

## The Cancer Professionals Podcast

### Supporting the whole person: Mental health and cancer care

(Intro music)

**00:00:10 Lydia**

What does inclusive care really look like for someone balancing the weight of cancer and a mental health diagnosis?

**00:00:15 Siobhan**

And if I could look back, it was really surreal. It was like, I was another person on another planet just going through the motion, so, yes, it would have been lovely if somebody had just stepped in and said Siobhan, really, how are you really feeling? Isn't this awful? Isn't this a tough old road you're walking? Yes it is.

**00:00:35 Paul**

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

**00:00:38 Lydia**

And I'm Lydia and I go by she/her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. In this series, we chat to a wide range of guests, including health and social care professionals, to lift the lid on current issues faced by the cancer workforce.

**00:00:54 Paul**

This episode is in collaboration with UKONS, the UK Oncology Nursing Society.

**00:01:01 Lydia**

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**00:01:18 Paul**

In this episode where we explore the crucial topic of mental health and cancer, we're joined by Siobhan Heaton, who was diagnosed with breast cancer. She shares her powerful story about living with cancer while managing a pre-existing mental health condition.

**00:01:34 Paul**

Siobhan opens up about the support that made a difference and what was missing.

**00:01:39 Lydia**

We're also joined by Dr Jeff Hannah, a registered nurse and lecturer in clinical cancer nursing who offers expert advice on best practises for providing mental health care during cancer treatment. He shares insights on how mental health care and cancer settings can be made more inclusive and tailored to individual needs.

**00:01:58 Paul**

This episode contains conversations about lived experience of cancer and mental health, which you may find upsetting or triggering. Listener discretion is advised.

**00:02:09 Lydia**

So we're here today to talk about the really important topic of mental health and cancer. We know that people living with cancer and other long-term conditions don't get the support they need. So hopefully today we can pick that apart and come up with some really great advice for those of you listening, on how we can make care more inclusive.

**00:02:27 Lydia**

So first off, I'd just like to introduce our speakers. So Jeff, can you just tell us a little bit about your experience, your background and what brings you to the podcast?

**00:02:37 Jeff**

Yes, so I'm Dr Jeff Hanna. I'm a lecturer in clinical cancer nursing, which is a joint clinical academic post with Ulster University and the Southeastern Health and Social Care Trusts here in Northern Ireland. And I suppose I took a very scenic route into nursing. Nursing is not my background, my first primary degree was in psychology. I spent a period of time working in research positions, doing teaching abroad in Italy, and then had actually subsequently come back and completed my PhD in the School of Nursing at Ulster University and post PhD, I completed a number of post docs across England and Scotland and Northern Ireland within psychiatry, social work and nursing, but I still very much had that mindset- if you want your research to make a difference to practice, and you really want to make that difference and influence your colleagues, it's really important to be in practice, so I did make the decision to complete my masters in professional nursing and subsequent to completion of that I've joined Ulster University in the Southeastern Trus, within that joint clinical academic post.

**00:03:46 Lydia**

Great. Thank you. So you've got a wealth of experience to bring to the podcast, which is absolutely amazing. And Siobhan, can you just give us a little insight into why you're here to talk to us today?

**00:03:57 Siobhan**

Well, my background career wise is relevant because I worked all my life in social work, mental health addictions, working as a practitioner, chasing the money and becoming a manager and then eventually became a Commissioner of Mental Health Services for children and whilst there was working in those posts, I always felt that we weren't getting the pathways right and they were missing bits and pieces that we were missing out on, and I have left that work a long time ago, about 11 years ago now, I've retired, but I have been a cancer patient and have mental health issues, and so also from the patient, if we want to describe it as that, that so for the purposes really of this podcast, I'll be talking from as a recipient, really, of the services that I've received.

**00:04:51 Paul**

Thank you, Siobhan. So to get us started, would you be happy to share your experience with mental health and cancer.

**00:05:02 Siobhan**

Absolutely yes. Umm, so I have had mental health issues for a long time now and certainly when I was working and have accessed mental health services only really through a GP because for me, That was the only way that I thought you could do that really, unless it was extremely severe and whilst my issues around mental health are severe and are difficult for me, I've never really been referred onto a mental health nurse support, although I should have been and could have been, so I've always accessed my mental health from there. About 10 years ago I was diagnosed with breast cancer, and what I would share with you and I've shared with lots of people is that the first doctor I saw said to me "don't worry, we can do something with this", and that was hugely powerful. And I mean really, hugely powerful because it meant that I didn't need to worry, that this was something that clinically, he could do something about.

**00:06:02 Siobhan**

So, so that was a comfort, really, but beyond that, all my access to cancer services was really about the clinical and never about the mental health, and I would suspect had I been asked, I'd have glibly said I'm fine because I was following a clinical path that said- do this do this, do this, do this and you're done.

**00:06:26 Siobhan**

So I guess that's part of where I feel there were missed opportunities with me where people could have asked maybe a deeper question about how I was actually feeling.

**00:06:36 Siobhan**

My clinical notes would clearly say I'm on medication, but nobody ever touched on that. they asked me- was I on medications and they gave them the list, which was short then, but never actually picked that up. So that's kind of missed opportunities for me. And so I glibly went through the process and sort of fell off at the end where I was left just to get on on my own.

**00:07:02 Paul**

Thank you. Yeah. So you talked about your how your mental health was impacted when you received your cancer diagnosis. Can you maybe share a little bit what that felt like?

**00:07:18 Siobhan**

OK, it felt surreal. It felt bizarre. I behaved oddly. I just rang my sister and said- here's what's happening. This is what's going to happen. I'm having my breasts removed and having this chemo and that's it. Now can you tell everybody? So I really went, I sort of stepped back from it all because my mental health couldn't cope. I just couldn't cope with what they were telling me. And although the doctor told me that I was going to be okay.

**00:07:45 Siobhan**

It's pretty scary, really. It's really scary to be told that you've got something like that when there has been no history in the family, nobody you've ever known has had cancer, only those that have died. So, yeah, and to lose my breasts, I knew I was going to lose my breasts was quite scary.

**00:08:04 Siobhan**

I made my husband go out and buy me a lovely Pandora charm that cost him about £100 to make me feel better. It was one with two little swans that are mate for life and I said- look buy me that and he did, God bless him. So you know, I did behave. I did behave very bizarrely, you know, it was like- this, this isn't rational, but deep down, I knew that this doctor had told me I would be OK, but very, very scary and nobody to take it to. I'd been allocated a breast nurse, but of course I haven't met her yet, so I had nobody really beyond somebody that I knew in cancer care.

**00:08:41 Siobhan**

Yeah, that was it- one person in cancer care that was able to support me at that stage, who actually had never been referred to me, it was somebody I knew.

**00:08:50 Paul**

And just reflecting back then on your particular experiences, were there any kind of specific points during your diagnosis and treatment, where perhaps you felt your mental health, or you felt you needed mental health support, it was more critical?

**00:09:12 Siobhan**

I would say, what I did was I looked at the process and I just followed the process. So what I did was- I knew it was a three-week term. So the first week I was awful. The second week I did everything I could with everybody I knew.

**00:09:31 Siobhan**

I went out all the time, went out for meals, more I'd ever dream of doing now. Out all the time, made the most of my life and the third week I batted down and got ready for the next lot.

**00:09:42 Siobhan**

So actually I think very much I was in denial about what was actually happening, and physically it was horrendous, you know, and losing my hair, which, by the way, I look better without hair. Just to let you know. But you know, physically and mentally it was tough going and there wasn't anybody really. My husband was amazing, but to be fair, the person who is the carer struggles the most because it's very hard for them to watch somebody they love in that situation. So there were times when I could really have done with, even just as low level as- how you're doing, really? How does this really feel for you?

**00:10:23 Siobhan**

So I focused very much on the process and there were times in there where, if somebody had maybe just asked me that question, I could have had that conversation. I never thought about upping my medication to help me cope- My other medication, my mental health medication. I didn't think about reviewing it. Nobody ever asked me- did it need reviewing.

**00:10:46 Siobhan**

And if I could look back, it was really surreal. It was like- I was another person on another planet just going through the motions. That's what I would describe. Just going through the motions. So, yes, it would have been lovely if somebody had stepped in and said- Siobhan, really, how are you really feeling? Isn't this awful? Isn't this a tough old road you're walking? Yes, it is.

**00:11:07 Paul**

And did you get any support from your, or any acknowledgement from your oncology team, who are focusing obviously on your cancer diagnosis and cancer treatment. Any acknowledgement of your mental health at that time?

**00:11:24 Siobhan**

No. Absolutely no, no. It's interesting, the oncologist, when I first was going into my chemo, and I was thinking about this earlier today, she read every single side effect that could possibly happen to me.

**00:11:37 Siobhan**

Then she wrote it down, and read it as she wrote it down. And then she told me it again, and that's what I got. That was the level of support, thank God, it never said anything positive. This is just- your hair will probably fall out and it'll never come back. This will happen, and this will happen, and this will happen. And she told me that three times and then left me with it.

**00:11:59 Siobhan**

So, that was actually quite traumatic, really, and quite scary.

**00:12:05 Siobhan**

You know, that it might not come back and I might have a very, and I did have a tough road but no acknowledgement of mental health or how that might actually feel to hear that, not even from my breast nurse, to be fair.

**00:12:19 Siobhan**

She just always said- oh, you look great and you look amazing and look at the way you've matched all your clothes, and your lipstick matching your clothes. And it was always that superficial stuff, not- what's going on in Siobhan's head? You know. But that's- no. The answer, the short version is- no.

**00:12:35 Paul**

Gosh, yeah, that sounds that sounds really difficult for you. And I mean my next question was going to be- what kind of support you offered, but I think we've, we've clearly heard at that period there was there was none being offered.

**00:12:48 Lydia**

What you've said there, Siobhan, I think it's it's quite common, especially like, you come across quite bubbly and quite a big personality and I think that there's quite often a perception from health or social care professionals that if somebody comes in with a lot of energy that actually they're OK, when actually you need to be checking with everybody, don't you? How are you really doing, as you said. Or that double tap of asking twice- are you OK? Just to allow people to open up because you never know what's going on behind closed doors or, you know, internally, for someone. So yeah, that's really important.

**00:13:24 Paul**

And Siobhan, I mean, you might not be able to answer this question, but I'll ask it before we kind of bring Jeff into the conversation. Were there any specific practises, behaviours or approaches from any of the professionals that did make a positive difference to you during that period?

**00:13:43 Siobhan**

People were pleasant. They helped me through the process. Umm.. no, is the truthful answer.

**00:13:54 Siobhan**

I got my support from the person I knew who worked in cancer care and sought stuff there, and with my family. Not my children. It's too much for my children and they were dealing with what they were doing, so I couldn't tell them always. But the answer is no, I didn't you know, and it's- that's very sad to say really.

**00:14:15 Paul**

Thank you for being so honest about that. If we could bring Jeff into the conversation, Jeff, perhaps- how can mental health problems impact an individual's treatment pathway and their experience? Any views from you on what you've heard?

**00:14:32 Jeff**

Yes, thank you Siobhan for sharing more about your own experience and one of the things I like to think about between being a researcher and a clinician is- the key commonality between them both is, you know, we're like detectives and it's about exploring what's going on for that person and one of the, you know, important messages, which has been very, you know, positively highlighted at the beginning of the podcast is that, you know, many people living with cancer are living with other health conditions.

**00:14:58 Jeff**

Whether those be mental or physical. But for many people that I've cared for, often it's it's about having undiagnosed health conditions, and in particular relation to undiagnosed mental health conditions.

**00:15:13 Jeff**

You know, cancer brings about a lot of new uncertainties. You know, what's it going to be like navigating that experience? And Siobhan spoke very well to that. You know, you had your three-week window where your week of, you know, going out, doing everything that was working well. You had that week where you were pretty rubbish.

**00:15:29 Jeff**

But you also had that week where you were trying to prepare yourself for that cycle resetting itself again.

**00:15:35 Jeff**

You're also living with those uncertainties, you know what's going to happen in the future. Maybe it's even talking to children about an illness. Younger children. Um, so everybody's, you know, managing and dealing with lots of new uncertainties at this point in time. But everybody has their own story, and as health and social care professionals, we're in that ideal central position to be asking people, you know, what's going on with you? And Lydia, you spoke very well to it.

**00:16:01 Jeff**

It's asking that question- how are you? But it's not a simple- How are you? Yes, I'm fine. It's the really- *How are you?* And trying to get to the core of what's going on for that person in that moment in time and giving them the permission to talk about, you know, what's going on and trying to unravel some of those concerns and managing any anxieties regarding treatment or future uncertainties. And unfortunately, Siobhan, as you've mentioned, that wasn't your experience, but, in an ideal world, you know, as health and social care professionals, we would be there to, to pick up on that and to address those issues as opposed to thinking your GP is your only point of contact there to talk about issues related to mental health.

**00:16:49 Paul**

Are there any other specific barriers to care that people living with cancer and mental health problems face more frequently that you've seen?

**00:16:57 Jeff**

I think it's very much that the uncertainties of what's going on for each individual, whether that's on certain days to treatments, if you're still awaiting test results and there's often, you know that period of living in the unknowing and, you know, you've maybe had scans, you've had tests, but you're still waiting on the results of those.

**00:17:17 Jeff**

And then even you know, for some people who have maybe come to the other side of treatment, there's, there's still those ongoing investigations and follow up. You know, there's that fear of any reoccurrence of the cancer coming back. So for many people it's getting through the cancer experience, and then there can often become that point where you've lost that connectivity with your health and social care team, and you're often navigating, you know, aspects of getting back to adjusting to life very much what might feel on your own.



**00:17:47 Jeff**

And often that's whenever you're presented with those late effects of treatment, you're dealing with, living with the side effects and long term effects of going through treatment. And often it can feel like- well, how do I now manage these aspects on my own? And it and it can impact onto that individual's mental health, particularly if they're not prepared for them happening after their treatment has occurred.

**00:18:11 Siobhan**

Yeah, Jeff, that that's exactly what it's like. It's- you have your treatment and you get to the end and then, you're dropped off the end and you're left with some long term conditions. I have lymphedema and I have osteoporosis.

**00:18:27 Siobhan**

And I've always been a well person and the medication has caused this, and it left me, if I'm 100% honest, very angry.

**00:18:36 Siobhan**

I'm angry because I've had to be on this medication for 10 years. Now, my friend went through breast cancer, and I know everybody's different, she only had to be on it for 5, so I was very, very angry because I hate this medication.

**00:18:52 Siobhan**

Luckily, I'm coming to the end of it, but I'd even negotiated- could I finish early, because I really hate it so much, but they've said hang on. So, yeah, and it's that bit. And I think if anybody was to ask me about my cancer journey, the most difficult but probably is the the aftercare and the no mental health support to say- this is why you're on this for 10 years. This is why you've developed this. The lymphoedema is because they removed your lymph nodes, I get that, but nobody ever said that. And that sounds ridiculous. But I because I have this friend in cancer care, that person helped me through it. Had they not been there, I'd have been just... lost. So yeah, it's quite scary when you've finished that, and what you described about where you're no longer with health and social care professionals, you're just out on your own. I did reach out to an organisation for support, but they only wanted to talk to me about financial support, and I wasn't entitled to any. So that was the end of that.

**00:19:52 Siobhan**

So, really, it's quite difficult to find that support out there, but anyway. So just to pick up on what you said, Jeff.

**00:19:59 Lydia**

And I suppose it's, you kind of would hope that the oncology team, whether that be one of the doctors, nurses, whoever, would at least be able to signpost you to something, an organisation that can better offer support, even if it's perhaps not something that they can offer because you've been discharged or whatever.

**00:20:19 Lydia**

You would hope that you'd get that that onward signposting.

**00:20:23 Jeff**

I would completely agree with you, and I'm very familiar of a model that's used quite well and sexual well-being and cancer care known as the 'EASSi' framework, and I think it's something that we can apply to all aspects of conversations, particularly in relation to mental health, and it stands for 'engage, assess, support and signpost'. And I think as clinicians that's, you know, a good model of what we could be coming in to do and to help people who are navigating issues related to mental health. So engaging with the person with cancer, identifying what their concerns are, and assessing for those- what support can you give in the here and now? And then identifying whether signposting and referrals are the appropriate pathway further for that individual, and for many people it's not necessarily about having the signposting on to other organisations. Often they want to have that conversation with the health and social care professional about what's going on in their life, and having those other supportive services there as that safety net if and when they're actually required.

**00:21:29 Jeff**

Because often what can happen is, referrals can be made out to other services, but often we're not sure- what are we actually making that referral for? And how often can those services pick that that referral up? And what is the timely nature of that being able to happen?

**00:21:44 Jeff**

And for many, health and social care professionals, it feels somewhat normal practise to be able to lead into that signposting role and often challenging with- how do we provide that support in the here and now?

**00:21:56 Jeff**

And, you know, amongst many of my colleagues, and I can fully appreciate, there's often that fear- What if I open up that can of worms here and now? What if I unravel something that may not have been there? And what if I can't, you know, be able to support that individual in the here and now? But it's about being able to have that confidence, to have those conversations.

**00:22:17 Jeff**

And exploring what's going on, and identifying what you can do here and now. Can you equip that person to have some self-management techniques and strategies to deal with those anxieties and concerns at that particular point, and then having that onward support if required.

**00:22:35 Siobhan**

That's 100% what you need, that bit about having the conversation then, and I absolutely understand that people don't want to open a can of worms. But equally, when the signposting and the framework that you describe looks great, and I hope it's working well. But it's also having all the partners signed up to that.

**00:22:54 Siobhan**

So everybody understands what they might get. So for- just- this is my own personal thing- I was very ill. I vomited for days, they needed to give me an intramuscular injection and nobody would give it to me because GPs don't do that apparently and somebody else didn't do that. So I was just left to vomit for days. So that's sort of.

**00:23:15 Siobhan**

My hospital thought they were referring me to the GP to get that, and the GP wasn't doing that. So it's that communication as well, so everybody needs to be signed up to whatever that process is, I think.

**00:23:28 Lydia**

I agree, Siobhan, that the model sounds really great, so we'll definitely link to that in the show notes so that people can access it and you know, think about applying it to other areas of care. I think that's really important.

**00:23:40 Lydia**

And Siobhan, I know that you've spoken about the fact that you very much got a lack of support throughout your cancer diagnosis and treatment. What do you think, apart from, I guess, first of all, somebody asking you how you're actually feeling- Is there anything else that you can think of that would have been helpful for you during that time?

**00:24:00 Siobhan**

I don't want to say it was all negative because that would be mean and not true, and the nurses were amazing at doing the bit that they did. I think for me, just that understanding of what could possibly happen. It's the conversations and the support and maybe other people in a similar situation, you know, who were going through the same things. There

wasn't really that chance to have those kinds of conversations when you were in having your treatment. It wasn't that kind of scenario.

**00:24:31 Siobhan**

But I think, just start making sure- no, I think the conversations and the links to all the people would've been probably, for me personally, I know. So I can only speak for me can't I really.

**00:24:44 Lydia**

Yeah. And I think there's so many other people out there that really value like a group support, you know, meeting other people through charities, as you know, as well as through their own local area. So I think that's really important to highlight.

**00:24:59 Jeff**

I think the role of peer support is definitely something that we shouldn't undervalue or definitely not undermine, certainly within the research space where I've been, but also even clinical with the number of people who I've looked after living with cancer have significantly reported the benefits of meeting other people. Hearing how they have navigated their experiences, what has worked for them, what tools and strategies are they using whilst they're living with cancer, living beyond cancer to help them manage the situation and it's very much gleaning the tips from them as to- this is what worked well and this is how I've got to this stage, and for many people who are attending, you know, support groups, particularly where there's maybe cancer moving towards end of life or even into that bereavement stage, it often can provide that sense of hope. You know- here I am meeting somebody who's two years post treatment, I'm six months post treatment and it's looking to them to thinking- well, they've got to this stage. This is what's helped them and it gives them hope for the future of being like- I can get there too, just as other individuals have done as well. So I think as clinicians it's it's really important to understand the value of meeting other people who have lived through similar situations and experiences can be helpful in helping that individual identify what might be helpful for them as they navigate through issues related to mental health whilst living with them beyond cancer.

**00:26:26 Lydia**

Yeah, thank you, Jeff. I think what you've highlighted there is just how important and valuable that peer support can be for people. So yeah, I think that's great.

**00:26:37 Lydia**

And Siobhan, what do you think professionals could do to improve patient experience?

**00:26:44 Siobhan**

I think from both my professional and my patient experience, I think we tokenistically listen to our patients, and I don't think we always pick up and act on what they're telling us. And the key thing for all patients is communication.

**00:27:00 Siobhan**

For me personally, I can probably cope with most things if you tell me what it's about, not for everybody, because I know it's not for everybody. But for me, I like to know what's going on, and what that will be like, and what else, and what else. Not- the side effects might be, that's that's not one I want to know, you know. Like the three-week slot that I quickly sorted out, knew what it was about. If somebody said to me- this is likely what it's going to be like, I'd have been fine. And it was fine.

**00:27:27 Siobhan**

So I think sometimes it's tokenistic listening to patients- are we getting the right people to feedback? I don't know, I don't know, but I think that's the important thing and to act on it, it's it's like asking people- what do you want? And saying- that's very nice, but this is what we're giving you, so get on with it. I would love 24 hour care with GPs. Sorry, we're still only going to do 9:00 to 5:00.

**00:27:51 Siobhan**

You know what I mean? So it's that kind of conversation, you know, it's the same principle, isn't it, you know.

**00:27:57 Lydia**

And Jeff, I wonder from like a professional sort of perspective, obviously we have a whole manner of different ways that cancer can affect your mental health is obviously the people that come into cancer saying that they've got a relatively good mental health. And then obviously that obviously takes a dip because of that diagnosis.

**00:28:16 Lydia**

But in this conversation, we're talking about people who have had that pre-existing mental health condition, and then that, you know, have thrown cancer on top of that.

**00:28:24 Lydia**

And I wonder, you've spoken a little bit about the barriers for people affected by cancer, but I wonder if you could talk a little bit about what barriers professionals can experience in terms of helping people access mental health, or even coordinating care with pre-existing mental health teams?

**00:28:45 Jeff**

I think that's a really important point that Siobhan you've just mentioned and I think the important thing is clinicians, we must remember is- whose agenda are we actually trying to achieve? Is it the person who's living with cancer's agenda or is it a healthcare agenda to suit us as clinicians?

**00:29:00 Jeff**

And as clinicians were very much taught within a person centred framework, and if we're thinking, what does that actually mean? It's, it's spending that time at the beginning of each consultation, each appointment or wherever it is, you know, you see your patients in practice, and asking that question- what's important to you being here today? What are your priorities for care? And it's about identifying what's going on for them, and figuring out how you can get the best out of that consultation, that appointment, that you're able then to send the person off to be able to manage and to cope with whatever it is they're going through whilst living with this cancer diagnosis or even living with and beyond in a post- treatment phase.

**(Ad)**

**00:29:45 Paul**

Before we hear more from Siobhan and Jeff, here's a quick message from Liv about additional learning in this area.

**00:29:52 Liv**

Did you know, Paul, that 66% of people with cancer have at least one other condition and almost half have at least two? This includes mental health problems.

**00:30:01 Paul**

Oh, really? So where can people learn more about this important topic and how we can support people with cancer and mental health conditions?

**00:30:09 Liv**

So, there's a range of resources on the Macmillan Learning hub, including e-learning courses on psychological support skills to enhance cancer care, and cancer and other conditions.

**00:30:18 Liv**

You might also enjoy our February podcast episode 'I see you cancer, and I raise you the ocean', which explores the mental health benefits of cold water swimming for people living with cancer.

**00:30:28 Paul**

That's great to hear. If you'd like to know more, see the episode description for more details. Now let's get back to the conversation.

**00:30:37 Lydia**

And what do you think is missing? Obviously healthcare systems, sometimes it can be a bit of a postcode lottery I guess, but from your experience, what have you seen that's been missing that we could do better on?

**00:30:48 Jeff**

I think one of the biggest challenges that does face a lot of health and social care professionals is trying to understand- what is the best way to try and approach these kinds of situations, and often there are this lack of referral pathways of trying to figure out, you know, if somebody is in an acute mental health state that requires sort of urgent attention. It's trying to figure out- how do we actually navigate and manage at this point?

**00:31:13 Jeff**

There are certain areas where there are protocols in place. If, you know what it is you're supposed to do, whether that's a referral to psychology or psychiatry. But many areas are actually lacking in this, and I think it comes back to that barrier of- fear of opening up that kind of worms. If you're a journalist, nurse working within an acute setting, you're maybe focused on what it is you're doing and thinking well, if that's an issue related to mental health, that's up to mental health practitioners to pick up on that and thinking it's the referral onto there.

**00:31:44 Jeff**

But even if that referral is made, what are you doing in the here and now? So, I think it's a combination of people feeling they don't have the confidence, they don't have the skill and it's about trying to upskill, provide that training so that everybody is able to do something at least here and now and ensuring onward pathways for support are provided.

**00:32:06 Lydia**

And I think, perhaps not in my clinical role, but certainly since I've left my clinical role, whenever you talk to somebody like, you know, we've had previous podcast guests, whenever you talk to them about, you know, where people are scared of saying something wrong or scared of not saying it right.

**00:32:23 Lydia**

Quite often people are like- just go for it and say it, because actually in that moment that person's wanting you to say it and wanting you to address it. So it's quite often not opening a can of worms because they've already thought about it.

**00:32:35 Lydia**

And it's actually that it's a bit of a relief- Thank you for bringing that up. I really wanted to talk about that, but I didn't know how to bring it up.

**00:32:40 Lydia**

So yeah, I think that's a really good.

**00:32:43 Lydia**

And I think the important thing is trying to address that stigma in around mental health conditions, whether they're diagnosed or not, and often I have seen as part of admission processes there is that question that often appears- do you have a diagnosed mental health condition? And often it's that- yes or no.

**00:33:01 Jeff**

And often if the response is no, it's moving on. But for many people you know, maybe they're not living with it, you know, as being a diagnosed condition. But they are living with those uncertainties and they are living with those anxieties.

**00:33:12 Jeff**

And it's about just creating that space for that individual to talk about, well, what's going on for you and what can I do for you now today?

**00:33:21 Paul**

It might be a good time to kind of move the discussion slightly to maybe talk about how mental health care in cancer settings can be perhaps made a little bit more inclusive and, and tailored to individual needs. As we've we've heard a lot of of where the gaps.

**00:33:38 Paul**

So Jeff, from your point of view, how might cancer care settings become more inclusive and perhaps, you know, offer a more tailored approach to individual patient needs?

**00:33:51 Jeff**

I think it's very much focusing on the person that is in front of you and getting to the full extent as to- what is their story. As I mentioned earlier in the podcast, everybody comes with their own story and we have this, you know, unique opportunities, health and social



care professionals to figure out what is going on in their lives, and where can we best provide this support here and now as a health and social care professional?

**00:34:18 Paul**

And and I think some of these, kind of, you know, kind of touches on all of the the whole holistic view of of people, and, and Jeff you mentioned holistic needs assessments.

**00:34:32 Paul**

Is there anything else you want to kind of elaborate on that, that, that might be helpful?

**00:34:38 Jeff**

I think you if we're coming in as health and social care professionals, we're very good at using this term- We've completed a holistic needs assessment, but it's about trying to break down- What are you actually doing when you're completing a holistic needs assessment? Are you looking at that person from a complete psychosocial, spiritual perspective of understanding what's important to them physically, mentally, socially, spiritually, and how are we actually addressing those needs?

**00:35:06 Jeff**

It can often become very easy as clinicians to get focused on to those physical aspects- managing pain, managing symptoms. But are we spending time with our patients and talking about- how are you managing socially? How are you managing spiritually? Is there anything that we can do to help you as you navigate through your cancer experience?

**00:35:32 Jeff**

So it's about making sure that we're spending time and and focusing on all of these elements that are important to the person that we are caring for, and consciously making that effort and asking those direct questions related to psychosocial, spiritual aspects.

**00:35:49 Paul**

Siobhan, so kind of just listening to Jeff there, is there any reflections that you might have?

**00:35:55 Siobhan**

I think it doesn't necessarily have to be the clinical nurse that has that conversation, sometimes about other people who work within the ward setting or whatever setting it is, I mean, I'm a mother of five. Nobody ever said- how are the kids doing? And that would have been enough for me.

**00:36:11 Siobhan**

Because actually the kids were struggling, and still struggle a little bit and they're still very aware that I was ill and they could have lost me. I mean, they were never going to lose me. But that's how they see it. So, you know, even if somebody said, how are the kids? How are they doing? How are the grandkids? You know, that sort of stuff, even that kind of conversation.

**00:36:30 Siobhan**

So, there's other people and other opportunities within the ward for people to do that, although absolutely the holistic assessment is the way to go. But my worry, being a past practitioner and also, sometimes people do tick all the boxes rather than, as you say, ask those questions, even if it is in that setting. So there are other people within that setting that can fade into that process.

**00:36:53 Jeff**

And that's a really important point, Siobhan. We get very focused and we have done as well in our podcast. We've used the term health and social care professionals, but who are we talking about when we say health and social care professionals? And at least from my perspective, This is everyone's responsibility. We all have a key role where we can pick up with an individual and ask them what's important to them. If it's an issue related to mental health, don't think as a generalist nurse, but that's that's the role of the mental health nurse, you can do something in the here and now that actually can be very important and very powerful for the person you're taking care of. And the one thing that stuck with me after many years, is somebody always said to me- as a patient, you will never remember what somebody's done for you, but you'll remember how they made you feel. And picking up on what's important to that person is the key way to being able to deliver that full, as we're using our term, 'holistic person-centeredness'.

**00:37:51 Lydia**

Yeah, I think you know within this conversation, we obviously wanted to talk about inclusivity of mental health and cancer care, but actually we're touching on so many other subjects here, aren't we, of person centred care, good communication as well.

**00:38:06 Lydia**

It just shows how important that sort of like, well-rounded approach is to bring, to bring to sort of like everyday conversations.

**00:38:14 Lydia**

And sort of thinking about best practice, I think it would be really good to hear probably from both of your opinions really, of how you think it would be best to approach

supporting an individual who is struggling with their mental health during cancer treatment or during a cancer diagnosis?

**00:38:33 Siobhan**

What worked well was people being honest with me and open and, it would be wrong of me to say it was all awful because it wasn't all awful. It just could be better. So I have to lay that out there first. I've said it before, I know, but I suppose if somebody had just asked some of those simple questions and said- I see you've got it, even if they asked me about my mental health, I'd be quite happy to say- yeah, I'm doing OK or- are these medications because? And how are you feeling today? And then from there pick up and have a quick conversation- and how is this treatment affecting you? And- are you OK? And, you know, as simple as that, it doesn't have to be desperately clinical, it just has to be that conversation where I could maybe openly say- do you know what? I'm really struggling, and my medication's not quite as good or- do you know what, I could do with talking to somebody else or.. just enough to open that door. So then from there, and it's interesting because we talk about referrals, and referrals quite often take a long time and that's the other issue. We can refer somebody on, it's three months before they're seen by which stage you're halfway down the process anyway. But you know it's about making sure that we can have those open conversations and Jeff did talk about it earlier, not being afraid to have the conversation because let's be honest, we all know something about mental health.

**00:39:49 Siobhan**

We might not know the detail around schizophrenia or bipolar, but we know that people have issues and- talk to them about it. So I know I'm simplifying it, but that would have been enough for me.

**00:40:02 Siobhan**

So that it could open that door and refer on.

**00:40:07 Jeff**

I just want to echo what what you've said, Siobhan. It is very much that, coming back to that key skill of communication and engaging in that conversation with somebody about what's going on, giving them the permission that- this is OK. I am this safe space of, you know, someone you can talk to about this conversation.

**00:40:14 Siobhan**

Yeah.

**00:40:26 Jeff**

But in terms of providing that support, and support will vary for individuals depending on where they're at, but immediate support of what you can do- identify, you know, beyond leaving that consultation, that appointment today, you know, is there somebody you're able to talk to maybe about this situation at home? What social support networks are available there for that individual?

**00:40:47 Jeff**

Does anybody else know about what's going on? Do you feel able to talk to anyone else?

**00:40:51 Jeff**

Maybe as the health and social care professional, if it's a loved one, maybe they're sitting in the waiting room and maybe you could help to facilitate or at least start that conversation or give the patient you're looking after those tools that they feel equipped that they can go away and talk about this situation with somebody else.

**00:41:08 Jeff**

And identifying those ways of, well, how am I going to be able to manage this? What is it do I need that's going to be able to help me, maybe from a pharmacological or that non pharmacological perspective? And maybe you're a health and social care professional, maybe you're not in that prescribing capacity, but we all work within our multidisciplinary teams and it's about working with our colleagues and identifying- what else could we be doing here and now, sharing the learning amongst our teams and identifying- Is there anything else that we could actually be doing, let's not undermine the importance of supervision and debriefing from situations because we can all learn from different experiences that will ultimately impact on patient care and that patient experience. And then of course we have our further signposting and referral pathways and Siobhan, you're absolutely right in what you're saying- A pathway for a referral could take a very long time before it's getting picked up, and that's why it's so important to be able to do something in here and now to ensure that a situation can be managed but ensuring that there is going to be that onward continuation of support because you might not be that same health and social care professional who will see that patient again, so it's about ensuring that continuous aspect of care, being able to um, be ongoing.

**00:42:27 Lydia**

And when you talk about that here and now Jeff, are there any resources or tools that you could recommend or you found particularly helpful in the past, that our listeners could perhaps engage with in that moment?

**00:42:42 Jeff**

I think one of the important things that spans across all health and social care professionals is your communication skills, and communication is the key to the success in all of this. It's about having confidence to have conversations and being able to progress those forward. There are advanced communication skills courses which are offered throughout the UK.

00:43:00 Jeff

And if you haven't had the opportunity to be part of one of those, I would, you know, strongly recommend identifying if there's possibilities for those within your own locality or within your own trust area, and also very much maximising what is within your own local trust.

**00:43:17 Jeff**

So identifying if there are pathways and protocols existing, what are they? Do you have easy access to those, and do you know them, or if not, is there kind of a cheat sheet that could be available within your clinical area that you're able to access to know if you're faced with an acute situation, how do you manage that in this moment?

**00:43:37 Lydia**

And previously as well, you sort of mentioned in terms of one person not picking up all of that work and sort of sharing it. You know, you may not be a prescriber, but you've got other people in the team. Do you have any thoughts on how we can work more collaboratively as a healthcare workforce?

**00:43:56 Lydia**

Perhaps even, you know, including not just oncology teams, but perhaps how they could work with their local mental health teams. Any advice there?

**00:44:05 Jeff**

I think it's part of our multidisciplinary teams. It's about ensuring everybody is sitting at the table, who, who has a place to be there and often mental health practitioners, whether they're mental health nurses, psychologists, often don't necessarily find themselves at that table. So it's about creating scope and capacity as to- is this the way in which the team can be expanded as to who else needs to be sitting at the table.

**00:44:29 Jeff**

But I think within our teams, it's about making sure we're maximising who is currently there. If we're having multidisciplinary team meetings and we're picking up on patient care, making sure that everything is identified across, umm, what's important to that individual, beyond those physical aspects. So what else is going on from that psychosocial, spiritual

aspect and making sure that those are being routinely addressed at each appointment or each consultation. So whether that's a speech and language therapist who might be seeing the patient on the Tuesday who won't maybe see them for maybe another week or so. But in between time a dietician might be out to see that professional, ensuring that they are abreast of what is actually going on and that they can pick up that reassessment of maybe any mental health concerns. So that might be- I understand, whenever the speech and language was here two or three days ago, you had a conversation about this, how are you doing today. So it's just about that ongoing continuation of care that it doesn't just fall to one health and social care professional, that we're all bought in and that we're all engaged in this important aspect of care.

**00:45:32 Siobhan**

Can I just pick up there as well and it's about the aftercare. When I say aftercare, when somebody say has a short term of cancer treatment and it's done and dusted like mine, that its picked up with the professionals that they then work with, or whatever, or the support groups or the peer support- and that's vital.

**00:45:51 Siobhan**

So the beginning is great and you're right and it has to be right within that setting, but also it has to be taken out into the community, and I have actually met a fabulous GP who really got mental health, but it's like- all of us, all of us have, all of us, including me, as a patient, have... what's the word I'm looking for? We should be, as part of our responsibility- that's the word I'm looking for- responsibility to be looking out for our fellow human being. And it's not just about professionals. It's about all of that. So, you know, once we're chucked out of this of the clinical system, making sure that's ongoing.

**00:46:28 Lydia**

Think you've made a really great point there, Siobhan, and it really sort of highlights how important person centred care is and treating people as human beings. So thank you for that.

**00:46:40 Lydia**

Just to sort of close off the episode, I want to move on to our final feature where we ask three questions of all of our guests. So Jeff, if I could start with you, if you could go back in time to the start of your career, what piece of advice would you give yourself?

**00:46:56 Jeff**

Gosh, I think if somebody told me 10 years ago that I would eventually become a nurse, I think I would have laughed at them because I'd just never seen that where my career

trajectory was going. So I think the important thing for me is- trust the process and learn from the experiences along the way.

**00:47:12 Lydia**

Great. And Siobhan, if you could go back in time to when you were first diagnosed, thinking about obviously the topic of mental health and cancer, what advice would you give yourself?

**00:47:24 Siobhan**

I think the advice I would give myself would be to ask more questions, to seek out the answers. Really, even if it's only about the medical stuff as well as my mental health. Just to ask more questions, see where I could get help, because I didn't.

**00:47:44 Lydia**

Lovely. Thank you. And Jeff, what change would you like to see to improve the lives of people living with cancer?

**00:47:51 Jeff**

I think for me it's really important that people are actually getting that care and support that they need, and they're being equipped to manage those uncertainties, issues, anxieties as they navigate their way through their cancer experience and living beyond afterwards.

**00:48:08 Lydia**

And Siobhan, what change would you like to see to improve the lives of people living with cancer?

**00:48:15 Siobhan**

I guess there's that wider aspect of, and it is much improved that we all talk more about cancer, thank goodness. And it's not the big C as it used to be, nobody discussed it. So I would like to see this more openly discussed, that people share their experiences.

**00:48:32 Siobhan**

That they we become role models for people following behind. That said, look, I've done OK. You'll do OK too.

**00:48:40 Siobhan**

That's one of things, and that people can access the services they need as and when. And that, as I say, becomes more of general conversation within the workplace, within clinical settings and outside of clinical settings in the community.

**00:48:56 Lydia**

Jeff, finally, what would you like listeners to take away from this episode?

**00:49:00 Jeff**

For me, it's for health and social care professionals to step up and to step forward into having these courageous conversations.

**00:49:09 Lydia**

And Siobhan, final take home message. What would you like listeners to take away from this episode?

**00:49:14 Siobhan**

I think I'd like them to listen. Listen to what we're saying. Communicate better with us, make it more of the everyday conversation within that setting.

**00:49:24 Paul**

As we bring the episode to a close, thank you so much for your time today to talk about this important topic. I think we've learnt so much from you both today and it has been really thought provoking, talking about where the gaps are and how the healthcare professionals can maybe start to identify those patients who might have mental health needs at the same time as a cancer diagnosis.

**00:49:47 Paul**

And thank you both so much for being so open and honest with us today. Thank you.

**00:49:51 Siobhan**

Thank you for asking us.

**00:49:53 Jeff**

Thank you.

**00:49:55 Paul**

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**00:50:17 Lydia**

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If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by Af Marseh, who was diagnosed with testicular cancer, and Callum Metcalf O'Shea, Advanced Nurse Practitioner and UK Professional Lead for long term conditions at the Royal College of Nursing.

**00:50:35 Lydia**

Together, they talk about the importance of person centred care and the difference it can make to a person's cancer experience.

**00:50:42 Paul**

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**00:50:56 Lydia**

I'm Lydia

**00:50:57 Paul**

And I'm Paul, and you've been listening to the Cancer Professionals Podcast by Macmillan Cancer Support.