

The Cancer Professionals Podcast

The power of person-centred care

(intro music)

00:00:10 Paul

When care is truly person-centred it changes everything. But how do we make it happen?

00:00:15 Af

Person-centred care, it can be the difference between a manageable journey and a quite frustrating cancer journey. I still hold the people in my heart dearly that gave me a positive cancer journey.

00:00:32 Carly

Hello, I'm Carly and my pronouns are she/her.

00:00:35 Paul

And I'm Paul and I go by he/him. 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.

00:00:51 Carly

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00:01:11 Paul

In this episode, we explore the power of person-centred care, what it truly means, why it matters, and the real difference it can make when we get it right. We're joined by Af Marseh, who was diagnosed with testicular cancer aged 29. He shares his personal journey, reflecting on the moments when care felt truly tailored to him and the times it didn't. His story highlights why seeing the person beyond the diagnosis is so important.

00:01:39 Carly

We're also joined by Callum Metcalfe-O'Shea, an advanced nurse practitioner and professional lead for long term conditions at the Royal College of Nursing. With years of experience supporting people with cancer, Callum shares practical insights and top tips on how healthcare professionals can embed person-centred care into their daily practise.

00:02:02 Paul

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

00:02:11 Carly

Welcome Af and Callum to The Cancer Professionals podcast.

00:02:15 Callum

Hello.

00:02:16 Af

Hello.

00:02:18 Carly

Thank you so much for being here today to talk about person-centred care. So, shall we start with some introductions? So telling us a little bit about yourself and your background. So Af can we start with you?

00:02:35 Af

Yep, so hello everybody. My name is Af, it's Af Marseh is my full name. I am working in events, usually in sports. I was diagnosed at the age of 29 with testicular cancer, went through some chemotherapy, and that was a few years back now and then since then have remained trying to put a positive impact into the cancer community and I'm an ambassador for a couple of charities. I've written a book about cancer and yeah, so just trying to pay it forward, really with with a lot of the what was given to me back then.

00:03:13 Carly

Thank you and Callum?

00:03:16 Callum

Yeah, hi, hi, everyone. Yes, I'm Callum Metcalfe-O'Shea, I'm the UK professional lead for long term conditions at the Royal College of Nursing. And as part of that role, I support the cancer portfolio. However my background is I am a nurse, so I'm still working in primary care, specialising in long term conditions and in terms of my cancer experience, what what I've been involved in is I was a previously for cancer care reviews in a practice and I've worked with patients many years living both with and beyond cancer and really great to be here today to talk about the importance of person-centred care particularly about the benefits it can bring, and also about how workforce, particularly around nursing other healthcare professionals, are really key to supporting individuals. So yeah, it's really great to be here and have this opportunity to discuss it further.

00:03:59 Carly

Lovely, thank you so much for joining us. So as you've mentioned, Callum, this episode is about person-centred care. So I think it could be a good start to really define what person-centred care is. So yeah, Callum, could you tell us a bit more about actually what we mean by person-centred care?

00:04:20 Callum

Yeah, of course. So I think when we look at person-centred care, it's really about focusing on the care of the needs of the individual and from that, it's really looking at people's preferences, their needs and their values. And for us, as healthcare professionals that can help then guide some of our clinical decisions, but also make sure that we're providing care that's really respectful and responsive to individuals. I think that's really key working with individuals to make sure that they feel they're at the centre of all the care that's delivered. I think particularly it's about how we work in partnership. That's really key because we know that evidence can show that provides better patient outcomes by doing that. And also if I look at sort of my profession and other healthcare professionals, we have really key skills to support this process and that's through our strong relationships we build with individuals, but also what we mean by an holistic approach. So this is looking at a whole person. So that's considering many different factors, not just maybe the physical symptoms, but lots of other ways that we can support them further, so psychological, emotionally, spiritually, there's lots of ways that we can do that and this can take place in lots of different settings in both what GP surgeries, in hospitals and again, a lot of professionals are involved to do this. So yeah, I hope

that gives a bit of a sort of a setting, the scene for what we mean by person-centred care.

00:05:38 Carly

Yeah, it does. Thank you, and Af, I'm actually interested to hear from your perspective, what does person-centred care mean to you?

00:05:49 Af

I mean person-centred care, it can be the difference between a manageable journey and a quite frustrating cancer journey. I think there's obviously so many stages of the diagnosis and the treatment stages. And yeah, there's different approaches to the person-centred care as well for that I mean I was diagnosed, uh, eight years ago now and I still hold the people in my heart dearly that gave me a positive cancer journey and I was actually diagnosed, well, the first time they did the scan and found a tumour I was in Brazil. I was in Copacabana hospital so quite the fall from grace. I went from Copacabana beach to Copacabana Hospital and the Brazilian Healthcare is different to the to the UK healthcare system and yeah, like I said I remember the people that treated me. It's a part of your life, one of the most important and traumatic times of your life. So yeah, it's about not feeling like a patient and and feeling like a person, a friend, valued, and that doesn't just happen. When someone's going through a cancer journey, it's not just that person that's in the treatment chair, it's the family around them, the support network, the friends. So with, with patient-centred care as well, that can actually mean extend to that support network as well.

00:07:22 Carly

Yeah, I think that's a really interesting point, that person-centred care isn't necessarily just about the person with the cancer diagnosis, but actually everyone around them. One thing I was interested Callum, is for you what does person-centred care look, what can it look like in practice?

00:07:39 Callum

Yeah, I think it's a really good question. And I think it differs depending on the sort of clinical area you may be working in and sort of your background and the experiences you may also be able to bring, you know Af talked about that from, from his personal perspective, but also think from a healthcare professional, we obviously have lots of experience of working in different settings and different with

with different people. You may have different experiences of cancer and also personally whether that's individually or as loved ones. We know cancer effects, so many people. So I think in terms of what it can look like in practise is a way about how we can structure that approach and a really good way of doing that is the holistic needs assessment. So Macmillan have the holistic needs assessment that we can use and this is really great for our healthcare professionals who can help to have those conversations with patients a bit what I talked about earlier around some of the different areas of of cancer care, not just maybe the physical symptoms but emotional, practical, financial or spiritual concerns that may be impacting them. But you know, Af talked a lot about this, about having having being a person not a patient. And that's where that person's at the heart of that decision making. But its about allowing those individuals to be involved in what they do. You know, sometimes within healthcare settings just due to the nature of demand and that busy-ness things are happening, we can often focus very much on a certain scenario at a time, but actually it's allowing that individual to be involved and allowing them to guide the consultation, guide with their decision making and say this is what's really important for me. So I think that's a really good way of, of being able to do that in terms of how we can, what it can look like in practise.

I think it's just really important that we're working with our team as healthcare professionals. You know, when it comes to living with and beyond cancer, we have to recognise that there may be times when we need to refer to different services or different specialists to help support that individual as well. And it's just about having really good communication and I know that's something we are we fall back on a lot in healthcare profession, but it is it's really important we have appropriate communication but allow that individual to guide that communication as well and understand what's important for them, because sometimes we may come in and think this is what the, you know, main concern may be, but actually that individual may come back and say, no, actually this is what I want to focus on today. So I think just some points there about what it can look like in practise, but particularly how we can structure it using a holistic needs assessment tool.

00:10:01 Carly

Yeah. Thank you. Yeah, there's a lot of different things in there isn't, isn't there? So you mentioned about the holistic needs assessment. You talked a bit about how people can be supported living beyond cancer and then also of course the

importance of communication. Af, I was interested to know, did you have a holistic needs assessment at any point during your cancer experience or anything similar?

00:10:27 Af

Not that I could not that I can remember, but to be honest, there's so many things going on during a diagnosis and so much information that you can't even withhold, you know about your medication and things like that. So it it it's so much brain fog going on during a diagnosis that even if people are handing me leaflets or something like that, it is soon gone and forgotten about. So I wasn't actually given that approach. But in the terms of the things that Callum mentioned, I was privy to a lot of those things in terms of the financial support, I had some spiritual support, but not not necessarily directly from healthcare. And yeah, yeah, I feel like it did have probably a holistic support, but it wasn't as branded as that or titled as that.

00:11:25 Carly

Yeah, absolutely. And like you said, you know lots of things going on and actually you would have been part of lots of conversations. So actually, you know, being able to take it all in is a different thing, isn't it? When Callum talked about communication, I was interested to know whether you'd be happy to share any examples of communication that you had had, or interactions that you had had with healthcare professionals, maybe conversations that you felt were helpful and were person-centred but then even on the flip side, whether there was any that wasn't so helpful for you?

00:12:08 Af

Yeah, I I think the thing with communication and like I said, I I'm involved lots of cancer communities and charities and I get this feedback and I have people contact me every single week, multiple people, a lot of the messaging from people who are newly diagnosed is the biggest bugbear is they think sometimes healthcare professionals are withholding information from them. So a lot of my messaging to those people is actually they probably don't have the results right now. They don't have the information. So that can be a big part of what can break down communication between a healthcare professional and someone receiving treatment is that thinking that there's a lack of trust there. So I would say that's the important thing with the communication and and that can go as far as a line of "we won't know the results until we get the results of these tests". I feel like there's a lot of that, just a miscommunication.

Also, I had health care professionals give me a lot of medical terminology, which was way over my head again at the time when you have a lot of brain fog going on. Just before my surgery, I was about to have a testicle removed and that all happened within about four days of getting a diagnosis and the the surgeon was talking about. He actually said so the tests have come back and they show that you're pregnant. And I was like what? And he said, yeah, you got your HCG hormone is very high right now and the AFP hormone. And I was like, I have no clue what you're talking about right now you're about to remove a testicle. Have you got the right person in here? Obviously, then found out testicular cancer. Is it that over-active HCG hormone, which if you were to pee on a pregnancy stick and all that it would test that positive but at that time it was total gibberish to me. It made me even more nervous about the procedure that was about to happen. And and my mum and sister were in the room as well at the time. And and he was started basically talking to them as if I wasn't there or that I was a small child and I was 29 years old at the time. So that, yeah, it it just caused a lot of confusion, which then actually erupted into the waiting room with a big argument between my family. So, you know, these sorts of things spill over into other scenarios where tensions are already high.

00:14:42 Carly

Before we move on, just a quick note to highlight that while it's known that testicular cancer can lead to a positive pregnancy test, this isn't the case with all instances of testicular cancer. Any symptoms suspicious of testicular cancer should be properly reviewed and investigated by a clinician.

00:15:02 Af

But on the flip side to that, obviously I had many amazing positive experiences with healthcare professionals and I think the thing about my experience as well is I was treated at a city Hospital which is very busy. It's like a conveyor belt of patients. You are a bit of a number because you actually take a number from a sort of meat raffle counter style thing for your blood test. But I was also treated at a County Hospital and and a hospital in a town, and there was a massive difference. And I understand that the the busy-ness affects, you know, the the patient care and everything as well. But that difference of yeah, feeling like you're a you're a person and I had the e-mail address of the person at one of the smaller hospitals. So if I ever had a an evening pain or anything like that, I would e-mail them and they'd say, oh no, that's fine or yeah, come in for a blood test or something. Whereas my

cancer nurse at the city hospital it was a lot more phone this line, go on to hold and and all this stuff. So that was a lot more nerve wracking and and pressure and stress.

00:16:01 Carly

Yeah. So it sounds like then the the difference between the bigger hospital and the smaller hospital was very much aligned to what you were talking about earlier about feeling like you're a person and not just a number or not just a patient. And of course there will be people and professionals who are working in big hospitals, which, you know, perhaps might be their closest hospitals so the one they need to go to. But from your perspective, what what else do you think could have been different or could have been better for you and your experience to help it be more person-centred at that time when you were going to that bigger hospital or what would have made a difference for you?

00:16:48 Af

To be honest there, there's nothing tangible. It's it's a, it's more of a feeling. Than say oh, I could have free car parking or there's a better check in system so it it's more about the people and that probably comes again with with the the the busyness of everything. But there was amazing healthcare professionals in the city hospital. But yeah, they spoke to you like a friend, they had energy. The, the, the nurse ward at the City Hospital was absolutely amazing. My my, my grandma recently passed away a couple of weeks ago and she was in hospital for about 10 days. And all the family were visiting and everything, and and my cousin said something to me whilst we were outside getting some food and they said, oh my God, I I can't stand it here, hospitals are so horrible, it's it's like, you know, you just feel that you don't wanna be there, you know? They said to me, you must feel this way. And I was like, no, I feel totally fine here. I feel totally relaxed. Hospitals now actually fill me with hope because there's so many people doing an amazing job 10-12 hours a day that why would you feel nervous coming into this place? These people are doing the utmost thing to keep people alive and and healthy. So yeah, as a as a cancer patient now, I'd actually just feel safe in the hospital.

00:18:30 Carly

Well, that's great to hear.

00:18:31 Callum

That's really great to hear. Yeah. Really nice to hear that.

00:18:34 Carly

Yeah. I'm sorry to hear about your Nan as well. And so hearing Af's experiences as some of the examples that Af shared, Callum, is there anything from your professional perspective that you wanted to add to that?

00:18:47 Callum

Yeah. I just want all of the healthcare professionals who are listening to take that away. I think Af talked a lot about how we don't address the condition we address the person and I say I think sometimes in the busy-ness of a clinical setting, whether that's in hospital, GP, lots going on sometimes we can get very condition focused, you know, this is the task at hand and this is how we need to to complete that as such. But actually there's so many different factors going on and just taking a couple of minutes to address that and really have those open, honest conversations. As Af said and being transparent and actually maybe saying, I always say this to a lot of my nursing colleagues or students, that don't be afraid to say you don't know all the answers because that will there will be time when that happens. And actually as you know an individual, they really respect that and you know feel a lot more open and being able to trust that individual, that healthcare professional following it. And I think for me all these conversations we've talked about today actually a lot of it comes back to for me workforce particularly if I look at a nursing workforce at the minute. In some of the barriers to living potentially person-centred care because everyone is busy, everyone is stretched. And you know, it's not just in nursing and it's in other healthcare professions as well that we are finding some of these barriers to impacting or having conversations can be because there is just so much going on and so many more patients that we need to care for in, in a limited time, but it still doesn't take away the opportunity just to have open, honest conversations to really deliver that person-centred approach. So yeah, Af, thank you for sharing your experience and whilst I understand there was some challenges, it's really great to hear from, particularly from a nursing aspect that you had some really good interactions as well. So yeah, all healthcare professionals really take that way when you're listening to this, that importance of not being just condition focused, but person-centred.

00:20:31 Paul

So thinking about from a practical point of view and and I'm kind of going to come to perhaps come to Callum first, you know for our listeners, can you maybe share some really practical examples of how professionals can really make sure that their care is really person-centred? And I know you've already mentioned kind of the communication angle and and we do have a a podcast that we've done previously which has talked about some of the importance of that, but you know from a really practical point of view cause we've we've got a really broad audience who are listening to this episode.

00:21:12 Callum

Yeah, of course. I mean, I think one of the biggest part of obviously is sort of setting the scene again, if we come back to that and and really allowing what we call a culture of psychological safety and what we mean by that is where we give opportunities for individuals to air any concerns but freely and again, coming back to recognising what is important for them and giving them a safe space to do that because you know, Af, talked about busy-ness, lots of different consultations, that brain fog from a diagnosis. And actually at times, no matter who you're communicating with, if everyone feels safe psychologically to be able to air concerns and really address some of the issues that matters for them, that's a really effective way to start. The scene is safe or promoting person-centred care, which, as we said, we talked about communication, but open questioning is really key I think that allows individuals to be able to again start conversations and really recognise what's important for them, and we spoke a lot around holistic needs assessment and that tool to structure approach and for those who don't know in primary care we utilise a consultation called a cancer care review, which is where we can do this at three months post diagnosis and 12 months post diagnosis to have conversations, and that's again where that holistic needs assessment comes in as an effective way to to start person-centred care where you really addressing those individual needs.

I think for me one of the biggest ways of being able to support individuals is having a strong what we call therapeutic relationship. So that's professional relationship between an individual and a healthcare professional. But from that, you know, Af talked about those really great interactions of people feeling like your friend, and you feel really comfortable with them. And that is a really, really important thing we have to take into account in, you know, a cancer journey. There's lots happening. You know, there could be ups and downs, but if there's some individuals there that

people feel they can trust and who they can go to when at times of worry or need. That's really important because people, as I say, feel they're being cared for and looked at as a person rather than a condition. Another way I think is understanding that health, particularly across the the journey of a patient with cancer, not all healthcare care professionals may be specialists in that particular cancer. But they're again as healthcare professionals, nurses, paramedics, doctors, whoever you may see, if we don't know the answers, we can sign posts or refer on to different specialties who can support that as well, and I think it comes back to this not being afraid to say, maybe, I don't know now, but I know someone who does. Or we can look at how we can do this together.

And then finally, I would just want to talk about empowerment. I think allowing an individual to feel empowered during a consultation, conversation, interaction. So we focus not just on some of the negatives or some of the you know, side effects of treatment or what may happen in the future, but the positives about what's happening now and where you're at and that journey and what you can look forward to and what you can expect post treatment, so hopefully just give some practical examples there for what you can look at in the different healthcare settings.

00:24:09 Paul

And Af can I just ask, do you think the way you approached the healthcare professionals that you kind of met along this journey, how how you approached this do you think that was a kind of a factor in in kind of how you were treated?

00:24:31 Af

It it may, I think it probably did as the journey went on, so if I had a not so positive experience with someone at the start I was less likely to form that bond by the end of it. There would always be, you know, someone else that could actually bring me that light and that that energy. And yeah, if there was someone that you connected with you would stay connected with them and you would purposely try and find them out and you would as as crazy as it sounds, you'd be excited to go to some of the sessions because you got to see that person again. And that was one of the things I wanted to say is when you leave, your final treatment there's a bit of a gap and a psychological gap. Because in a way I wanted to go back and personally thank everybody that had affected me on that journey. But you can't just like rock up to a chemo ward one day and go "Hey, I've got you a cake". But there was

something missing from me that I personally wanted to go and thank everybody, and I hope that, yeah, anybody listening knows that even if you haven't got a personal thanks, it's in our hearts every day that we wish we could.

00:25:59 Paul

Thank you for that's, you know, really kind of heartfelt there, I really felt that. And Callum, could I just come to you and ask in terms of you know we've talked about kind of primary care, secondary care and and and their experiences around being person-centred. Is there a difference? Is it the same?

00:26:22 Callum

Yeah, it's it's a really great question. And honestly in terms from healthcare professionals it's questions we have in that setting as well is what happens in primary care, what happens in secondary care. So if we're looking at a GP setting to a hospital setting for example. So if I sort of look at the patient journey, that's for me why I think it's really important to understand those contacts and the different clinical setting. So if we start from a primary care, so a GP setting for example, and the interactions an individual may have with nurses, doctors, healthcare assistants, different individuals there. But it's really opportunities to support, really, essentially around early detection and diagnosis of any cancer symptoms. So if there's any red flags that may come up or something that doesn't seem right about again understanding the processes and how we can get that early detection. But again, it's a really good opportunity for healthcare staff to educate patients on signs and symptoms of particular cancers or have those open discussions again about what they may need to do and who they need to go to. And obviously we've talked a lot today in primary care around the Cancer Care review. So where we're doing that review at three months post diagnosis and 12 months with that holistic needs assessment because it gives the opportunity to allow the individual to understand what support is available, where they can be signposted to. And for me personally, as you know, my role here at the Royal College as the lead for long term conditions. It's great to see that cancer is now being recognised as a long term condition and that actually we need to provide that further dedicated support for patients who are living, you know, beyond cancer as well. And that's where primary care can really have a good opportunity to do that. You know, working with different teams, professionals. And having again make it we say in the NHS, making every contact contact counts and I think that's really important when it comes to primary care as well having those opportunistic discussions for patients either living with or beyond

cancer. So for me that's where I see primary care that fits into it. And then in secondary care you know obviously it's really where we come down to the specialist treatment advice that's provided by all the different clinicians. And again, if we're thinking of a journey of someone living with cancer and beyond cancer, they will have a lot of interactions with nurses, particularly who are involved at a different stages. And that's where we can mainly nurses, but other healthcare professionals providing support through care pathway, liaising with different services, but also that can include liaising with primary care. And you know, we've got some really great work going on I know from NHS England in terms of how we're trying to promote that better communication between primary and secondary care for patients living with and beyond cancer as well. And we know the specialist services are vital in terms of that access to treatment and obviously identifying when patients may need to come back to them for further advice and support. So yeah, I think they they do have different parts to play, but it's really great to see that we're trying to improve the communication and for me, obviously nursing and healthcare professionals are key to be able to do that.

00:29:12 Carly

Yeah, thank you. I wanted to touch on living beyond cancer, actually, which you mentioned just now and also a little earlier as it's something we've touched on in other podcast episodes. So in the episode, just before this one, which focuses on mental health and cancer, we talked with a lady who was diagnosed with breast cancer and she talks about the support she received following her cancer treatment, but also was what was missing and I was interested to hear from you Af after you finished your cancer treatment and what support did you receive and what impact did it have?

00:29:50 Af

Yeah, so my life after cancer, it's been like I said, I'm I'm eight years down the line now. The first five years I think I described it in my book as like you feel like the Genie, the Genie in Aladdin, when you when he's got the cuffs taken off and he's finally allowed to fly free. You feel a bit like you're released from prison, but you're still on probation, right? Not like I've ever been to prison. But I'm guessing that's sort of what it would feel like. The first year was tough because that psychological milestone of the first year, you're just sort of living in doubt the whole time. In terms of touch points from from NHS, from the NHS and the healthcare point I just had my nurse from Dorset on an e-mail. You know, I had the regular tests every

three months for the first year and if I got really scared and nervous, I would e-mail her and she would respond and send me some more forms in the post or say this is normal or things like that. So that was excellent in terms of that, because to be honest, for the first three years, if I had a little back pain, I'd be like, oh my God, it's back. You know, you you live in doubt all the time. So having her on the e-mail was amazing, but in terms of holistic, I didn't really have anything apart from the charities which I again didn't dip into for years down the line. I got involved with Trekstock who are a cancer charity for people in their 20s and 30s. I'm part of a thing called the Cancer Club, which is a charity for men and there's a WhatsApp group and everybody talks and welcomes each other. And there's different channels in there. Sometimes people just want to talk about sport or Man United losing again or something like that. But but every now and then, you know, there's a sort of buddy up system and you have people to talk to and and everything like that. That is amazing. It it's life changing to be honest. But there wasn't that. There wasn't that, you know, like when you join a new job, you get an onboarding process. What? What is it when you leave a job?

00:32:29 Callum

An exit interview.

00:32:37 Af

Yeah yeah yeah an exit interview. Within the exit interview or redundancy I needed a package. I know some men have spoke to me about they've been given a little bag and it's got loads of leaflets in there and there's some charities to get involved with, communities to get involved with and and things like I wasn't given that at the time which. The counselling part, I would have loved to have had some counselling therapy. I've had that for for a different health issue in the past before cancer makes a major difference. Yeah, it was a bit like it's done now over back over to you and you're just like, oh, my God, what happened to this whirlwind part of my life? And now I'm just expected to just get on with it again and so holistic stuff was was difficult. I was unemployed as well at the time, so I had no job, had no income, I was back living with my mum, which was fine. I was like nearly 30, unemployed and single. So it was like regressing to being 15 years old again. So yeah, I didn't have much. I actively went and seeked it or sought it, whichever is the word, and but now like I said with with, with the book that I've put out into the world and I've done TikTok videos on my treatment and diagnosis, I've done Instagram reels on it. I have at least once a week a random person saying I've just

been diagnosed, the doctor's told me this, what next? And I'm like, you know, we become friends or whatever. And someone asked the other day they've got a wedding in April, his hairs about to fall, fall out. Will it grow back before his wedding? You know all these other questions that aren't necessarily medical questions, but how you're going to feel and act and be able to cope.

00:34:33 Carly

Yeah.

00:34:35 Af

So yeah, in terms of exit interview, I didn't really feel like I had the best one, but on the flip side of that, they don't want to give you a full exit interview because you're not totally gone so yeah some question marks, but it sounds like for other men that I spoke to that a big package of next contacts next steps is useful.

00:35:02 Paul

Is there anything you wanted to add Callum to?

00:35:04 Callum

Yeah, I definitely want to come in here at this bit. Af first thing I really appreciate you sharing your experience there and I think that's so crucial to recognise that again, when I've talked a lot today about today and not just being condition focused, but person focused and actually recognising, yes your treatment may completed but there is a you know as you say that we've now got to live beyond that aspect. And this is where I really feel primary care can come in and have those really key conversations with individuals and provide that signposting support that you were talking about and like for me, what something I think we all need to get better at in, in the healthcare world is actually using patient experts, patients such as yourself Af who have gone through that experience. If you know how to have those conversations and utilising in the communities you've talked about to be able to have conversations and really work together. And I think for us as healthcare professionals, it really helps us to understand right we know an individual what they've been through and what advice they can give to someone else. Going through that and having some of those conversations whilst we talk a lot about psychological safety, open questioning, sometimes individuals want to speak to someone else who's gone through it and really can relate to it, you know. And I think if I look at nursing and other backgrounds, we really try and be empathetic

but that lived experience, you can only get from someone such as yourself who is a patient expert. So I think that's a really if we're all healthcare professionals listening to this today, I think that's a really good point about how we can work with patients and utilise their experience and lived experience, particularly to help guide and provide resources and sign posting to others who are going or living beyond cancer.

00:36:36 Carly (ad)

Before we hear more from Af and Callum, here's a quick message about a new programme for primary care. Michelle, can you tell us a bit more about why this might be the right programme for our listeners?

00:36:46 Michelle

Of course, the person-centred primary care programme, launched in 2024 and it works through the process of implementing or improving either holistic needs assessment or cancer care review clinics within primary care practice. It's a blend of digital learning and facilitated virtual classrooms, which build skills and confidence ahead of your service improvement project. You can find out more on the learning hub.

00:37:11 Carly

That sounds great. For more details, see the episode description. Let's get back to the episode.

00:37:17 Paul

You know, I'm curious. What made you want to kind of go away and and write about your experiences and and where did the idea for the book come from?

00:37:26 Af

Yeah, I got the the all clear, I went into remission and I thought that's brilliant back to old Af. Let's go. I think 3 weeks after getting the all clear, I got a one way flight to Cuba. Went travelling, went to Mexico. Bad decision, too early for me to be doing that. And then gradually people started messaging me saying, oh, my friend's just been diagnosed. Can you talk to them? Or, my cousins just got diagnosis. Can you send them a message? And I'd always write them a letter and send it in the post. And it would be great. And people would connect and I'd try and support them through the journey. And and then, yeah, I thought rather than writing these

individual letters all the time, or I just put it all in a book, and then when someone gets unfortunately diagnosed, we can send them the book and it can be a support companion for for people going through treatment. And it's not just for the person through the treatment, because when you're getting chemo, reading is sometimes the last thing you want to do although it is on audiobook. It's written for the support networks of people going through it as well, and like I mentioned, all the all the healthcare professionals that I've spoke about today, they've all read it. They're all in the book and they recommend it to patients now. I've had people reach out to me saying someone in Dorset Hospital just sent me this book. So that's kind of cool because ultimately, like I said at the start, top of this conversation. It was trying to pay it forward of what support I was given through my journey. Because you cannot do it alone, it's all about support, support networks and the healthcare that goes on around it. So hopefully it's my little thing that can go into the world and I've been going around to companies and charities and I do talks and and I do stand up comedy now and and try and make some jokes about it.

00:39:25 Paul

It's great that you've been able to use your experience to write the book and be able to help other people, Af. Was there anything in particular that stood out to you or that came up in the conversations you were having that you wanted to write about and talk about in your stand up?

00:39:38 Af

I think that one of the toughest things about a new diagnosis is opening up the conversations about it. And especially for men, and especially for young men. So for men, some I spoke to, they held on to their diagnosis since the point of chemotherapy, even to their own family. Because they're meant to be strong, stiff upper lip. Keep calm. Carry on. But you know, we know cancer doesn't care for that. So I want to lower the barriers for, for communicating about it openly. Because when you do even mention the word cancer, it brings a sadness to a lot of people. People tilt their head in sympathetic ways straight away, so that you as a patient can't talk about it openly all the time and half of the the battle is, you know, a problem shared is a problem halved. So I can tell you for me personally as well, when I did the comedy, lots of things were in my head. Before I wrote the book, a lot of things are in my head, weighing down on my shoulders as soon as it's out in the world. It's not there anymore. I'm I'm happy, I'm content. Life is beautiful.

00:40:55 Carly

It is a really great book and as you mentioned, I listen to it as an audio book and it is no doubt it will no doubt be very helpful for people who are going through that experience and having that offering as a supportive tool for people you know to hear your experiences, and actually there'll be so much that professionals will be able to learn from your experiences as well. So yeah, it was a really great read.

00:41:25 Paul

Can you tell us what the book's called?

00:41:28 Af

The book is called Tumorous Hesticles: Just say cancer. The whole thing for me was, no one would say the word cancer around me. He's sick, he's ill, he's got the big C I'm like, just say it, my dad wouldn't say it until I got the all clear and I was like just say it. So I wrote a book about it.

00:41:53 Paul

Thank you Af we'll add details of the book to the show notes and you've kindly given us some codes to share with our listeners which will give them access to the audio book for free. We'll put details of how to claim one of the codes in the episode description. Callum, is there anything else you wanted to add because you look like you're itching to?

00:42:10 Callum

Well, yeah, no, completely right there. I think Af it's just it's really and it comes all back down to this lived experience, really great to to hear your views and thoughts today all around how as healthcare professionals, no matter your background nursing, say doctors, paramedics, etc, whoever any contact you have in terms of a healthcare professional some of the really important factors, again coming back to addressing the person, not the condition and not being afraid of you saying maybe to say we don't know all the answers or actually addressing the elephant in the room we've talked about, we say cancer and understanding that living with and beyond. And for me that's where it's really important as healthcare professionals, even if you're not a specialist or if you may not know all the answers about understanding what is important for that individual and working with them that you become. You know, Af you talk to you, become the expert around your symptoms

your diagnosis you. You know your journey, and I think that's so key today and that's why an opportunity to read or listen to your book. I think it's really great for healthcare professionals to really gain that insight and experience. We can often get lost in, as I say, the busy-ness, demands and what's happening and for me, I know every day when I spoke to patients and I get a thank you or they've just say actually this has made an improvement. That's what we're here for, that's why we get up every day and do that. And in healthcare, at the minute it you know it is demanding, it is challenging. You know I know nursing particularly has some issues around workforce pay and how we address that. But at the end of the day it's all about providing good patient care and I appreciate I know you had different experiences along your journey and but actually hearing those positives ones is really what drives us to continue to improve the standards so yeah, thank you for sharing for that today. And I would say I really hope there's some key messages that all healthcare professionals can take away from it.

00:43:54 Carly

No doubt there will be lots of things that we've talked about in this conversation that healthcare professionals can take away and to do to help ensure that they are giving person-centred care and providing that support. I wanted to ask you first, Callum actually, is there anything else, anything practical? So this could be maybe anything that you could signpost to any resources or even any practical tips that professionals would be helpful for them to to learn about and to hear about that they can take away if they're looking to build their skills in person-centred care.

00:44:34 Callum

No, I think that's a really a good point. And obviously Macmillan has some really great resources for our healthcare professionals to look at with a range of the different cancers. I know when I was in my role as a cancer care lead for that within the practice, they were really key to allowing us to signpost individuals and give them some quality evidence base for them to go away with and really understand their condition in a bit more detail now that they're in a different stage of either diagnosis or treatment, so definitely recommend coming to Macmillan in terms of looking at those resources.

Another practical guide which I found really useful is actually understanding what's happening in your local area for them from a voluntary or a charity perspective. Because there's so many different areas that have really great resources that

healthcare professionals can tap into. We've done some work with as a college with move against cancer who are an organisation to support physical activity. So again, there's lots of ways that healthcare professionals can work with organisations that may not be they may not know about, or it may not be sort of obvious from sort of some of the traditional referral routes. But there are so many organisations out there that can help support you as a healthcare professional to support the patients. So yeah, there would be definitely some practical measures I would think about understanding looking at their evidence base, which Macmillan has some really great resources on that about the different types of cancers. And again, just giving it a basic overview of cancer for those who aren't the specialist. If I'm thinking of like a primary care perspective, it's a really good opportunity, yeah, and understanding what's happening in your local area. So you can sign post patients and make sure they receive the support because you know they'll have a probably half an hour appointment with you in a primary care setting, but it's outside of that. Who else is available to help support individuals along the way?

00:46:15 Carly

Lovely. Yeah, absolutely. And you mentioned some of the resources and the learning resources that we have on through Macmillan. Yeah. So we have Macmillan learning hub and there are quite a few resources that we have on there that would that are centred around personalised care and support planning. And there's loads of resources on there, that could align really that align really well to this topic. So yeah, absolutely we'll pop a link to those in the in the show notes as well. But yeah, thank you and thanks for adding some of the other things that could be useful.

00:46:49 Paul

Thank you. So kind of as we bring the episode to an end, we've got a little feature where we ask all of our guests 3 questions and Callum, I'll start with you, if that's OK. So if you could, if you could go back in time to the start of your career what piece of advice would you give yourself?

00:47:10 Callum

Oh where to start? I think the first thing is about being courageous. Think it's really important in healthcare professions at the moment. Be bold, don't be afraid to challenge or question areas that you really want to make improvements. And I definitely think of an area I'd look at maybe not being afraid to say no at times,

depending on how busy you are. But yeah, that would be some advice I'd give myself.

00:47:30 Paul

Thank you. Thanks. Thanks for that and Af if you could go back in time to when you were first diagnosed, what piece of advice would you give yourself?

00:47:42 Af

I'd probably say don't panic Mr Mannering. I would probably, you know, this is what I try to try and tell a lot of people that speak with me these days is as hard as it is you've got to live in the moment you've got. You can't be thinking months down the line. You have to live it for now. Get to the point of acceptance as quick as you can. Don't sit in denial or anger or ignorance. Don't sit in those stages. Get to acceptance and communicate as well in in, however, that is whether that's writing or talking openly lots. I mean my family years down the line, said I didn't know you thought like that. And I was like, I thought exactly like that. And that's why you annoyed me that day. So I think communicate, communicate well and get to acceptance.

00:48:37 Paul

Brilliant. Thank you. That's really kind of honest, an honest answer there. Thank you. And Callum, I'll come back to you. What change would you like to see to improve the lives of people living with cancer?

00:48:52 Callum

Yeah. No, it's a great question. And for me, obviously, my passion, the background is primary care and I really feel this is an area you do need a bit more support and focus on, particularly around education and understanding of living with and beyond cancer and primary care. But if I look at our workforce, particularly our general practice nurses, I think they're really key to help support them and develop cancer specialism in the primary care setting, I think that would be really key to help improve the lives of people living with cancer and beyond it.

00:49:19 Paul

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

00:49:26 Af

Living with cancer, I'm not really sure today, but one thing I would like to see is like we spoke about earlier, the exit interview and the the beyond the Beyond Cancer, I know not everybody is fortunate enough to get to that stage, but living beyond cancer, I think there's a bit of a gap with the mental health side of things with, with the offering of counselling and the signposting that is the things I would add.

00:49:53 Paul

Good solid advice there. Thank you. And and last question, what would you like listeners to take away from this episode.

00:50:00 Callum

I think there's so much for that. I think I'd like to just start by saying primary and secondary care services are working tirelessly to improve cancer care across the UK and you know, for all those individuals listening today, I think it's recognising the importance of a person-centred approach, utilising that lived patient experience and actually focusing on the person, not the condition. They would be my key message.

00:50:25 Paul

And Af If you want to give us the the last word, what would you like our listeners to take away from this episode?

00:50:32 Af

I would probably say if you're working in in cancer or primary or secondary care, a healthcare professional, you are an absolute saint, you're an absolute legend and I want you to know that. Be confident in what you are. Be happy in what you're doing, even though some days are tough because you are changing lives every day and not just for a short time, but for people's entire lives. Your memories will stay with them forever in a positive manner, so thank you. You've got this and keep doing what you're doing.

00:51:09 Paul

Wow, thank you. I don't. I don't think we can say anything, anything more, but kind of, you know, thank you both so much for your time today, for, for giving your time to join us on the podcast. I think it's been fascinating to hear the insights, the stories. Af thank you for your honesty from your own experience. And I'm sure our

listeners will have so much to take away from from the conversation. Thank you very much.

00:51:40 Carly

You've been listening to The Cancer Professionals Podcast, which is brought to you by Macmillan Cancer Support. If you work in health or social care, visit macmillan.org.uk/learning to find out more about our learning hub, where you can access free education and training for links to other resources mentioned, see the episode description.

00:52:01 Paul

If you enjoyed this episode, follow us so you don't miss our next conversation, where we'll be joined by Bami Adenipekun to talk to us about equity in cancer care.

00:52:12 Carly

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 Wednesday of each month.

00:52:25 Paul

I'm Paul.

00:52:26 Carly

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