

Living well with cancer at Christmas

A podcast by Target Ovarian Cancer

Jessie: Hello and welcome everyone! I'm Jessie and I work at Target Ovarian Cancer and I'm here with Katie, who is our Information and Support Manager and Val, who is one of our brilliant Nurse Advisers and we're going to do a podcast today looking at some Christmas and holiday themed questions that you might have if you're living with ovarian cancer, or just any cancer, really. Katie, can you tell me a little bit about why we wanted to do this podcast today?

Katie: We know that Christmas can be a very difficult time of year for lots of people, it's so busy, there's lots of pressure to get things right, cook the right food and buy the right presents. And obviously that gets harder with a diagnosis of cancer, so we wanted to address some of the questions that people have and hopefully provide a bit of support at this time of year.

Jessie: We haven't seen a lot of information on this topic online actually, so hopefully this will be helpful to some people.

Val: And already we've seen the questions we get on the Support Line start to include elements of worrying about the festive season.

Jessie: Also, the questions we talk about here are framed through Christmas but potentially the emotional issues could crop up at many other times of the year so it may be useful at holidays or other big occasions. So shall we get started with the first question?

Katie: So one of the questions that we've had is around feeling the responsibility to be your best self all the time at this time of year. It is: I want to see my family and friends but I get so tired, how can I tell them?

Val: So this question comes up time and time again all year round. Christmas as we all know is a time of excess, and we often try to cram in as much as we possibly can. After a new diagnosis of ovarian cancer, you and everyone else around you might be in shock still, and if you're further into your diagnosis then perhaps you're coming to terms with things and you and your family all want to be together to rejoice in that and make the most of it. My first thing to remember would be that there are 12 days of Christmas and not just two, I think we're all very guilty of doing everything on one or two days like Christmas day and Boxing day. Think about spreading time out over Christmas, and do a little bit every day rather than trying to cram everything in at once. Try and talk to someone close and explain that you'd love to see everyone but that you are feeling quite exhausted and you just

might not be able to manage it. Get someone to act as your spokesperson and think about setting time limits on things, a bit like how hospitals have waiting hours because they recognise that you need some rest after a little bit of 'on' time. Having visitors, as lovely as it is, is exhausting, especially if it's at your house because you become the host and it becomes your responsibility. Getting someone to put those things in place for you is very helpful because it can be difficult to do that yourself. We all suffer a bit with over politeness and we'll struggle on rather than risk offending people. Remember that normal rules don't apply at the moment, you have to make time for yourself and you have to prioritise your health. People will understand that – you just have to be brave enough to tell them. You'll also find that people are understanding and that people like to have boundaries set. If you or your spokesperson is able to put those boundaries in place, people will appreciate that because quite often everyone is trying to do the right thing but isn't sure if they are. If you're able to set those boundaries you might find that it creates more of a relaxed Christmas, and a bit of – normality really.

Katie: I suppose it's a way of making sure that your cancer isn't the focus of Christmas.

Jessie: That's such a good answer to that question Val, and I guess it's so ironic because you're worrying about saying something to people, and they're worried about whether they're doing the right thing. If you just tell them what's best, well, then they know!

Val: Everyone tends to circle round and everyone's worried about sensitivity, and that's how it goes wrong so often, because no one's actually saying anything. Actually, it's up to the woman herself to say what she'd like, and then everyone is so happy to have some kind of guide.

Katie: So just following that up, you mentioned there's practical tips in terms of setting visiting hours and things, is that the same whether you've been newly diagnosed or whether you're coming out of treatment? Is there anything people should be aware of in how they're feeling at this time of year?

Val: I think the answer to that is that there is no right or wrong answer, everyone will want to do things in different way. It's all about what's right or wrong for you, so just keep that in mind. It's about the individual.

Katie: So Val, Christmas is a time of excess in terms of food and drink as you've already mentioned, but also in terms of presents and visitors. Have you had any calls to the Support Line about that sort of thing?

Val: Actually yes, we had one lady who called the other day and was talking about how much she loved this time of year and how much she loves buying presents, but that this year she really doesn't feel like she has the energy to do that. Now, it's a huge cliché but if you're worrying about the same

thing, what you have to remember is that Christmas isn't all about presents. For most of us, Christmas is a massive time of stress, and if we're not careful then the essence of the festive season can get lost in that, which I'm sure anyone would agree with. Then obviously those feelings are going to be so much more magnified if you've just had a diagnosis of ovarian cancer, you're going through treatment, or you're living with ovarian cancer and navigating around those obstacles. Perhaps this is a time for a positive change - let's try and put a positive spin on it! Everyone knows this has been a difficult time for you and what they won't want is for you to push yourself too hard. If you can show your loved ones that you're taking Christmas in your stride, then that will help them to worry less about you.

Katie: If there are things you still need to get, presents to buy etc, do you have any practical tips to make the physical act of shopping any easier?

Val: Yeah, having just stressed all the negatives of Christmas, for me present-buying is actually a joy. Although we're saying, you know, don't push yourself too hard, for a lot of people it is something they want to do. Shopping locally is something that we're all being encouraged to do, helping your high street and so on. For anyone it can be a good thing to slow down and think more about that way. If you're shopping locally you don't need to plan a big trip into town, you can just set aside an hour to take a look, give yourself a cut-off point knowing you can do another hour later in the week. If you don't feel up to it, obviously you can get so much online nowadays, a cup of tea by the fire and a browse online can be a lovely way to spend an afternoon. For women who are in treatment at the moment, the long hours in chemo can be a good time to flick through your phone, pick up a few things, maybe make some decisions on menus and presents etc. But the big take home message is that we should try to accept the perfectionist ideas about Christmas, and accept that good enough really is good enough.

Katie: We have a blog on our website that has top tips on chemotherapy from women with ovarian cancer and I think plenty of them would agree that using it as shopping time is a great use of those hours!

Jessie: Those practical tips are really useful, and it's good to remember how much more accessible everything is now, you know some of the shops are open til 9/10pm on certain days. There's lots of times when it might be quieter and less stressful.

Katie: So our next question is a very important one, it is: can I have all of the food and drink at Christmas?

Val: That is a very important question Katie, you're right! Now, the short answer is, yes of course you can. Eating and drinking is one of life's great joys, and never more so than at Christmas. If you're feeling well and your appetite is good then just enjoy it, make the most of it like you would any other time of year. If your appetite is poor, then don't feel under pressure to eat and drink large amounts. A practical tip would be if someone else is cooking then just ask them to give you a small amount of food. You don't want to feel under pressure to eat everything out of politeness if you're not feeling able to. Another thing is just to be kind to yourself, there's no right or wrong, have whatever you fancy. If you just feel like roast potatoes and gravy then go for it, if you want to skip the main course and go straight for pudding then do. The emphasis should be on enjoyment, that's what Christmas is all about. It's not about nutritional or calorific value, just forget that for a few days. Everyone else eats, drinks and is merry, so why not you? And in fact – especially you!

Jessie: That's actually made me think about what you said earlier about Christmas not just being one day. I don't know about you but I love the Christmas canapes and stuff, and you can have all of that all the way through December, so it's all about not being strict with yourself.

Katie: Christmas is an intense time of year, with all of the food and drink and the pressure and all your loved ones want to make sure you're well fed and having the best time. Do you have any advice on how people might deal with the emotional stress that comes with needing to be on top form all the time?

Val: I spoke to a lady a few weeks ago who was asking how to talk to her family about how she wants to enjoy Christmas but she's also feeling sad and overwhelmed. We talked for quite a long time and my advice was that honesty is always the best way to deal with any situation. It can feel like the difficult option but it's not in the long run. If you're feeling sad or overwhelmed and you try to hide it, it just won't work. It will only make people worry more. You end up with a situation where 2 and 2 adds up to 10. Tell people that although you want to enjoy Christmas, it does come with some difficult emotions. A good idea might be to plan some quiet time, like we talked about in the other questions, where you can escape and have some time to yourself. You need a rest from being your best most jolly self. So perhaps if there's a trip out somewhere maybe you say "okay well let's all have a coffee together in the morning, but then you lot go out and enjoy the walk and I'm just going to have a sit by the fire and chill out". Time for reflection is always helpful. If you're honest and open about your feelings then that will help them to help you. Sometimes people just need permission to allow you to not be jolly, because they see it as their role to make sure you're cheered up all the time.

Katie: So I guess what you're saying then is just give yourself and your family permission that Christmas day is just like any other day where you can't control how you're feeling physically or emotionally, and however they feel or you feel - it's all okay?

Val: Yeah and if you chat about that beforehand then everyone's on the same page and no one's worrying about anyone else.

Katie: Following on from that we have another question which is a really difficult one. Christmas is a time spent with family and friends, and that might surface some worries about the future and what that holds. Do you have advice on how someone can make the most of Christmas?

Val: Any big occasion like this, can be wonderful times, but for women with ovarian cancer they can be very emotive times as well. Thoughts might come in and out all year round, but at this time of year they can come bubbling up and reach tidal wave proportions. It can force you to confront the fact that time is limited. We all assume the luxury of time and we don't appreciate that it actually is a privilege. Once you have a cancer diagnosis that privilege is lost, and your absolutes are challenged. We all do it where we say 'I'm going to go on a world cruise' but that's just at some time, you know, we assume we'll do that one day. Other women who have been diagnosed a while ago might have been through a few Christmas' already and might be thinking that this could be their last, and those are emotions that women have expressed to myself and Joan, the other Nurse Adviser, at all different times of year, usually brought on by a major event coming up. My advice would be to live in the now, which is very easily said and almost a little bit trite, but I think it's something that all of us should take heed of. Try to look at the facts - you are here now, you might not know what the future holds for next Christmas, but you do have the privilege of this one. In truth, none of us know what next year's going to bring. Some women listening to this will have no idea about the changes that were going to come this year. Perhaps you're feeling guilty because you don't feel you appreciated all the things you had last Christmas, but don't feel guilty, just focus on enjoying as many of the positives of this Christmas as you can. Some of you will have spent last year worrying about not being here this Christmas, and now here you are, you are here this Christmas. I think a lot of women talk about planning ahead being very difficult after a cancer diagnosis, and they don't have the confidence in their own health to do that. We're only a few weeks away from Christmas, so for most people, nothing much is going to change. So enjoy it, make the most of this wonderful time because it is nearly here. Take a mindfulness approach, take it slowly, notice as much as you can, put away thoughts of the future. Give your mind a holiday, and once Christmas is over you can pick it all up again and start to think about the future, but for now, just put all that aside.

Katie: I love that idea of giving your mind a holiday.

Val: We could all do with that couldn't we! But it is true, women call up and they say they're worried this might be their last Christmas and, well, it might be. But I usually say 'did you think that last year' and they say 'yeah I did actually' and I say 'and you're here now'.

Katie: Women must feel quite guilty about worrying about their feelings, and the fact that they might feel preoccupied with worries about next Christmas when this one is happening now. Especially when everyone else is in the Christmas spirit.

Jessie: I think family and friends can all be feeling that way and can take on board some of the advice you've given their Val. One gentleman that we've done some work with, he said something which comes to mind now which is that 'life is uncertain, with cancer it's more uncertain'. Cancer diagnosis can bring those feelings to the forefront, but it is true for all of us, we don't know what's coming next.

Katie: Yeah you've got to make the most of it.

Jessie: Thank you so much for that Val. We have quite a lot of information and resources on our website targetovariancancer.org.uk, but also, do remember that Val, who has been giving all of the advice today, is one of our Nurse Advisers. She helps run our Support Line, which is available 9-5.30pm every day for any ovarian cancer questions or concerns. Do you have anything you want to finish on?

Val: Well for me the biggest message I'd like to give, for women at any stage of their diagnosis, and for relatives as well actually – and that's to have the Christmas that you want. Don't feel under pressure to have the Christmas anyone else wants, don't feel guilty about anything, which is impossible I know. I just want to wish you all a very happy and peaceful Christmas, and remember there is no right or wrong way to spend it.