

Ovarian cancer, sex and intimacy: transcript



*This is a transcript of a conversation between Katie from Target Ovarian Cancer and Lynn Buckley, Clinical Nurse Specialist and Psychosexual Therapist, about the impact of ovarian cancer on sex, intimacy and relationships. To download the recording, or for more information on this topic, including our **Ovarian cancer, sex and intimacy** information booklet, please visit targetovariancancer.org.uk*

Katie: A diagnosis of ovarian cancer and the resulting treatment can cause emotional and physical difficulties which can impact on your sexuality, sex life and relationships. My name is Katie and I'm Information and Support Manager at Target Ovarian Cancer and I caught up with Lynn Buckley, Clinical Nurse Specialist and Psychosexual Therapist, to talk about what physical and emotional issues you may face and how you can seek help and support. This podcast was recorded at our Supporting You event in Cheltenham, during a tea break, so please forgive the clattering of tea cups during our chat...

Katie: Hi Lynn, thank you so much for joining us here today.

Lynn: Hi Katie, thank you for asking me to sit down and talk with you about this really important topic.

Katie: So we're just going to start by asking, what impact can an ovarian cancer diagnosis have on sex and intimacy?

Lynn: Well, for some women it won't have any impact at all: their sex life will go on as it were before, they won't find any changes. For some women it might be that they want to have sex more frequently, because they want to feel closer to their partners, and for some it may have a massive impact where they don't want to be sexual at all. If that's OK for the woman then that's OK – and for her partner, obviously.

From an emotional point of view some women may feel that they need to be closer to their partners. Some women may feel like they really need to avoid sex. Some men may not want to push a sexual relationship on their partner at this point and often there might be missed messages between the two. However, it's important to find out what's right for you as an individual, as a woman, and for you in a partnered relationship.

Physically though, there may be some changes that can cause sex to be more painful, more difficult, different to how it was before, and these can be increased tiredness or fatigue because of treatments you're having. So they may be things that will come and go throughout your treatment, or come and go throughout the rest of your life. Just like anybody else who maybe hasn't had cancer, sex at some points is really important and at others it isn't.

Katie: I think that's so important to keep in mind. We have lots of women who ask us, "Is how I am feeling normal?"

Lynn: Yes! There's no book that tells us how we should feel so - you are an individual; you have your own background; your own beliefs; your own values; you have your own feelings and emotions and history that makes you the person you are and having cancer can change that, so you know, it's normal for you, there's no textbook. You may not even be thinking about sex - but I'm presuming because you're listening to the podcast, sex is on your mind.

Sometimes feeling sick, when you're having chemotherapy, might not make you want to kiss your partner, but if you're not kissing a partner then you might not want to have sex with them either, because you haven't got that closeness at that moment. As we said before, there may be some short term experiences that, once you've finished your treatment, they go back to normal. You may have a changed body image because you've lost your hair, there could be lots of things that are affecting how you're feeling so, yeah, how you're feeling is normal for you. Just be kind to yourself though and give yourself a bit of a break, it's OK to be you.

Katie: If women are thinking, I have had a diagnosis but I still want to have sex, I'm finding it really difficult though, is there any advice that you can give them?

Lynn: There could be lots of reasons why sex is difficult. It could be from a physical point of view or it could be emotional, it could be that your head and your body just aren't connected at the moment, because there's a lot of other things happening, and often you tend to avoid intimacy if you don't want to be sexual. So there may be some strain put on your relationship with your partner because that relationship's changed - they're maybe trying to care for you and they don't want to hurt you - so there could be lots of factors that are affecting how you are sexually.

It could be that there's problems with being aroused. It could be problems with orgasm. It could be that you've gone through the menopause which can affect things - so there are lots of things that you can do to help yourself. Using vaginal moisturisers if you've gone through the menopause, regularly, not just during sex or, when you're being sexual, using vaginal lubrications. What you should do is speak to your Nurse Specialist to get some help and advice for that.

The other thing that's important is sitting down and talking to your partner, seeing what's special and important for the two of you and working out how you want to be and where you want to move forward. If you haven't got a partner, there's nothing wrong with wanting to be sexual on your own. If you're in a same sex relationship then your sex may be different because you're not wanting to use sex aids at the moment, but keeping that intimacy is really important.

Katie: So what about if sex is painful, specifically, and some women are worried about all aspects of penetrative sex because of the pain that it might cause?

Lynn: Well if sex is going to be painful it's going to affect your desire so you're not really going to want to have sex if it's going to hurt - why would we want to put ourselves in that situation? What often happens is, if we imagine that something's going to hurt, we protect ourselves so our bodies will brace. So you've got muscles in your vagina and they may tighten which would make it hard to get anything in there, basically. Learning how to relax that pelvic floor muscle can help, using vaginal moisturiser as I've already said, but using vaginal moisturiser regularly.

It might be that you can have HRT but this is something you'd need to discuss with your health professional to make sure that it's not going to affect any of your treatments or any of your risk factors from the ovarian cancer.

During sex you need to make sure that you're fully aroused so lots of foreplay, using lubrication - there are different ones, such as water-based and oil-based and silicone lubrication, so finding something that works for you. And there's different ways of using them - so if you're going to use condoms you shouldn't be using oil-based lubricants. And they do advise that when you're on some of your chemotherapies that you need to use condoms so if you need some extra lubrication use a silicone or a water-based lubricant.

It's worth finding a different position that might be more comfortable. It's worth finding the time that you're not too tired to be sexual: you don't have to have sex when you go to bed. It might be

that you're most comfortable and most relaxed at 10 o'clock in the morning and your partner can have a half day on a Thursday so Thursday at 10 o'clock might be the day that you want to be sexual! Being close and intimate sometimes is more important than the penetration, there are other things that you can do – sex shouldn't just be about penetration. Sitting down and talking to somebody who can help you, such as your Nurse Specialist or your consultant, your GP or a therapist, may help to give you other specific tips depending on your specific situation.

Katie: Brilliant. So I know you've mentioned both moisturisers and lubrication - how can we go about getting hold of some of these things?

Lynn: So vaginal moisturisers, there's lots of different types, usually they come in an applicator. You can get them on prescription so speak to your GP, your Nurse Specialist and ask if you can have a lubricant. Some of them are hormonal, again you would need to check, but there are lots of non-hormonal ones that are available.

Then with the lubricants, there are different types. So often I would suggest to my clients that they use a combination: using an oil-based lubricant on the external genitalia and then water-based on whatever you're going to be putting into your vagina, often helps - it's a bit like a slide and glide situation! Or using a silicone lubrication, but again you need to be careful - if you're using condoms you can't use an oil-based; if you're using silicone, you can use that with condoms but you can't use that if you're using silicone sex toys because it can damage the material. So choosing something that works for you, checking it out on your hand to make sure it isn't going to be sensitive on your vagina or your vulva, and incorporating it into foreplay so it's not the, "Ooh just stop a minute, I just need to get the lube out!" So just incorporate it into having fun!

Katie: Brilliant! So what if there are women who think actually, I don't want to have sex at all. Is there any specific advice for them?

Lynn: If it's not a problem for them and they don't want to have sex, then don't have sex, it's OK.

It may impact on your relationship and that's something you need to explore with your partner. It may be that your partner is OK with this so for some women that don't want to have sex but their partners do, then it's about finding a middle ground and a compromise that suits both of you. And if you don't want to have sex that's OK.

It's also about deciding if you want to be intimate because sex doesn't always just have to be about penetration. It could be that you're wanting to be intimate, holding hands, kissing, cuddling and not go ahead with penetration so that's why it's important to speak with your partner as well because that might be OK with them too.

Katie: We also have questions from women whose partners are worried about having sex with them, possibly because they don't want to hurt them and they're very conscious that women have had surgery and maybe they've just, they've pulled back as well because they're thinking that sex and intimacy isn't something that is appropriate now for their partner, so what can women in that situation do?

Lynn: Sit down and talk to the partner. The partner is going through the same journey as they are – OK it's not happening to them, but they're going to have emotions that are going to be connected to it. They're going to suddenly feel like a carer at times and so the roles may have changed a little bit whilst you're on treatment, so trying to get back to that place where your relationship was before, and finding out what you both need.

Sometimes it's not what you want, it's what you need, so sitting down and talking to each other, exploring why they've pulled back, letting them know that it's safe, letting them know it's something

you want and as we said before about penetration, sex isn't always just about intercourse, it's about closeness and intimacy, so letting them know that that's OK.

For some people unfortunately relationships may take a real nosedive because of what's happening. They may not have been that good to begin with. Cancer may have just impacted on making that a bad relationship so you may need extra help - you may have needed that help anyway - but you may need extra help to see where you're going in life. In a loving relationship it's worth sitting down and talking and being open and remember that if you're going to kiss, you want to kiss your partner like you'd only kiss a partner and not like you'd kiss Great Auntie Mabel on the cheek! It's your partner.

Katie: And what about women without a partner? Is it OK to continue with masturbation and being sexual?

Lynn: Absolutely! Totally. If somebody's single, or if somebody's not in a relationship but wants to go out and have sexual relationships with other people, that's absolutely fine. This is you and your body: do what makes you happy.

Katie: And for women who aren't in a relationship and they're scared of starting a new one and having these discussions, is there any advice that we can give them, anything that they should be thinking about, is there a specific time that they should tell their potential new partner that sex might be difficult or might have changed for them?

Lynn: I suppose with new partners, you don't know what your sex life is going to be like anyway, and if you're wanting to be sexual with somebody, then you're obviously feeling comfortable enough to be sexual with them. You've just got to do what feels right in that relationship. If it doesn't feel right then take your time. If it feels right to say something when you first meet them, then tell them when you first meet them - but we don't always tell everybody our whole life stories in our first meeting, it depends on you and the person you are, because you are still that same person as before you had cancer. So being open and honest at the beginning, if they run a mile then they weren't worth it, but if you're not ready for that and you don't feel safe to discuss where you are and what you're at then wait until you do.

Katie: For women whose libido has been affected, so their sex drive is maybe different from before they had their ovarian cancer diagnosis, some women say that their libido is low, is there any advice that you can give to them?

Lynn: Yes, it may be that it's from a hormonal perspective so they could see if it was safe to take hormones again, depending on their age as well, so some women may still be able to have HRT.

You may have heard of testosterone. It is something that potentially is used but it's not used on license so they would really need to seek specialist help and it may not be appropriate for each individual woman. It doesn't always work, we do have some good success with it in sex therapy but there's lots of other things that go alongside.

Sometimes it's that willingness to be sexual. It might not be that you've got that sex drive to want to go and seek out being sexual but you would be responsive to sexual stimulus. I think a lot of women have read 50 Shades of Grey or, if it didn't affect you, you probably know a friend who would be reading 50 Shades of Grey and say "Well yes, it did something for me," - it's the same type of thing: if you're willing to be sexual and the partner that you're with uses the appropriate sexual stimulation, be that visual, be that touching, be that kissing, whatever it is, and your body then starts to engage then at some point you may still enjoy sex without desiring it in the first place. So it's willingness to be receptive. As long as it's good, you'll enjoy it and then you'll seek it out again.

Katie: And finally – I know that we both agree that sexual recovery is very important so how do women get support from specialists in this area?

Lynn: Sexual recovery - I think if we think about it as sexual rehabilitation – you know if you were having a problem like you'd broken your leg and you needed to go to physiotherapy until your leg was back [to full strength] - so why can't we do something similar for sex? So if we think about the problems you may be having as a result of your ovarian cancer and let's look at some sexual rehabilitation.

It may be that you had problems beforehand. In certain surveys it suggests that 80 per cent of the population have problems with sex anyway, it's just that they just don't seek help. So remember what your sex life was before, how it is now and what the difference between the two are and where you want to be.

So if you ask for sexual rehabilitation, for want of a better term, then there are your Nurse Specialists who can help; your consultant may be able to help; your GP, or you can ask for a referral to specialist service such as a psychosexual therapist. COSRT is an organisation (the College of Sex and Relationship Therapists) that lists sex therapists so you maybe decide you want to go privately and seek somebody out. Some areas have sex therapy on the NHS, some areas don't, so speak to your Nurse Specialist or your GP.

Katie: That's perfect, thank you very much Lynn. This has been a really brief overview of some of the questions that we've received about sex and intimacy following an ovarian cancer diagnosis, but if you have any questions we've not covered, or you would like to speak to someone about ovarian cancer and the impact it has had, please get in touch with our Nurse Advisers by calling our Support Line on **020 7923 5475** or visiting targetovariancancer.org.uk/supportline.