The Cancer Professionals Podcast

Let's talk about: Sex, intimacy and cancer

Episode transcript

(Intro music fades in)

Paul (00:05)

If we know cancer and its treatments can affect sexual wellbeing, why is it still so hard to start the conversation?

Caitlin (00:12)

Think about the person, think about the community they live in, think about the family that they're in, think about how their relationships work. Just because someone's single doesn't mean that sex isn't important to them and intimacy isn't important to them.

All of these things are really important it's about having these things in mind when we're having conversations

Paul (00:30)

Hello, I'm Paul and my pronouns are he him.

Carly (00:33)

and I'm Carly and I go by she, her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. This is part two of our three part series. Let's talk about fertility, sex, intimacy, and pregnancy and cancer.

Paul (00:47)

If you enjoy this episode, please subscribe, rate and share with your colleagues and friends. We'd also love to hear from you. Please get in touch to ask questions, give feedback, or even to suggest topics you'd like us to cover by completing the short survey linked in the episode description, or by emailing professionalspodcast@macmillan.org.uk.

(Intro music fades out)

Carly (01:09)

This episode contains conversations about the lived experience of cancer and discussions about sex and intimacy which you may find upsetting or triggering. Listener discretion is advised.

Carly (01:20)

Welcome to the Cancer Professionals podcast. Today we're talking about sex and cancer and how cancer and its treatments can affect sex and intimacy. And we know that for many people, sex and intimacy following a cancer diagnosis can be a big concern. These can be

Difficult topics to navigate and talk about. So in this conversation, we'll explore why sexual wellbeing is an important part of holistic cancer care. we are joined by three amazing guests who all bring their own experiences and expertise to this very important topic.

We've got Elvin, Jo and Caitlin. So welcome to the podcast. Let's start with some introductions. So telling us who you are and actually what brings you to talk about this topic today. Elvin, I'll start with you.

Elvin (02:06)

Thank you very much indeed. My name is Elvin, Elvin Box. I'm here today because in 2016 I had a prostatectomy because I had aggressive prostate cancer

It had a difficult impact on my sexual relationship with my loving wife. And what brings me here mostly is that probably for some six or more years, I've done a lot of work with Macmillan on the subject of sex with cancer.

Carly (02:33)

Thank you so much and thanks so much for joining. Lovely to have you here. Jo, shall we come to you next?

Jo (02:38)

Yes, hi, I'm Jo, a consultant clinical psychologist and I lead up the cancer psychological support team at St George's Hospital in Tooting in London. So I'm here because as has been pointed out already, cancer has a big impact on sex and intimacy for a lot of people and we know that this is something that those individuals want to talk about or want the space or opportunity to to explore and understand and have the appropriate support. But we also know in the shoes of healthcare professionals, there can be all sorts of challenges and barriers to having those conversations from practical ones to confidence in initiating those conversations. So I'm here to advocate and support those conversations from both sides really.

Carly (03:24)

Thank you. And yeah, looking forward to getting into that, into the conversation. Thanks, Jo and Caitlin.

Caitlin (03:30)

Hi, I'm Caitlin Harvey. I am the head of nursing for cancer at St. George's. And the reason I'm here is because part of my job is to make sure the patients get holistic care. And one of the things that we really find is this part of holistic care is sometimes really challenging for professionals. And we wanted to really think about how we give people confidence around having those conversations to make sure that patients get the best support that we can. So how do we do those bit more challenging holistic conversations with patients and open up those conversations well and that's what I'm really interested in and what I professionally when I'm looking after patients and as a leader want to want to improve.

Carly (04:10)

Lovely, thank you so much. Yeah, really grateful that you're all here talking about this today. So obviously this episode, as we know, is about sex and cancer. And I'd like to come to you, Elvin, first, if that's okay. And I'm interested, could you take us back to, you said that you were diagnosed with prostate cancer in 2016. Could you take us back to that time and walk us through how did that cancer diagnosis at that time, how did it affect sex and intimacy for you. Can you talk us through that a little bit?

Elvin (04:40)

Yeah, the operation, we were told the biggest thing I would notice, we would notice, is that I would have erectile dysfunction. And so that's pretty important when you're trying to have a sexual relationship. The other thing that went with it is that we were told my continence had a very, very good chance of coming back, but not immediately. With the erectile dysfunction, that was more complex because it was explained that to do the surgery successfully, which is ultimately to clear the cancer, there was a necessity to remove some of the bundle of nerves that give you and hold erections.

But there was very good chances that I could get back erections, maybe take two years, different ways of doing it.

We knew I could no longer ejaculate anymore. we both knew there was no more semen. was unfortunate. That's unavoidable because there's no prostate. This is what you're left with. And they mentioned dry orgasms. So the first time we attempted for me to actually get back up on the bike and to help me to get an erection, there was whee coming out. It was a whee-like substance.

And then getting to understand, well, can we control this? Is there a way of getting round this? And that was, was, so I thought,

I hopefully I'll ask the question, does that give an indication of just how difficult it was to initially get back to having full sexual intercourse

Carly (06:22)

Mm-hmm.

Elvin (06:23)

and also to be able to work through and to fully rehabilitate my reproductive system and so that we can have satisfactory sex again?

But the upshot is that it's taken... over eight years, close on 10 years, I'm still learning now how to actually overcome this. The things are unavoidable, we have to go with that. There's some things that are preventable.

And although I'm, know, yes, I'm so grateful I'm here 10 years on, can't express that. What I can't bring back is that we've lost basically 10 years of a happy sexual relationship.

Carly (07:05)

Yeah, absolutely. I was really interested to know. How did you and your wife sort of navigate that together?

Elvin (07:14)

initially for the best part of the first 12 months, we were very team like. And Jude was extraordinarily supportive and patient. And so we did everything that we had been told. And initially it seemed like we got this under control.

The challenges occurred in and around the first 12 months. I was becoming very anxious and paranoid. And I was quite a destabilized person at the time. I kept on thinking. So I was told it's going to take years, two years, two years. It's going to take two years to probably get back to 60%. It wasn't actually mentioned how quickly I could overcome the challenge of this climacotura, this urine associated trying to get orgasm. And actually when you don't ejaculate as normal, you ejaculate a urine-like substance.

Carly (08:07)

Mm.

Elvin (08:08)

the paranoia became because I thought, can't believe Jude I wouldn't want an opportunity to do this properly again. At the moment, is ham-fisted. And I was really, really frustrated. And I will be honest, we went back... This is in 2017, and we had an argument, realising we'd been together as a couple since 1973.

So getting off of 40 years later, I bring up an argument we had at 17 years of age.

And it was really, really difficult. She was trying so hard. But we were, unfortunately, not purposely, we were faffing. That lovely phrase, we were dancing in the dark because we didn't know, you know, if I only knew then what I know now, we could have put all the stuff in place. This is OK. We get back on the bike in and away you go.

And so the relationship struggled because Jude was being patient, understanding and kind and I was the complete reverse. I was the other end of the scale.

My sexuality had been hit. My masculinity had been actually thrown in the bin and it was an extraordinarily important part and still is of our relationship. It was disheartening because I was doing everything I could to get back to being fit again, working on my pelvic floor the best I could, working on my general physical fitness as well as I could, making sure that my cardiovascular was working well, heart beat the whole nine yards. And it still this stumbling block. We were both scrambling for what do do next? And do we just say, the hell?

That actually wasn't an option. That wasn't an option. We had to. We had to keep trying. And so, sexuality-wise, masculinity-wise, I felt completely deflated.

And I wish someone had said, you've got to really take it easy and you've got to really understand you're to have to project manage this, it's going to take this time, but these are the quality things that you've look out for and this is the health and safety bit.

Paul (10:17)

Thank you, Elvin. I think that was really, you know, kind of really open and honest hearing about your journey there. And Caitlin and Jo, I wonder if I could bring you into the conversation we've obviously heard... Elvin's story and a little bit about Elvin's journey, but perhaps some of the other kind of common ways that this affects people's sex and intimacy.

Caitlin (10:42)

Yeah, absolutely. So I think Elvin picks up on some really great points in what he says. And I think there's a real truth in having open conversations, which means you can get people the help they need quite early on. And I think that

Elvin (10:52)

Hmm

Caitlin (10:53)

is not just in prostate cancer, that is in lots of cancers and cancers we wouldn't expect to have an effect on sex and intimacy. So sometimes we think it's about the functional

aspects of sex that would stop us having that intimate, intimate kind of time with our partners. But we talk a lot about breast cancers because

There is some functional aspects of breast cancer treatment that will affect women becoming able to have sex in the same way and finding often finding penetrative sex quite painful after after treatment. But then also thinking about cancers, even even cancers that just change the way we look and the way we feel about ourselves, make it really difficult to become intimate with our partner or ourselves or how we feel about sex personally. So I think there is that real need for broader understanding that

there are some bigger cancers that we always see the kind of sex and intimacy piece sitting around, prostate cancer, breast cancer, but if you've had a head and neck cancer and had changes to the way your airway works, we need to be thinking about how does that affect the way that people want to then be intimate with their loved one. People want to share intimacy in so many different ways. Often we think of it in the way that we believe that we should have sex in our intimacy.

As a heterosexual, may think that penetrative sex is the way that everybody would want to be having sex and intimacy but actually it is very personal to that person. So thinking about how people are understanding that person, their relationship and how they sit within their community and their culture and thinking about cancer and sex more than just the obvious I think is a really important piece to take away. I don't know whether Jo's got anything to add to that and that's something I think we really try and get our professionals to think about, to think about more than just.

the obvious. Think about the person, think about about the community they live in, think about the family that they're in, think about how their relationships work. Just because someone's single doesn't mean that sex isn't important to them and intimacy

Carly (12:52)

Yeah.

Caitlin (12:53)

isn't important to them. All of these things are really important and we just need to make sure we keep that in mind. And it's about having these things in mind when we're having conversations with people. And how do

we open up, have that conversation and get people to the right specialist so that they can get the help and support they need. I think that's the bit that I always want to push as a message.

Paul (13:14)

Jo, is there you want to add?

Jo (13:16)

it is just thinking about things that do potentially feel less obvious, even just the side effects of treatment, fatigue, nausea, pain, discomfort, inflammation, all of that can have a broad effect on people's desire for sex and intimacy.

as well as their arousal or their ability to have whatever form of sex or intimacy that is typical or normal for them. So it is just about holding that in mind. I remember we talked about a particular project that we have at St George's, a kind of Macmillan professionals conference, and we had a wonderful nurse working in skin. And she sort of finished our session. said, I would never have thought about that link between sex and intimacy and skin cancers. But actually you've talked about scars, you've talked about pain, you've talked about...

So it's just keeping it kind of on our radar, know, how might this impact on different cancers, on different people.

Paul (14:07)

And I wonder, just maybe expanding a little bit, coming to you, Jo, and I wonder, perhaps lots of professionals might not be specialists in this area, but Are there signs that show people might need additional support or additional? signposting to different services.

Jo (14:28)

I guess it does depend on the particular individual and potentially their cancer as we've sort of alluded to there. There may be cancers that are more specific to the genital area or that

Elvin (14:38)

Hmm.

Jo (14:40)

affect things more directly so we've talked, know, Elv has talked quite a lot about his experience in prostate cancer.

And often in the NHS, we will have specialist nurses or specialist provisions within certain pathways of cancer. So there may be those that are more obvious in that area. But even within that,

there might be things in those pathways that we haven't thought about. So I think it's just giving yourself as a professional to a moment to think about how might these particular treatments in the area I work in impact on someone's intimacy or sex life.

And as I said, that might

Carly (15:14)

Mm.

Jo (15:15)

be, you you might be thinking more directly in terms of say, gynaecological cancer, that there

might be some surgery or radiotherapy that makes any kind of form of penetration more painful or more difficult, but there might be more broader discomfort. This might be, you know, someone who's got abdominal pain more broadly or fatigue. So it's just thinking bit about that. Or in breast cancer, you know, a common thing might be around hormone treatments and going into an early...

So you don't have to be an expert, but it's just trying to understand what are some of the potential impacts and can I kind of go away and explore that or understand a little bit more or educate myself a little bit more. But I guess the thing I want to say as the psychologist in the room is that you also don't have to have all of the answers. I think what becomes a really big barrier for us as healthcare professionals in talking about sex and intimacy is like,

Elvin (16:03)

Okay.

Jo (16:08)

gosh. or what if I have opened up something that I don't know anything about or I don't know where to signpost someone

Carly (16:13)

Yeah.

Jo (16:14)

to or

Elvin (16:14)

Yeah.

Jo (16:15)

I upset someone or actually my clinic's really busy and really haven't got the time. It's sort of okay to just open up and say this is something we can talk about if there's things that I as a professional need to go away and find out for you or things that I can signpost you to is that collaboration and saying, you I might not have all the answers, but I'm so glad that we're able to talk about this and start to understand the impact this

Elvin (16:40)

Mm.

Jo (16:40)

is having on you. And we together can make a bit of a plan as to what we can do to make that better or start supporting you. And with that.

Elvin (16:48)

Hmm.

Paul (16:50)

And how can how can professionals perhaps open up some of these conversations? Thinking about being inclusive, being sensitive, not making assumptions of what sex and intimacy somebody might be doing, should be doing, all of the things you've already kind of mentioned.

Caitlin (17:08)

I think for me and what I say to my team, I think the bit that's really important about understanding people is about asking permission to have the conversation and not being scared of asking permission because somebody can say to you, actually, I'm not comfortable with having that conversation with you. You've not offended anyone. You've asked permission, but you will be amazed about how many patients actually really want to have a conversation with you about

Carly (17:32)

Mm.

Caitlin (17:33)

this stuff and open up because they've got no one else to speak to and I think it's about that thing about not having bias. Just because somebody is religious, comes from a different culture to you, doesn't mean they're not wanting to have a full and intimate life

with their partner on their own. So I think it's that asking permission that's really important and then I think Jo can talk more broadly about then how you do that, how you manage that. Once you've asked permission, how you then probably manage that conversation.

session.

Jo (17:59)

Yeah, that was beautifully teed up. But I

Elvin (18:00)

Hmm

Paul (18:01)

Hahaha

Jo (18:02)

think that's right. And I'm conscious of my role as a psychologist. you know, this is about helping you with your own, you're going to have your own style of communicating. But these are just a few tips and things to sort of think about and weave into your practice. It's not about

Elvin (18:12)

Hmm.

Jo (18:13)

forget having a perfect conversation. No conversation is perfect. It's just making it safe enough for you and for the individual that you're talking to. So absolutely, it's about seeking that permission. In combination, think it's about normalizing as well and just making this part of a natural part of your routine conversation with people to some degree, isn't it? So it's not, gosh, there's this thing, and I'm going to leave it to the last minute and the end of the conversation because it's uncomfortable. It's kind of going, know, cancer is treatment impacts all parts of our lives. know, Caitlin's talks about kind of holistic care can affect. of how we're doing things day to day, it affect how we're feeling, our relationships as part of that, that can impact our intimate and sexual cells, it can impact how we feel about our own bodies

and we can say is that something that's affected you or you're bothered by? So we can say many people do find that their cancer treatment or cancer care impacts on their intimate lives, on their relationships and on sexual intimacy.

Is that something that's bothered you that would be helpful to talk about today? So you're normalizing and giving that bit of permission. Sort of saying, look, this is what, you know, this impacts lots and lots of people.

Elvin (19:25)

Yeah.

Jo (19:27)

Is it something that affects you and is it something that you

Carly (19:29)

Mm-hmm.

Jo (19:30)

want to talk about or think about here? And people can say no, like Caitlin said, they can say no, and you can say absolutely fine. And if

Carly (19:37)

Yeah.

Jo (19:38)

that changes... This is a space you can come back to. can talk to anybody in the team at any point if you do struggle. Or you can say, is it OK if I sort of check in on that a little bit later down the line just to see if it's something that's bothering you at a different point in time with equal permission to say, hey, Jo, no, that's not something I want to or need to talk about. So I'd say

Carly (19:58)

Mm-hmm.

Jo (19:59)

those are kind of a couple of things that go nicely together. And also maybe just thinking about something that you might feel comfortable starting a conversation about or thinking about and again it's going to depend on the area you're working in but it's almost sort of being a bit brave and kind of having a go at having a conversation as I said not making it perfect but just saying look with this particular cancer treatment we do know that produces vaginal dryness or we know it can impact libido or erectile dysfunction.

just saying it and not even necessarily having to have all the answers but just that normalising and is that something that bothers you? you, would it be helpful space to talk about it? And trying to use more concrete language as well. think we're getting a, and maybe kind of there's an apprehension on both sides that everybody sort of talks about down there or,

Elvin (20:33)

Yeah. Mm.

Jo (20:50)

But actually just again, it just normalises it. you if I just talk about a vagina and I'm clear about what I mean by vagina, which is the internal female genitals, you know, it just makes it that bit easier for the individual to

Elvin (21:03)

Yeah.

Jo (21:03)

feel comfortable and that we're not being unclear or fuzzy, that we can kind of normalise it and make it part of the language that we're talking about with other aspects of their care, like neuropathy or whatever else they might experience.

Carly (21:17)

Mm-hmm.

Paul (21:18)

Thank you Jo. And Elvin, was there anything from your perspective that you found useful to open up some of these conversations when you were going through your own experience?

Elvin (21:32)

Yeah, it's great question, Paul, very, very fortunate, I am the son of a nurse.

And so it was always the case of, me know what's bothering you.

And so she was the first person that I've met, because obviously with a young son at 13, 14, 15, start to learn about the old fashioned birds and the bees, was that she really,

Caitlin (21:54)

Mm.

Elvin (21:55)

really did talk about intimacy, just like she would talk about other parts of the anatomy, like the leg, the foot.

And I think in answer to that, Paul, is that's how I found it best, was

Carly (22:07)

Mm.

Elvin (22:07)

don't be shy, don't be overt, just tell it how you understand it, which is try

not use the medical terms, use the terminology that I think everybody would understand and then check back in, you understand what I'm talking about?

And the greatest thing Paul was actually talking about my problem and being explicit or candid, but just saying, for instance, yes, my penis did shrink, girth and all. And yes, it has now got curvature. And yes, unfortunately, I had lots of trouble trying to hold back from urine coming out everywhere.

Paul (22:44)

and Jo and When should these conversations start happening from your experiences?

Caitlin (22:51)

I think that's a good question. I think it's when the patient's ready to have that conversation, but we should be offering quite early. When we talked to patients before we started a project we did around the pelvic consequences of cancer care, patients told us they wish they'd known before it all happened, so they knew what was going to happen, so they could normalise it. So if you're, for example, having some cancer treatment that is definitely going

Elvin (23:10)

Thank you.

Carly (23:11)

Yeah.

Caitlin (23:18)

to affect

Elvin's talked about, your sexual function. People need to be really open with you about that so that you don't feel like you're the only one, that you're different and not know where to find help so that you can come back and say, actually, you said that might happen. It now has what help is there? How can I have that? So that we've opened a door for people to

Elvin (23:30)

Hmm.

Caitlin (23:39)

come and have that conversation with us when they're ready. So I don't think there is ever a particularly perfect time, but really thinking about the treatment that we're giving, how that may affect the person, but also thinking that actually we might not be doing something that will affect physical function in terms of sex and intimacy, but may affect the emotional piece and the psychological piece. And how do we also open up that conversation? You may feel differently about yourself. If you ever feel like that, that's not odd, that's not unusual. Come back and talk to us and opening the door for people is a really important aspect. don't know if Jo wants to add any more to that, but I suppose what I really want to get across to professionals, be confident. You don't need to know the answers. Patients will find great relief in just somebody who will listen to them. And that emotional

Carly (24:26)

Yeah.

Caitlin (24:27)

kind of outlet is really important too, and patients tell us that. don't worry about, we learn in, think Elvin hit the nail on the head around nurses. We learn in the nursing school about the functions, about fixing things, about making things better. Sometimes we can't always make everything better. We can't always fix everything, but we can listen and we can support and that is also a really important part of what we do in cancer and what we do in cancer nursing particularly.

Jo (24:50)

And I think we know from a more psychological emotional adjustment as well after anything, any sort of big treatment,

Elvin (24:57)

Hmm.

Jo (24:58)

that if you have some idea of what you might expect afterwards, then you adjust a lot easier. If a lot of this is completely out the blue, then it is much harder psychologically, emotionally.

But as Caitlin said, that it might be that different people take in information at different time points. We know from the project that Caitlin has talked about, some people wanted lots of information before. And sometimes that's because that might impact directly on their decision making about their treatment, for example, or that just might be how they are. Other people felt like, gosh, it was information overload. But great if you can slip me some information leaflets that I can come back to, or we can then.

Elvin (25:14)

That's right. Yeah. Okay.

Jo (25:34)

nudge people as professionals a little bit further down that kind of permission seeking that checking in you know there's there's lots of ways this impacts there's lots of information i'm sure you've been given before can i would it be okay if i check in on these sorts of areas

Carly (25:48)

Mmm.

Jo (25:49)

and this goes back as well maybe to the previous question but sometimes the way of it's interesting talking to Elvin and Caitlin here from thinking about Elvin's mum as the nurse and Caitlin in her nursing role. Sometimes it is just being really matter of fact and pragmatic and clear and

Carly (26:05)

Yeah.

Jo (26:05)

we are gonna talk about this or this is something we can talk about. Sometimes it can help to do what we call a kind of funnel technique and that sounds like a fancy technique, it's not really, just imagine a funnel. So the idea is that you might not go straight into thinking about.

sex and intercourse, giving that information. There's times and a place for that 100 percent, but it might be that you open up and think about, I just want to think about the ways treatment might be affecting you day to day.

Elvin (26:29)

Yeah.

Jo (26:30)

One of those areas can sometimes be on our relationships and then you might be, if someone tells you a bit more about relationships, what relationships matter to you because we know our intimate relationships you can go, relationships, intimate relationships, you can be guided and then think about. And one aspect of relationships

Elvin (26:42)

Yeah.

Jo (26:45)

is also our intimate and sexual lives again. that's really common or any normal. Is that something that is bothering you or you would like to talk about? So you don't have to panic that you're going to go straight in with something very direct. You can when that feels right, but also you can use a little bit of that start

Carly (27:02)

Mm-hmm.

Jo (27:03)

and then you can come towards it. But try and avoid

Carly (27:05)

Yeah.

Jo (27:06)

doing that right, know. Also there can be a tendency that we talk around it for too long and we leave the sex intimacy bit to the end and we run out of time.

it's about balance, about introducing and coming down to something without waffling and noticing in you, is that because I'm a bit anxious about asking about it or just checking in with yourself on that.

Elvin (27:18)

Hmm.

Carly (27:24)

Yeah, yeah, I think that's so helpful. And that's such a really nice, know, using that kind of funnel technique, if you've described it a really nice way to kind of start opening up that conversation. And yeah, I really found what you were saying, Caitlin, about actually, you know, trying to open up and start the conversation early on, but actually really listening to that individual and actually when is the right moment for them, which is different it sounds for different people so working with them. So yeah, thank you. I found that really, really helpful and really interesting. And we've talked a little bit about support.

But I wanted to ask, is there any other support that is available to people working in healthcare professionals? to support them in this conversation, start in the conversations or even how they can support the people that they're supporting. What else is available to them?

Caitlin (28:20)

So in terms of signposting patients, there is loads of resources out there to support this piece. There was lots of support groups out there in terms of this piece, that peer support, Outpatients charity have an amazing resource out there. Their website is full of information.

absolutely tell every healthcare professional to go and look at outpatient charities website. They talk a lot. There's loads of resources. There's resources for patients, but there's also resources for healthcare professionals to learn more. There is, yeah, that's what I would suggest. And I think it's about knowing your services within your local You need to know what services in terms of pelvic function, in terms of your local services around. Around where you need to be referring on to and where you should be signposting to, so that we can get people to the right people at the right time.

So listening to people so that you can get them to the right place, but knowing what is local to you. So every hospital,

Carly (29:11)

Yeah.

Caitlin (29:12)

unfortunately in the NHS, et cetera, is set up slightly differently.

where your specialist. think also learning from your other professionals. So for example, in our our hospital, our prostate CNSs are really well versed in managing some of this stuff and talk a lot about sex and intimacy and we will often get them to do some teaching supporting of other other other tumour types who are less well versed in that. So going to the tumour types that doing this stuff all the time, go and speak to your breast

Elvin (29:19)

Hmm. Hmm.

Carly (29:36)

Yeah.

Caitlin (29:39)

cancer CNS and go and speak to your prostate CNS in your in your hospital. because I bet they know where all the local resources are, where to get the, you know, which lubricants to suggest to people, all of those things, those practical supports. So everywhere's slightly different, but they're the things I would advise doing. And I don't know whether Jo's got anything to add in terms of site posting, et cetera.

Jo (30:01)

I guess just to kind of complement what you said, Caitlin, I guess there's sort of different depths of conversation you may or may not have, depending on the particular, as I said, cancer type or other particular issue or your particular area of expertise. So there's quite a nice model that we talk about the PLICIP model.

So this talks about four levels of kind of intervention, I guess, in terms of sex and intimacy. So the P is for permission. So that's sort of permission to have those discussions around sexual concerns with an individual or a cuppa and offering that signposting. So that kind of real level, universal level one. So like Caitlin said, there's particular charities, know, Macmillan Cancer Research has some really brilliant broad resources on libido, rectal dysfunction.

vaginal dryness, menopause and so on. Or as Caitlin said, those specific charities, know, Maggies, Outpatients, and there's Orchid, CrossState Cancer UK. know, I CrossState Cancer UK do a particular session on hormone treatments. So that's again, another kind of peer-led nurse education session. So it's sort of dabbling with and exploring some of those charities and what they do.

Elvin (31:00)

Hmm.

Jo (31:09)

you've got some sort of signposting to some general resources. And then the next level is that level two is limited information. So that might be advising on the impact of specific treatments on sexual function and assisting people to make some informed choices about their treatment. And again, that might vary on your kind of level of input or expertise

Elvin (31:27)

Hmm.

Jo (31:30)

as a healthcare professional. But again, that might be thinking about the impact of specific treatments on sex and intimacy. For some people with hormone treatments, they may decide whether that's something that they want to balance out, what's the benefit of having that hormone treatment versus the impact it might have on quality of life. And then the third level is around more specific suggestions. As Caitlin's alluding to there, that might be more specific pathways that are specific advice.

but that would be, I guess, professionals who are maybe working in areas where we have more of that expertise or like Caitlin

Carly (32:02)

Yeah.

Jo (32:02)

said, that there's more awareness of those pathways. I echo what Caitlin said, I don't want to repeat, but just knowing what those pathways are into andrology or urology or pelvic physio or women's health. Is there a menopause clinic within your setup? So it's again, kind knowing what your pathway is, but it's starting in that level one and moving down and just thinking.

where does this conversation need to be pitched and where am I resourced to help and support and if that's beyond me and that next level where can I guide people to and the last level does tend to be more kind of intensive input with sex and intimacy and quite a lot of that is around individualised psychological or psychosexual support and again we can kind of give some signposting resources sometimes referrals into services like some of the cancer charities again peer

groups and conversations that happen around these particular areas or the impact of treatment is enough for people sometimes having some individualised input through those charities or there are services like mine across the country and just finding out

who those are. Again, sometimes just having that input, you know, we aren't specifically trained psychosexual therapists but we would know about the impact

Elvin (33:09)

Hmm.

Jo (33:11)

of relationships and mood and navigating communication within.

their own relationships as well as getting support in the hospital and that we could signpost

Carly (33:19)

Mm-hmm.

Jo (33:20)

on to any other services as needed.

Carly (33:23)

Can I just go back very quickly? I just wanted to touch on, you mentioned andrology a few times. Could you just explain just a

Caitlin (33:29)

Mm.

Carly (33:29)

little bit about what that is

Caitlin (33:31)

I think Elvin probably could Elvin probably could explain

Caitlin (33:34)

it more about andrology than us I bet but if you've been to the service but do you want to go Elvin and explain it?

Carly (33:41)

Thank you.

Elvin (33:45)

From my experience as an end user all I knew of actually was urology. And so I went off looking for a urologist to support me with this challenge I had with Peyronis.

And very nice, because even though it was 56 weeks, whatever it was, I had lots of really lovely people trying to help me get it there quicker. And a guy came back and said, look, we found out that this is not the domain of urology. said, no, it's a prostate cancer. Yeah. But this is actually to do with the penis itself. So and you need the specialist called the andrologist.

And I was

Caitlin (34:22)

Yep.

Elvin (34:23)

very, very fortunate to come across an expert in the field.

who was able to put all my concerns to one side and explain about the penis. I even was talking, I took a photograph of my penis erect for him to look at, which is a first. But what was brilliant was that he was, because he knew

what he was looking for. Yes, this is okay. We can do this. This is okay. We can inject you. I think it'll be okay. Now you go away and literally play with it and let me know how you get on. And he was all to do about with the penis itself and how it functions. And also, is there a possibility that it is fixable? Hopefully that's a pretty good description.

Caitlin (35:13)

Yeah, it's yeah, you've used it well. it's looking at the function. So in this terms, in terms of erectile dysfunction, they are the experts in managing erectile dysfunction. So how you all of that stuff. And often these services are often nurse led services. So in my hospital, we have nurses running these clinics who are supporting patients who are doing their follow ups, who are having conversations with patients, thinking about how we get function around erectile function back for patients and how they manage that. So it's that piece rather than the whole of your water work system.

Carly (35:44)

Thank you. Thank you for explaining it.

Paul (35:47)

That's brilliant. Thank you. And I just want to kind of ask you all a final question, if I may. And Elvin, if I can start with you, what would you like our audience of professionals to take away from this episode about sex, intimacy and cancer?

Elvin (36:04)

I would like them all to consider when they're talking about sex with cancer, that some things will be unavoidable, other things, there is a very good chance they'll be preventable and some things will be fixable. And also to be very positive about it, help them with time. How long will this go on for? Because this is on the quality side. How long will it? I remember because a guy said to me,

It's been a year now, my contents is rubbish. How quick was yours? And then there's the health and safety bit. Listen, if you get this come up, is extraordinarily, it's serious situation. We can help you, but please let us know as soon as possible. And then the last thing of all is when you're helping people talk, show, and check back in. Did you understand what I was saying?

Paul (36:53)

Brilliant. No, thank you Elvin and Caitlin. May I come to you and ask you the same question?

Caitlin (36:58)

Yeah, so for me, the thing I would want people to take away is... being able to start that conversation, being able to just be brave, it's okay, you're going to get more out of it than you think. And, and, and, and enjoy helping people and enjoy

Elvin (37:14)

Yeah.

Caitlin (37:15)

being holistic in what you do, I think is really, really important and take passion in that. Because I think we are a little bit worried about upsetting or offending, but actually we're doing people a disjustice if we don't open up the conversation and give people permission to talk to us about things that are really important to them. And I think this is more than just sex and intimacy. This is about how we talk holistically across the whole of the domains. So I think it's really important. So that for me, be open, be inquisitive, ask your patients, try and understand them and don't be worried about offending. We can always say sorry. We can always say, no, maybe not for now. Yeah, but that's for me. That's what I would like people to take away.

Paul (37:56)

and thank you Caitlin and Jo.

Jo (37:58)

equally it's just being brave and having a go. We know these conversations really matter and are really wanted and no conversation is going to be perfect. But I think the other thing might be to just check your assumptions. You know, maybe just take

Elvin (38:11)

Mmm.

Jo (38:12)

a breath before going into a conversation we always talk about in our team about setting our intention. Just notice if there's a slight assumption that creeps in that

Carly (38:20)

Mm.

Jo (38:21)

this sex intimacy can't matter to this person because of this reason or you know, we accidentally miss a conversation here by some of our assumptions. We might assume someone's age, you know, another element of their background or just making an assumption about, you know, whether someone is partnered and what's our assumption about their gender, their sexuality and just trying to be open, like Caitlin said, open and curious and just setting that tension to be helpful to everybody and hold that in mind. And maybe just think about one thing you want to try next time you have a relevant kind

Elvin (38:54)

Yeah.

conversation or conversation what's one thing that you want to give a go or what's one thing that can help you feel more prepared is that going to check out some resources or some pathways or have a go in a mock situation with a colleague to kind of think about how you might approach it.

Carly (39:11)

Mm-hmm.

Jo (39:12)

And I probably also want to plug our St George's resources as well so we've got a project on as Caitlin said.

pelvic related concerns associated with cancer and its treatment. So we've got a lovely roadmap of resources. We've got some wonderful sort of short videos and resources and signposting. So we open that up to all to kind of use and have that in your armory as well. So a nudge to go and look at that.

Paul (39:37)

Thank you. And we'll definitely be including those within the resources. So thank you.

Carly (39:43)

Yeah, thanks. Thanks so much. yeah, what you shared there, all three of you in that kind of last question really for me sort of summed up some of those really key parts of what we've covered today and we've covered so much. And I think going back to what you said, Jo, about assumptions, that was one thing particularly that stood out to me about not assuming what sex and intimacy means for someone or what's important to them because

Caitlin (40:06)

Yeah.

Carly (40:07)

that will look different for everyone and actually it's about understanding and asking them what's important to you around that, not making the assumption that it's one specific thing. So yeah, I really took that and really just as we close to say thank you so much to the three of you for being part of this conversation and I found it's been so insightful to get such a variety of perspectives and experiences

from the three of you. So thank you so much and again.

Elvin, I thank you for being so open and sharing your experiences and being honest in what you have been through in a way that maybe lots of people might not feel confident in sharing. And I know just those experiences and your stories itself will be so helpful for our listeners. So yeah, just to say thank you so much for joining the Cancer Professionals podcast.

(Outro music fades in)

Carly (41:03)

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Paul (41:27)

If you enjoyed this episode, follow us so you don't miss our next conversation about pregnancy and cancer. We will be joined by Ellie Flanagan, who was diagnosed with lymphoma during her pregnancy, and Kate Stockton, a haematology clinical nurse specialist who supported Ellie during treatment.

Carly (41:45)

We'd love you to rate our show and share with your colleagues. Get in touch with us by emailing professionalspodcast@macmillan.org.uk. New episodes are released on the first and third Wednesday of each month.

Paul (41:58)

I'm Paul

Carly (41:58)

And I'm Carly and you have been listening to the Cancer Professionals podcast by Macmillan Cancer Support.

(Outro music fades out)