple of exercises that can be helpful at times to work through some of this, and some questions that can be helpful to kind of ask yourself. So, both of these are probably best done at a time when you have a bit of quiet space for yourself. And this first one is really about, sitting down and exploring what your roles in life are at the moment.

So looking at the major roles and sense of purpose that you have in life. So there might be a sense of, you might have a parent, maybe a partner. You may or may not be a worker or have a sense of career. You may have hobbies, or passions that are really important to you, and make up a big part of you. You may be a friend, you may be a sibling, a family member.

So to really get a sense of a mind map of who you are, and the roles that you play, and



then just at your own pace, in whatever way works for you, to kind of work through and explore some questions around that. So to look at first of all, what is still there? What aspects of myself, what roles for myself were there before I was diagnosed that have been there and carried throughout my treatment, that are still here now? And that's really important to give yourself a sense of foundation and the sense of stability. And then from there, opening up and exploring and look at, Well, is there anything that has changed?" Is there anything that's altered about me, about my roles, about what's important?" And once you've kind of explored the changes, then you can look at, Well, from here, where do I want to go? So what do I want to change from here, and what can be strengthened?" And is there anything that can be added to my sense of self, to give me" a greater sense of fulfilment or purpose?" Do I feel that there's anything missing that I need to kind of work towards?" And so, of course there's no guarantee that these questions will provide any amazing moments of insight, but I think that what they just do is, give a space for exploring, which can be helpful.

And the other activity that I wanted to chat about just quickly, was around values. So, values are really the fundamental principles that we use to guide our life. So I might say that one of my fundamental principles is that, I'm hardworking, and I care about being kind. So, it's not about states or emotions that you want to chase, but it's about principles that you use to live your life, and to be the kind of person that you want to be. And values can be a really nice thing to come back to when you're not feeling sure about yourself, and you're not feeling sure about the changes that are there. Because it just puts a compass into your hand, to give you a sense of direction. So it can help to think about different areas of your life, like your health or work, relationships, family.

And in each area, think about, what values do I bring? What principles and guiding lights do I bring to this area of my life? What do I want my life to be like, and how do I want to be as a person in each area? And if you do that, it can kind of create a bit of a mind map like this. Like this person's looked at relationships, spirituality, work, and leisure, and you can see in relationships for example, that they're valuing connection, generosity, caring, and loyalty. And once you've got some words to put to what's important to you, it can give you a bit more of sense of clarity around who you are now. But it can also give you a bit of a sense of future direction. So if you say, "Look, I really value connection, but through" my treatment experience, I've kind of dropped off the radar quite a lot" with a lot of my friends, and I haven't really felt that I've had the space" to be able to connect. And that gives you a bit of a sense of possible future momentum and direction when you can say, Well, this is a value that's important to me. Maybe this is why I've been feeling a bit off-kilter in my relationships." So this is something that I'm

gonna work towards now" because I can see that it's one of my compass directions."

OK, so that's really about it from me, in terms of looking at some of the most common emotional impacts from cancer. So, if anyone has any questions or comments, please feel free to feed that through into the chat. But, otherwise I'll just say this, been a real pleasure to be here, and to be able to talk to all today. I think it's something that is just so important, and sometimes a little bit unrecognised.

And it doesn't look like there's a huge amount, sort of coming through in the chat, so in that case, yeah I'll just say thank you very much, and I think I'll hand it back to the lovely Anna, for some more hosting duties.


ANNA GORDON:

Thank you Keely for your wonderful presentation. I hope it was valuable for people listening. I certainly learnt some things I didn't know before. I would like to now introduce our next speaker, and that is Margaret. And Margaret will tell you a little bit about the different supports that are available through Cancer Council Queensland. Margaret is a Cancer Support Coordinator for Brisbane Metro region, and her role includes engaging with health professionals and communities to raise awareness of our information and support services. She is also responsible for organising community and health professional information sessions, similar to this one, and coordinating volunteers within Cancer Council's peer support program. So she does quite a few different things, and anyway, I'll hand it over to Margaret now.

MARGARET NUGENT:

Thank you Anna. It's a privilege to be here with you today, and to talk to you about the support and information services offered by Cancer Council Queensland, to people affected by cancer. Because one person is diagnosed with cancer, every 20 minutes in Queensland. Cancer Council Queensland, we understand that the cancer diagnosis can have an enormous impact on an individual, and their family. With generous community donations, Cancer Council provides support services to Queenslanders affected by cancer, from patients, to families, to caregivers, and to health professionals.

Cancer Council Queensland provides a number of emotional supports and programs. 13 11 20 is the telephone number for any support or information about cancer. It's the gateway into our services. We also have regional cancer support services across Queensland, peer support, Cancer Counselling Service, and PalAssist.



Just want to tell you a little bit more about our number, 13 11 20 because we want to provide a clear gateway to our services, because we know that being diagnosed with cancer or supporting a loved one with cancer, can leave you with many questions. We want to help you find the answers. Our cancer support coordinators, like myself, and the ones on the telephone at 13 11 20 are trained health professionals who can provide cancer information, practical and emotional support, and appropriate referral to Cancer Council Queensland programs and services. So you can call this number 13 11 20 to speak to a cancer support coordinator about anything at all to do with cancer. So, it might be from smoking, that you might, people in the unit next door might be smoking, or your child might be spending too much time outside without a hat at school, and you're worried about that. Call us on 13 11 20 for more information. It's free and confidential service, and is available Monday to Friday, 9am to 5pm, excluding public holidays.

So we provide support in the community, to our Queensland community. We offer face to face support in our offices and hubs, available in the regional offices, and computation lodges across the state. So you can see there, Brisbane, Cairns, Townsville, Rockhampton, Bundaberg, Sunshine Coast, Gold Coast, and Toowoomba. And again, our cancer support coordinators work there and are available to you to talk about services, such as our Cancer Counselling Service, or to provide emotional and practical information support. We also have trained support volunteers who lead in the delivery in some of our programs.

One of those programs is peer support. Our peer support services are free, confidential, emotional, and informational support. Through our peer support programs, we provide a non-judgemental listening ear to patients, their carers and families, based on their shared cancer experience. We have face to face support with volunteers who are available within Cancer Council Queensland accommodation lodges, or in selected treatment centres and hospitals across Queensland. Most hospital-based peer support volunteers are found in the chemotherapy wards, but sometimes they're also found in surgical wards and day centres. Cancer Connect is our telephone peer support service, which aims to connect you, or your carer, or loved ones, over the phone with a trained volunteer, who has had a similar cancer experience to you.


So it's a one to one, telephone-based support service, which is provided free of charge. We match people with trained volunteers, who share a cancer-related experience with you. You may be looking for a volunteer who has experienced a similar diagnosis, or treatment as you, or would like to talk about how cancer's affected your family. You

might be a mum with two children, and you want to talk to another mum who's worked out how to communicate well with their children through the cancer experience. You might want to talk about your professional and social life. We'll match with you based on the specific topics that you would like to discuss. Each match is allocated a maximum of six phone calls. Though not all matches feel that they need to use all the six phone calls. Where a match is not available, this service will direct you to other support services.

As Cancer Connect's actually a national program, we can match you with volunteers right across Australia and New Zealand, and that means that we have a diverse pool of volunteers to draw from, which helps to ensure that we match you with a volunteer that most closely suits your needs. If you've experienced cancer as a patient or as a close personal carer to the cancer patient, you might be eligible for our peer support program, with our volunteer roles in the hospitals or the lodges, or in Cancer Connect. If you'd like to know more about those volunteering opportunities, please visit our website at www.cancerqld.org.au or contact our volunteer hotline on 1300 851 957.

Our Cancer Counselling Service is an exciting program that I love to talk about. The Cancer Counselling Service is a cancer-specific service, staffed by nurse counsellors and psychologists, and Keely who spoke earlier is one of those psychologists. The service is open to anyone experiencing distress as a result of their cancer experience, and that includes patients, their family, friends, and health professionals. You're able to ask to access our Cancer Counselling Service by calling 13 11 20 the number that we talked about before or emailing 131120@cancerqld.org.au and requesting a referral. Sessions are available via the telephone, with Skype availability, and face to face in selected regional locations. Sessions are appointment based, and of approximately 50 minutes in duration. Most sessions are Monday to Friday, 9am to 5pm, but there are a few after hours sessions available. So we try to extend this service to meet the needs of everyone. So there's sort of things that you might like to talk about in counselling, are adjustment to diagnosis, decision support, stress management, and coping skills, sexuality and body image, the sort of things that Keely's just talked to us about. Relationship and communication difficulties, cancer-related depression and anxiety, and fear of recurrence.

Cancer Counselling Service also provides some group programs and workshops throughout the year, that may be of interest to you. Our Living Mindfully, which is mindfulness meditation program, runs for eight weeks. Our Introduction to Mindfulness and Learn to Relax workshops are sort of half-day workshops for Introduction to



Mindfulness, and two and a half hours for the Learn to Relax workshop. Each of these programs provides an opportunity for people to learn skills to help manage their emotions and increase their availability to cope with the challenges of cancer. So they're great programs to become a part of. Information on upcoming events is available by calling 13 11 20 or accessing our website. And we do have a few programs coming up, so if you're interested, do follow that up. A member of the team will respond to all referrals within 24 hours. Another service that we offer, is PalAssist, which is a 24-hour accessible hotline. Sorry, I forgot to move on. For anyone that's experiencing life-limiting illness or condition, or their families and carers. So this is the only service offered by Cancer Council Queensland, that is not only for people with cancer, but is actually available for all life-limiting conditions. PalAssist is staffed by registered nurses, and allied health professionals, with palliative care assistance, and also like 13 11 20, offers emotional, practical, and information support, and referral information for Queensland palliative care services, and the facilities.

We really recognise at Cancer Council Queensland, that there is a plethora of information out there, available by Dr Google. So receiving quality information about cancer and cancer treatment options, is vitally important, and may assist you if you're more in control and prepared for what's happening. Cancer information is not designed to replace the information that you're getting from your health professional, or your treating doctor or care team. We do encourage you to talk with them and ask questions to them about any questions or concerns you have, but designed to complement those services, and to help you, at your own time, have a look at some of the information that we've got. And the way to access those resources and publications, is they're available via download from our website at no cost. So I'll just remind you again, that our website is cancerqld.org.au.


Each resource is regularly reviewed by cancer experts, so you can be confident that you're receiving the most up to date information. Depending on what you need, we can talk to you and our cancer support coordinators can provide information over the phone. So you ring us, and we can talk to you about what's available, and then send you links, or connect you with the information by sending it free of charge. Most of these resources are available on our website and can be downloaded and printed. And we can also post these resources to you. As with all our services, contact Cancer Council Queensland on 13 11 20, Monday to Friday between 9 and 5pm for more information and resources. So, we remind you that you can also talk to your health team, and they also may have some various resources. So the sort of things that you might be interested, that we have resources on, is cancer information on different types of

cancer, treatment and side effects, coping with cancer and the emotions of cancer, life after cancer, and practical support and information.

Another thing that we do provide support and information to our community, is to help keep you more informed and learn strategies for coping with cancer, which can assist you during your treatment and recovery, is to provide support and information sessions. We offer a range of them across the state, and this webinar fits into that as well as ones that we conduct face to face. We have ones coming up next week, and later on in the year for specific cancers. They're conducted in a supportive group environment, and so you can feel free to come with you and your partner, and family and friends, and become more informed about the particular session that you're interested in. They're provided at no cost, and cover a range of topics, including treatments, survivorship, coping tools, and mindfulness meditation, that kind of thing. So once again, onto our website or 13 11 20 for more information on those upcoming support and information services.

So we work with our community as well. People who are experiencing cancer, and health professionals, we run community activity programs. These are activity-based peer programs, available across Queensland, different groups in different centres. These groups bring people together who've been affected by cancer, to participate in regular physical leisure activity, and they're led by trained Cancer Council Queensland volunteers. So, some of our groups undertake physical activities, including yoga, tai-chi, walking, or leisure activities such as book clubs, singing and art sessions. So, we're always looking for volunteers for these as well, so if you'd like to know more about our volunteering opportunities, visit our website, or contact our volunteer hotline on 1300 851 957.

Another thing that we put people in touch with independent community support groups. Some of you might feel that a way to navigate your cancer, is to join a support group. So there's a range of independent support groups being run across Queensland, and all of these groups are independent of Cancer Council Queensland. We don't run groups ourselves. Some support groups are run by professionals, other are run by people who've experienced a particular type of cancer. For example, we know of breast, prostate, brain cancer support groups. While others are based on accessibility for certain regions and can be more broad. Groups can support patients or their family members and carers, and some groups welcome everyone who's experiencing or affected by cancer. Most support groups are run face to face, and others are online or over the telephone. So, once again phone 13 11 20 and speak with a cancer support

A large, bright yellow graphic element in the bottom right corner of the page, consisting of a curved, irregular shape that tapers towards the bottom right.

coordinator, who can help you to find the right support group relevant and accessible to you.

So, part of what Cancer Council Queensland does with the money that is fundraised by our community, is to fund practical support services aimed at reducing the burden of cancer for Queenslanders, and some of these are transport services, accommodation lodges. We run a wig and turban library, we make breast prothesis, and we prefer to legal and financial information, because we recognise that these are all part of the burden of cancer. You can inquire about any of these programs by phoning 13 11 20.


So our transport services. Airport arrival and departure transport services provided at no cost. Cancer Council branded vehicles meet people coming to Brisbane or to Townsville airports for treatment, so they will meet you at the airport, or at the train station, and the patients and their carers can then be transferred to either their treatment facility, or to their accommodation. For all Brisbane bookings for this service, phone 13 11 20, and in Townsville, ring the Townsville Lodge. At our accommodation lodges, which we have a few of across the state, and I'll talk about those in a minute. We have courtesy transport services, which are provided at no cost. So each lodge provides the specific service information, and buses run from the lodge, or vehicles run from the lodge to transport facilities, treatment facilities throughout the day. So inquiries for that are 13 11 20, and bookings are made direct to each lodge. Transport to treatment is a service which is relatively new service, where referral is made by a health professional, and it's aimed to help Queenslanders facing hardship in accessing treatment, because of financial hardship or difficulty in accessing transport. All inquiries regarding this transport service need to be directed to 13 11 20, and this service is delivered by transport volunteers. So we're thrilled with that, and currently available in Brisbane and Cairns, and excitingly starting in Townsville soon.

We also provide a home-away-from-home. So, we provide accommodation lodges that are independent living facilities in several centres across the state, close to treatment facilities in Brisbane North, Brisbane South, Toowoomba, Rockhampton, Townsville, and Cairns. Bookings are made direct to those lodges. Accommodation at no cost for those eligible for the Patient Travel Subsidy Scheme. Each lodge provides courtesy transport to treatment, that we mentioned before, and access to the cancer information, and support at the cancer support coordinator's view. So, their home-away-from-home includes self-contained unit with cooking facilities, onsite parking, so it really can become your home-away-from-home, while you're having treatment, and as long as you need it. And all of our lodges are of course 100% smoke-free.

Another wonderful service that's offered by Cancer Council Queensland, is our wig and turban service. We understand that hair loss is a common side effect of cancer treatment and can be very distressing. So we run wig library, which is a service offered free of charge, where people can come and choose a wig which is theirs to use as long as they require. The service is delivered by trained volunteers, and bookings are by appointment only, and can be made by phoning 13 11 20. Wigs are quality synthetic wigs and are kept in excellent condition. It really is, and a huge variety. It's so much more than what I imagined it would be. Wigs are kept for as long as needed, and then returned in addressed post bag. So once you're finished with the wig, it can be just popped into that post bag and returned to us. Turbans are not returned, they are yours to keep. So, we do want to let people know that we accept quality synthetic wigs as donations, but we don't accept donations for human hair. All our wigs are synthetic. Turbans are sewn by volunteers as well. So community members are welcome to sew for the service. And if you'd like to do that, give us a call on 13 11 20. We actually have wig library centres in Brisbane, Gold Coast, Toowoomba, Sunshine Coast, Bundaberg, Rockhampton, Mackay, Townsville, and Cairns. But do remember to ring 13 11 20 to make a booking before you come.

Another service that we support people with, is breast prosthesis. They're available, made by volunteers. You can request them by phoning 13 11 20. Our temporary breast prosthesis are fabric, and made with soft fill, and are sewn by community members. And they're to help you while you either wait for reconstructive surgery, or for a permanent prosthesis. And also we accept volunteers to sew for this service. So once again, if you're interested, 13 11 20.

One of the things that Cancer Council Queensland recognises, is that financial burden can be a big issue for people affected by cancer. Queenslanders facing financial hardship in accessing treatment can be supported with information and referral by phoning on 13 11 20, Monday to Friday, 9am to 5pm. And, what happens if you do phone us, this referral will be made back to professionals on the treatment team who will allow a full assessment of the situation, to ensure that you are getting the help that you need. We can refer into a pro bono service, which is where professionals volunteer their time to help with issues that we're aware of that affect cancer. So, there's a few prongs to that. Lawyers offer their time, financial advisors, small business accountants, and human resources and recruitment specialists. So this service can help with drafting wills, early access to superannuation, mortgage, hardship variations, credit and debt issues, insurance claims and disputes, managing workplace issues, budgeting and debt management. So there's a lot of things that we understand can be a by-product of



cancer experience. So do call us on 13 11 20, if that's something that you think that you could benefit from assistance with, or you know someone that will.

So, coming to the end now, that's a wrap up of most of our support and information services. Help us make sure no Queenslanders face cancer alone, that's our mission. There are many ways you can get involved, supporting us as well as receiving information from us, by volunteering with us, hosting Australia's Biggest Morning Tea, or take part in Relay for Life, or Daffodil Day, or just make a regular one-off donation. We're thrilled with that. However, your support and help really do help us to fund vital cancer research, run lifesaving education programs, and support for thousands of Queensland families affected by cancer each year. So thank you very much, I'll hand it back to Anna to finish off and take any questions that you might have and thank you for listening.

ANNA GORDON:

Thank you Margaret for your wonderful presentation. I just thought we can wait a couple of minutes to see if anyone has any questions, before we'll wrap up. So please feel free to type them in the chat box, or if there's a question you think about later once we finish, you can always call 13 11 20. As Margaret said, any cancer related question, just feel free to call. So I might give it a minute, and then if no questions we'll wrap up and let you all go and enjoy your day. Any questions? It doesn't look like anyone's typing any questions, but as I said, 13 11 20, we'll be able to help you answer any questions you might think of later.

I'd like to thank both Keely and Margaret for their wonderful presentations. And also thanks to everyone who attended. I hope you found the information valuable and helpful. And we have several face to face support and information programs, similar to this one, happening across the state in the coming months, so if you just go on the website, it'll have all the upcoming dates, and you can register and find out what they're about. Shortly after this webinar, we'll email you evaluation forms. We would really appreciate if you could complete the forms, as it helps us when we develop future programs, on how to improve them, what topics to do them on, that sort of thing. So if you can complete the forms and send them back to us, we will really appreciate that. That brings us to the end of this webinar, thank you so much for attending, and have a great day.