

## **The Cancer Professionals Podcast**

### **Episode 4 (April 2024) – Confronting racism in cancer care: From awareness to action**

**(Intro music)**

**00:08 Paul**

Are you ready to confront racism within cancer care?

**00:12 Helena**

It's actually just to do with the fact that black women are not taken seriously. That's it. They're not taken seriously because how is it there are 7, 8, 12 pages of wigs for white people to pick. But then there's one or two pages at the back for black people to pick from, and it's always out of stock. That's not equality.

**00:32 Lydia**

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

**00:36 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.

Expect to hear discussions of clinical practice, personal experience and practical advice to improve your knowledge and skills in supporting people affected by cancer.

**01:04 Lydia**

In this episode, we're joined by Helena Boyce, Anti Racism and Racial literacy educator, business owner and three times breast cancer survivor. Helena shares with us her own personal experiences of cancer and the challenges she faced as a woman of color.

**01:19 Helena**

Perhaps part of my feeling so disconnected because there was nothing around me that looked like me or felt like me, or that I could relate to meant that I didn't really sink into the moment of that diagnosis.

**01:35 Lydia**

Helena talks to us about her work as an anti-racism educator and ambassador of black women rising. She gives us examples of racism and cancer care and actions that we can all adopt to work towards inclusive care.

**01:48 Paul**

This episode includes examples containing sexual language, listener discretion is advised.

**01:54 Lydia**

Hello, Helena, and welcome to the Cancer Professionals Podcast.

**01:56 Helena**

Thank you very much for having me.

**01:58 Lydia**

First of all, are you able to tell us a bit about yourself and why you are so passionate about this topic.

**02:00 Helena**

Well, My names Helena. Why I'm passionate about this topic and equalities in healthcare as far as cancer is concerned, Obviously I've had my own experiences and being from a mixed race background, growing up in a very white space and sort of being always being that person, that was the only one that looked like me in the room, often it was usually I was the only one that looked like me. It's sort of highlighted a lot of those things that then when I came to having my own cancer diagnosis, I was able to pick out these things that do seem to single out people of color in a way that is undesirable. I would say unwelcome. I have a huge passion in anti racism and racial literacy and making sure that people are welcomed and able to have safe spaces to have these conversations, because I think the conversations aren't had enough, which is why these issues exist.

So I guess now is a good time for me to explain about what I do for work that I actually I run a company called YOUbuntu and that is what I do. I go around schools and corporate environments, colleges, universities, everywhere that there's a human generally, is where the work in anti-racism needs to be done, whether it be to give people of color some confidence in that they're not experiencing this alone. It's not being ignored or to, you know, people that are not of color to understand that these issues exist and how they can better serve to eradicate them. My work with black women rising, which is a breast cancer awareness charity. I'm a long standing member, I've been a member since almost day one.

I am also an ambassador for them, so with all of those things combined being my background and my experience of racism growing up, the want and the need and the passion to go and train people then having my own breast cancer diagnosis and feeling the being sort of singled out not really fitting the mold, so to speak. So all of that really kind of swirls up and puts into a pot and a focus where my passion comes from to raise awareness in the inequalities that can pop up in healthcare.

**04:37 Lydia**

Great. Thank you. And you talk to us there a little bit about your own diagnosis of cancer and you mentioned you know times perhaps feeling singled out. I wonder if you'd be happy to talk us through some of your experiences of health care during that time.

**04:52 Helena**

Yeah. So my first diagnosis of breast cancer, which was in 2014, came at a time when I was 36 years of age. I was long into my career as a dancer and a dance teacher. At the time, I was extremely fit and healthy. I was around 15% body fat and so when I sort of scratched my boob that, you know, one of the two boobs that I'd never checked in my life because I never expected that I would be that person to be diagnosed with breast cancer, finding a lump it was 2 1/2 by 4 1/2 centimeters. So it was quite a big lump that had just sort of felt like it popped out of nowhere. You know, it was a huge shock because OK, I don't drink, I don't smoke. I eat really, really well. I'm always, you know, working out and going to the gym and obviously, teaching dance is a very active job to have.

So to be diagnosed with breast cancer was a huge shock. As well as being really inconvenient, it's very inconvenient. The day that I actually went to get my results after having a huge number of biopsies was on the day actually, of my son's 8th birthday party and it's during the summer holidays. So because our children were quite small, somebody needed to be with them. So I went to my appointment on my own.

There was no query actually when I went into the room of have you got somebody with you, do you need someone with you or, but I'd I just remember, perhaps through feeling a little bit disconnected actually that I'd walked in to a space where nobody looks like me.

That can't be controlled. You know we can't control. Obviously, the people that are going to be sharing that space with you when you're diagnosed. But then when I was handed leaflets flicking through every page, I'm like, OK, White Lady, white Lady, White lady, none of this relates to me. Being so young, that is obviously that has its own challenge, but realizing that I was kind of the only person that looked like me and I think that kind of made me disconnect from the situation and so when I was given my diagnosis and I was told

right, you know, more than likely we we're gonna have to give you a masectomy, I'm like, OK, so you're gonna chop my boob off? Yes. OK. Can I keep my boob? No, we can't allow you to safely keep your boob. OK, fine. Take them both. I don't care. Like, let's just get it over with.

Then when I heard the word chemotherapy, I'm like ohh.

### **07:36 Helena**

Wait, that means all my hair is gonna fall out? I don't know how bothered I was at the time, but the shock of picturing myself as this sort of pasty Nosferatu, vampiric creature with bold head and sunken eyes, and it was a bit scary. And and I remember crying only for about 10 seconds. I just kind of went and then came back and I said OK, What else do I need to know and the surgeon was very sort of, you know, will only give you the information that you need as you need to know it. And I'm like, no, I need to know everything. Now. I kind of felt not that my intelligence was being insulted a little bit, but I kind of felt like, look, that, you know, you need to go on a person to person basis and I'm the person Who needs to know everything? Because I've got 2 little kids at home. I've got a business to run. I remember leaveing after kind of saying to the guy like, I'm like, just tell me everything. Tell me everything I need. I need it all now. And can you hurry up? Because I've got a birthday party to go to and my son's birthday party was literally in about an hours time, so I needed to go in the car, have a cry, drive to the place where the where the party was. Blow out the candles Sing happy birthday and you know, look back to normal again. But I I think what I'm trying to say is that I feel that perhaps part of my feeling so disconnected because there was nothing around me that looked like me or felt like me, or that I could relate to meant that I didn't really sink into the moment of that diagnosis. I just sort of laughed it off and got on with it. Then going straight into having my chemotherapy, I kind of blasted through that I carried on working as a dance teacher. I don't know why I look back at it now. When I go. What was I thinking? Still trying to teach dance and jump around with kids while my hair was falling out and having the chemotherapy I chose to have my mastectomy later rather than before the chemo because I wanted to be able to be functioning physically for as long as possible. You know, I didn't wanna have a mastectomy, then need to recover, then have chemo, then need to recover. I wanted to kind of just hold back all the recovery and do it at the end. So I had my mastectomy after finishing my chemotherapy and there was no radiotherapy with this one, but I was given the Herceptin injection for a year which was a breeze compared to everything else. But the experiences that I had throughout my cancer journey were things that I think maybe it took for me to go through with them, look back on them and realise that they'd happened so I wasn't able to access a wig that matched my hair texture, I felt at times I needed to over explain myself, So when I had one of my

Herceptin injections, now I don't know if you've heard of this sort of perception or idea that has existed for many years that black people are presumed to feel less pain. There's there's actually been a study about it. There was a wonderful man who invented the speculum, but when he was doing his gynaecological sort of studies and experiments, he did them on enslaved black women and he's he did it, his experience and his reasoning was black women feel less pain and they're not quite as intelligent, so we can do these experiments on black women. So the idea of black women feeling less pain seems to have been something that I certainly have experienced in understanding, but yeah, I did feel a lot like that. I remember kind of sitting in in the chemotherapy ward actually having my treatment and, you know, a lady to my left had been, her machine had been going off. Beep, beep. You know that awful noise and she'd been seen to that was great.

My machines now going off, but then the gentleman to the right of me gets seen so my machine's still going off. Then someone else in front of me gets seen to and I'm like, OK. Maybe because I was so young and a lot of the other people were somewhat older than me Or maybe because I was the only non white, but it, do you know it it kind of brings up those feelings and and it's it's really sort of regardless of whether I was the youngest and I seemed quite fit and well and capable of taking it or whether it was to do with the colour of my skin or my, you know, perceived race, everybody should be treated equally regardless.

**12:35 Paul**

Goodness, that sounds really difficult and thank you for sharing those experiences with us. And we know that culture and ethnic background is one of the key drivers in health inequalities, and there are lots of influencing factors which you touched on, especially when it makes you feel disconnected. And I wonder if you can maybe share some further insight into the unique barriers and challenges individuals from diverse ethnic backgrounds face when dealing with cancer diagnosis and treatment building on what you've said?

**13:07 Helena**

So we know that black women are at increased risk of being diagnosed at a later stage, that's why there is by default then an increased number of black women that are dying from cancer. I think that there's a few things that lead up to that there, first of all the many stories that I've heard, I'm lucky that I think I wasn't one of those people that wasn't taken seriously by my GP. He was very much right, let's get you over to the hospital, get you looked at, find out what's going on with this lump. But many of my friends, some that aren't here anymore, weren't taken seriously when they found a lump, or they found a difference. And often times they may be told well, Black women have denser breasts, they're more

lumpy in general, it's nothing to worry about, you know, just keep an eye on it. If anything changes, let us know. Then you've got the other end of things. Where because there is somewhat of a distrust, I believe from the POC Community in the healthcare system, whether that be culturally, they think that, you know, Western white medicine isn't something that's going to benefit them, that what they need to do is go home and take herbal remedies and old wives sort of tales and things of how to get rid of illnesses, or it's generally something where they don't feel comfortable to talk about it, whether it be to a doctor, family members, whoever. They just don't talk about it. There's definitely something to be said for Asian black communities that certainly you get a breast diagnosis, you might have had an auntie somewhere in your family that has had a breast cancer diagnosis and you never knew, you just didn't know because nobody talked about it. The family didn't talk about it, nobody said anything and don't say a word.

**15:10 Helena**

I think all of those things get in the way of then getting that diagnosis or getting seen early enough so that a potentially life threatening diagnosis could be made if we were more open and understood that going to the doctor is important. Following it up is important. Telling a friend or family member is important. Just having those conversations is what needs to be done, because I think that can often be the the biggest barrier culturally for many of us, as well as the worry that you won't be taken seriously.

**15:48 Paul**

That's really interesting and I definitely picked up there in terms of people not being taken seriously, and I wonder if you've got any examples about how this has impacted outcomes?

**16:02 Helena**

Outcomes for people who are diagnosed with cancer at later stages, which then becomes a life threatening issue, is the worst outcome for not feeling that you can perhaps trust the doctors, not feeling that you should talk about it. It's not even that people of colour perhaps feel like they can't talk about it. They feel that they shouldn't talk about it. It's almost in, you know, certainly in some cultures it's just not permitted, and it's what comes with that you know, perhaps your religious belief tells you that if you had been diagnosed with cancer, then you must have done something really terrible somewhere in your life for God to be so angry with you. It could be that you are no longer suitable to be married to somebody else from your culture because well, now you're broken as a woman. You're not healthy and you know you're not gonna be pursued by a man from your culture, from your faith, because you've lost a breast or because you've had cancer, so can you breastfeed

now? What does that mean for when you have children and things like that? So increased numbers of people of colour dying from cancer that could have been prevented, whether that's because they haven't been willing to talk about it to a doctor and follow that up. Or if it's because they were brave enough to go to a doctor but then weren't taken seriously. The end result really is the same that it puts them at much higher risk of being diagnosed with a later stage of cancer and then, unfortunately, losing their life.

**17:54 Paul**

And is this something that you see a lot of in the work that you do?

**17:58 Helena**

So with the work that I do with Black Women Rising, there are a number of women actually that are members of the charity that, unfortunately, are able to say I went to the doctor 2-3 times and he just said don't worry about it. It's nothing. It's a cyst. Oh, you've just got lumpy boobs, just go away. It'll be fine. Then, you know, months and months later, they've then been diagnosed with stage 4 breast cancer and they're like great. So now I'm just waiting to reach the end, and all because somebody potentially, it's that person's fault for not taking me seriously in the first place. Another lady actually that told me she'd been to the Doctor who was a older white gentleman. He had a look at her, her breast, when she'd been complaining of some discharge from the nipple. And he said ohh, I'm sure it's nothing, it's just an infection and kind of, sort of, you know, just shrugged it off as oh, it's just an infection. Here's some antibiotics or whatever, this will do the job and then suggested to her that had she not had so many young men sucking on her breasts, that maybe she wouldn't have developed this infection in her nipple. And that is a classic example of a black woman being over sexualised because of her race and just ignored through what obviously was something very serious. It was cancer, but was just written off by this particular doctor unfortunately. Who I'm hoping has retired by now. But you know, these are the examples of things that women are, you know, from the black community and Asian community are coming into contact with and then having to deal with. I think my own experience of not being able to get a wig, the last thing that I needed when I'm worrying about, am I going to live? How is this going to affect my two young children and my family and worrying about all of these things and everything that comes with a cancer diagnosis? The last thing I need to worry about is- can I get a wig that suits my hair texture. The catalogue that was presented to me to look through there was a page at the back that had Afro Caribbean wig, sort of textures, hair textures, but they're all out of stock. My guess is that they've been out of stock for a very, very long time. I'd then sent the wig lady some pictures of what my hair looked like before it all fell out, and this is what I'd like, and I even sent some links of some actual wigs that I found online to say this one's perfect, that one

would be great, and unfortunately it not only took her a really long time to get the wig, but when she finally got a wig, it was a mixture between something from Dallas and the 118 advert and Dukes of Hazzard style mullet thing. It was. It was horrendous. It was really, really horrific and a friend of mine came with me actually, she worked in the hospital at the time, and she previously had breast cancer and she's like, I'll come with you. We'll try on your wig. We'll see what it looks like. And I tried on this wig, and as I flicked my head back to show her what the wig looked like, she fell off the table that she was sat on in fits of hysterics because it was just so funny. But then if we stop and we just kind of zoom out a little bit, that's not funny. It's not funny. There was nothing about that wig that matched my hair texture or any pictures that I'd ever sent to this lady who's supposed to be an expert and assured me that she could definitely get a wig that suits me perfectly. Don't worry, nobody will ever know because I wanted to be able to go and stand in classrooms and, you know, in front of kids that I've been teaching for years and for them to never know any difference. You know, I wanted them to not realise- ohh, Helena has got breast cancer. I just wanted to kind of, you know, get through to the other end of it. So that was sort of my experience trying to find a wig, which eventually took 11 weeks and I had to say look, just give me the money and argue backwards and forwards until they agreed that I could just go and buy a wig which I got off of eBay and they would refund me the difference. But actually sort of circling back again to the experiences that women can have. And I know that I'm not the only one when it comes to wigs, but this wig lady had actually said to me- ohh well, you know a lot of coloured ladies like to use the straight wigs. Now if you know, which I hope most people do that are listening, coloured isn't a favourable word to use, it's not, it's considered quite offensive. And so the fact that she'd used that word to describe me, I was offended already. But then she said it's a great opportunity to try something new. If I'd known that I needed this opportunity to try something new, I'd have got breast cancer ages ago. You know, it's it's not an opportunity. It's not a fun chance to do something new. It's something where even understanding how culturally black women value their hair in such a way that it's devastating for a lot of people to lose their hair, especially as a black woman, when hair becomes such an important part of your identity and so had she had a little bit more understanding of how that works for black women, she perhaps would have been better equipped to deal with me as a person rather than the fact that I was just somebody who'd rocked up and needed a wig.

**00:23:23 Paul**

Thank you for sharing that experience, Helena. And I'm interested to know why you think that happened, that there wasn't a wig that met your needs?

**00:23:32 Helena**



Going back to understanding how I've grown up in a very white space, going through school all my friends were white, teachers were white, going through to college kind of the same university similar, you know, even where I live, you know, it's a very white area. I understand that sometimes thoughts of how things might affect people of colour are not at the front of your mind. Hence the work that I do going into schools and corporate and whatnot. But it also perhaps gave me a little bit of ignorance in the way where I'm kind of making excuses for people like ohh, it's, you know, it's probably because they don't really deal with this sort of stuff much and maybe they don't really know and you don't know what you don't know. So fair enough. And I remember thinking well, look, I live in Southampton. It's very white. They probably never see black people coming through here. So OK, whatever. But then when I spoke to some people from London and Birmingham, I'm discovering that they had almost exactly the same experience that I had. And then I'm like, OK, so this isn't an area, a regional issue. It's actually just to do with the fact that black women are not taken seriously. That's it. They're not taken seriously because how is it there are seven, eight, twelve pages of wigs for white people to pick. But then there's one or two pages at the back for black people to pick from, and it's always out of stock. That's not equality. Yeah. And so I think that what needs to be done is racial literacy. I think everybody on the planet needs to understand and learn and go and read books and research about how to actually be anti-racist because anybody can stand and sort of go. Ohh. I'm not racist, you know, my cousins, husbands, black or whatever. Ohh, I don't see colour. Everyone's the same to me. But if you're not reading books by black authors and understanding the black experience and, in fact even there, understanding the difference between the Black American experience and the Black British experience, which is very, very different. If you're not kind of educating yourself in these areas and reading real life experiences from real people, then you're not in a position to be able to navigate those spaces and be able to think along those lines to best provide for whoever sat in front of you. And I think that's what needs to be done. There needs to be more training, there needs to be more conversations. It's great that we have equality diversity, inclusion, all of these wonderful things happening in workplaces. But if they're delivered by somebody from a white background, how accurate is that? How real is that training and that experience coming across to people that are learning from that and we're not just ticking boxes then. Whereas I can stand up like I did at the EDI conference for Macmillan a few months back and I can kind of stand there as a black woman and go- This is my experience. Oh my God. These are the things that we go through. Can you feel my pain? And then people go woah, OK. And it's a lot heavier. It's a lot easier to understand I think when it comes from the horse's mouth, so to speak.

**26:43 Lydia**

I just wondered if you had any, sort of, recommendations of perhaps books or resources for people who want to educate themselves in this space?

### **26:53 Helena**

Honestly- Google, books about anti racism, how to be anti racist, the black experience and I mean I couldn't read out a list of books that would be you know best for you to read because it'll take me forever. Akala wrote a wonderful book called Natives, you get really placed into the middle of how it feels to be a black British person in this country. David Olusoga wrote books, Black British, which is really cool. So all of those things are wonderful to look at. But you know, it's not even so much books. I mean, head over to YouTube, podcasts, like this, interviews between people, even if you don't like them, you know, go and find out. Why are they the way that they are? And when you can understand both sides of an argument, you start to get a clearer picture of where you sit, and just, immersing yourself a little bit more in them. It's very easy to, when you're not affected by any of these things, to ignore it. Very, very easy. My mother, she may have been the whitest person you've ever seen. She's Irish, red hair, palest white skin ever, freckles all over. And you know she was educated, she educated herself in culture, not just black culture, but just culture of the world. Understood why people of different faiths celebrate what they do, how people dress, how they behave. At least if you take an interest in understanding what makes people the way that they are, you understand how best to protect them and that's why she was so wonderful at protecting us as kids from sort of microaggressions, and advising us when we experience racism at school and things and what to do, you know, that's an example of somebody who has gone out of their way to learn. But that's not to say that there might have been times where she may have not known, you know, she was always with me was very open with saying, look, you know, I'm not black, so I'll never understand it. I've never experienced racism. I know how I feel about my children experiencing racism, but that's not the same thing, because certainly our very Eurocentric curriculum here in the UK doesn't allow really a lot of swaying from one subject to another. I think my children probably still learn the same things for their GCSE's as I did 30 years ago and the world has changed an awful lot since then. There's a lot of very baseline things that need to be changed; things that need to be done to put us in a better place to be a more equitable society. For Sure.

### **29:31 Lydia**

I think you've highlighted really well there how educating yourself, it's our own responsibility and we absolutely should be doing it. And it sounds like your mum is a great role model for that, which is really lovely. Going back to some of the barriers and challenges that you spoke about earlier, obviously we've only heard a fraction of things that

are going on in the UK, in the world, during this conversation. I wonder if you can give us any thoughts on how we can improve in this area, how we can sort of help health and social care professionals support people in a way that is culturally appropriate and person centred.

### **30:03 Helena**

Well, I think I think the base of everything that I talk about, it always really starts with the conversation. Things like this is great. We need focus groups of people from varying cultures and backgrounds and have them all in a room, sitting down with a coffee in one hand and a biscuit in the other, talking about our experiences, understanding why those experiences happened, then learning how to avoid those things in future. I would love to see, you know, sort of people of colour advisory group of some sort put together for health professionals. People need to be paid for their time because it's not fair to ask people to to, to give their experience free of charge. You know, if we had an advisory group, even in different groups, in different parts of the country, because things are very different in different parts of the country- experiences and restrictions and the way that people feel or don't feel, it's gonna vary from one region to the next. And so having advisory groups for health professionals to have somebody facilitate questions and you know, lead the conversation of how the experiences of these people affect the way that they come through the healthcare system, what, what experiences have they had. That gives, I think, a unique way for healthcare professionals to be able to kind of tap in, listen, perhaps understand a little bit more about people and the way they tick. If you're a doctor or a consultant and people are coming in and you're seeing that one person every two to three weeks maybe, it's very difficult to build a rapport and to also switch your way of thinking based on who's in front of you when you've only really got enough time to understand what's in their notes. If you have it implanted in your thinking generally day-to-day that there are so many different types of people, they celebrate things this way, these sort of things are very private and maybe difficult to approach, Language barriers might be there, you know, the language barrier is OK, the way that you might say something might feel very different to them than it would to another person. So yeah, I think that would be something that would be a game changer.

### **32:09 Lydia**

And for any health and social care professionals who are looking to increase their knowledge in this space, we have resources on the Macmillan Learning Hub which you can access through [macmillan.org.uk/learning](https://macmillan.org.uk/learning). What you spoke about there in terms of like the focus groups, I think that's such a great aim to get to and something for us to work on. Is there any advice that you have for individuals who are perhaps thinking about how they

could make an immediate change with people that they're perhaps seeing in clinics later today, tomorrow, that thing that they can change on a personal level.

### **32:42 Helena**

I think that of course it's something I've noticed obviously that's that it's something that's been worked on over the years anyway, which is just talking to that person like an actual human. There are times when I might see somebody in a clinic and they're quite regimented and you know, how are you? Great. This is the situation. Wonderful. Alright. How are you feeling? Fantastic. Bye. Like that's just it. But then there are other times when I've walked into a clinic and spoken to a professional and they're- How are you feeling? How's things going? Are you all right? And they'll actually stop for long enough, not just to allow me to answer, but to allow me to think about my answer. Because my, my, my initial answer would be- Yeah, yeah, yeah, I'm fine. Yeah. Yeah, I'm great. Yeah. Yeah. Even though I might have actually been in tears in the car because the anxiety levels and panic attack risk goes up like a gazillion times just on my drive to the hospital, just driving to the hospital, I'm like \*loud breath in\*, but of course then when I get into the appointment, I'm like, yeah, yeah, I'm cool. Yeah, I'm great. Yeah. Yeah. Thanks. Yeah, everything's great. Yeah. So allowing me that that little bit of time to stop and go, am I really alright? How do I answer this? Yeah. Well, I'm OK, you know, so it's nice to kind of feel that you're not just being listened to, but understood for how you feel at in that moment. I've only ever needed a box of tissues, a couple of times in appointments, but there have been a few times where I've kind of thought, OK, I'm gonna cry. I'm gonna cry. And that whoever sat in front of me is giving off the vibe that they're not there for that. They're not interested in your tears. And whatever. I've had to kind of like choke it down and wait until I leave. But I mean, certainly I know that my second breast cancer diagnosis, which was in 2017, I was a horrific patient, I was horrendous, and can I take this opportunity to apologise to every single person that ever had to put a needle in my arm for those six months, and then for the further six months with the Herceptin, again- I'm sorry, I'm, I'm sorry, I'm very sorry. I was a horrific patient because again, this is something to understand about people. I've had my breast cancer diagnosis, in my mind I shouldn't have had it in the first place because I was extremely fit and healthy. I didn't know that I was at risk of something like that. So then coming into my second breast cancer diagnosis, I'm like, what? Why am I even here? I shouldn't have been in the first place. Why am I here again? And sort of my anxiety presented itself as angry, impatient, the horrible person. I remember waiting for finishing my chemo, waiting for the for the lady to come round and take the needle out of my arm. And I got really, really, because I was just. I felt like I was gonna have a panic attack. But of course I don't want to show that, OK, because I'm trying to be strong. I'm trying to be whatever. And I'm like, can you take this out my arm, please? Yeah, we'll be with you in a

moment. Of course, it's busy. I know that it's busy. There's lots of other people that need looking after. My anxiety doesn't care about that. I only care about the fact that I want this needle out of my arm. And I remember kind of just going, if you don't take this out in five minutes, I'm gonna do it myself and I'm leaving. And I did. I've whipped the needle out of my arm. I've got a bit of tissue from the box on the table. I pressed it down and I stomped out of that chemo ward, and I just remember hearing a chorus of \*loud breath in\* from all the people in their chairs. Yeah. So, you know, I literally after leaving and getting to my car, which was a safe space, I broke down. I was probably in the in the car park for about half an hour, whereas if I just waited an extra 5 minutes, I probably would have been able to just leave calmly, but I was too freaked out at that time. So you know, understanding how people behave and also making sure that we don't relate that to them culturally or their racial background, because I probably would have been seen as the angry black woman that day in the chemo ward.

### **36:57 Paul**

Do you think it would be helpful for listeners to discuss any cultural stigmas or misconceptions surrounding cancer that might hinder individuals from minority backgrounds seeking timely and adequate care?

### **37:11 Helena**

I can tell you from experience of people that I know and things that people who have experienced these things have told me. I've spoken to ladies from South Asian backgrounds that, through the worries surrounding no longer being wanted for marriage because of a breast cancer diagnosis, that meant that they kept it to themselves. Whether they kept it to themselves and ended up with a later stage diagnosis, or they kept it to themselves and isolated themselves, essentially, which meant they weren't able to access support groups, information, counselling, you know, all of the things that you need help with. I mean, counselling is the big one. You know, that's the great big elephant in the room. It seems, still even that it's not really something that's talked about that your mental health is so dramatically affected. If not during your, you know your treatment, your diagnosis and whatnot. Certainly afterwards. You know when, when, when the ball gets dropped and you're like, Oh my gosh, that was scary. Could have lost my life. And that comes with a whole bunch of other stuff. Talking to people from African Caribbean backgrounds, a lady that I spoke to was told by members of her family, ohh, it's because you live in England. You've been eating all that white people food. Well, that's not helpful because that may not be why she's been diagnosed. Might have been something completely different. But of course, you know the judgment that comes with that you know ohh it's it's because you've been you know, you haven't been to church. Have you been

going to church? That might be the first question or I've been diagnosed with breast cancer. Well, have you been going to church? What's that got to do with anything? You know, of course, you know, people will have their faith, and I know many people that have used their faith to get them through a cancer diagnosis but having a question which is based in judgment of- Ohh, you've got cancer? Well, have you been going to church? Maybe God's angry with you. What have you done? What have you done? You know, feeling like you've definitely done something wrong. You must have, because why would you be cursed with cancer? Being told- OK, if you take this concoction of herbs, which is something that's used in our culture, then you'll be fine. It's ignoring it, ignoring the seriousness of cancer and that the fact that this person actually needs to be looked at by a professional. So, you know, these are sort of things that culturally can pop up that inevitably mean that that person may not be able to access the support, and the care and the services that are there for them to help them to get through this diagnosis and hopefully not only improve their quality of life through the diagnosis, but actually to preserve their life.

**40:38 Lydia**

We've spoken about how people can improve or work towards improvement in health and social care space, but what can people do, I suppose in their daily lives, individuals or communities, how can they contribute to raising awareness about the disparities in cancer care and advocating for better support for minority groups?

**40:58 Helena**

Black Women Rising is a perfect example. That, that's, there's nothing else to say. Go to the Black Women Rising website and see what they do, you know. It's really incredible how the charity has just kind of zoomed and exploded into this wonderful environment where women can come together, not always from the same backgrounds, but are able to have conversations openly. And through Black Women Rising there is the encouragement for people that are members to share their experiences. And if you're that lady from an Asian or African, Caribbean, African culture, and you're in that space where you feel like you shouldn't talk about it, you can't talk about it. You mustn't talk about it. Keep it quiet, keep it to yourself. Don't tell anyone. And then you see one of these ladies on the television talking about their experience during breast Cancer Month or in a campaign. It. Look, it might not, but it probably will encourage you to go- OK. I need to go and do something about this for myself. And you know that what Black Women Rising is doing in encouraging women to share their stories, encourages other women to share their stories. The gallery exhibitions that Black Women Rising have done, which are black and white portraits of all kinds of different women with all kinds of different cancers, different types of cancer being shown in this sort of vulnerable but very powerful portrait of a woman who has survived

cancer. At this moment she is surviving. She's gone through whatever she's gone through. Whether it's a boob removed or both, or a kidney or whatever, and you're seeing this really awesome image, and I think from being part of that exhibition myself. Walking around the exhibition itself once it was up was like- OK. Representation really matters. Because when you see, people walking around and looking at these pictures and then perhaps coming to tears a little bit, or smiling, or saying ohh wow. Like it makes you realise how limited we are in the amount of representation we see for our own cultures, we don't see it enough. And maybe in my first breast cancer diagnosis, look, and my second, and my third, which was last year, had I been able to walk into my waiting room and see a poster from Black Women Rising, or a picture showing a black woman who's a real-life person that has had a cancer diagnosis? I certainly would have felt more comfortable, and that's just proof of how important representation really really is.

#### **44:28 Paul**

You mentioned earlier in the episode your role in Black Women Rising, which you've just talked about as well, and being an ambassador, and the work you do in schools and the work you do with your own organization YOUbuntu, is there anything else you want to add about the work going on in that space and how listeners, or what else listeners might be able to do?

#### **44:53 Helena**

Yes, I think, first and foremost with setting up the company YOUbuntu, it really came from an amalgamation of different things, and it took me until I perhaps had had my cancer diagnosis, and had watched my children grow to a certain age, and then putting it all together with the experiences that I've had as, you know, from childhood, and even up to, you know, just a few weeks ago. Incidences of racism, microaggressions, misogynoir, structural, personal, racism, stereotyping, all of those things. And so, first of all, you know, I've always, with the dance that I've been doing I've always worked in schools, which has been amazing because it's allowed me to teach dances of black origin, which always ended up as a bit of a black history lesson, to be honest. But then when I saw my son experience issues which were racially motivated at school, and we're not talking just from kids. We're talking from staff as well. And then my daughter coming home one day and being so annoyed, angry, probably that she was doing a history exam on Nazi Germany and Hitler. And she's like- why do I need to know this stuff? How is this going to impact my life? How is this going to change the way I go through into being an adult? And I'm like, good point because there's so many other things that we could be learning about in school that gives you a true representation of the society that you're actually living in now. So. it's a blessing honestly, to be able to go into a school and stand in front of the entire school and

talk about anti racism, racial literacy. Does anybody not know what a microaggression is. No. OK, cool. I'll explain it to you. And then suddenly we've got this huge pour out of multifaceted conversations just flowing everywhere and just, you know, kids have this wonderful way of just ping-ponging out sometimes the most awkward questions, and I love it because then I can just go right into it and explain stuff like- let's talk about some actual stuff that affects your life because you're going to go into the workplace, and you're going to have to work side by side with different people from different cultures and different religions and, you know, that speak different languages. You may even be a CEO of a company one day. You might be a surgeon, you might be a solicitor. So you are going to be better qualified in working in the world that we have now if you are able to have conversations in your younger years about why these cultural differences exist. And that judging people because of them isn't right, and so you're able to then go through life and be like, yeah, I understand what it is to be a Muslim, I understand what it is to be a Christian. I understand the experiences of black people. And then doesn't that make for a wonderful society in 10,20 years time where everybody is comfortable with having these discussions, but also all of the people from these minority, in inverted commas, backgrounds can go into a workplace and feel completely comfortable because they know that whoever's in charge, their boss or whatever, gets them. They get it.

#### **49:00 Paul**

We could talk about this all day long and I think you've given us such good insight into what's important and how we can all get involved. So to wrap up the episode, we've got our regular feature, which is three questions we ask all of our guests. And the first question is- if you could go back in time, what piece of advice would you give yourself?

#### **49:26 Helena**

OK, the only piece of advice I may give myself that is relevant to our conversation today is understanding the importance of really looking after your body and understanding, knowing, your body. I was perhaps lucky that the first lump that I found was so big, because then it was so obvious it was so. Had it been a lot smaller, I might have just ignored it, you know? And it was grade three. It was, you know, pretty aggressive. And maybe my ignoring it would have put me in a very different place a few months later. But. It's important to know what your boobs feel like, know how your stomach feels in general, and when you're looking for something different, knowing that your testicles are not supposed to have that lump on the side. That wasn't there last month, you know, and and not everybody has perhaps a partner. Perhaps there's a lot of people that are single living on their own. So they haven't got maybe another person that might spot something for them. So understanding and knowing your own body, not needing to sort of be in a



position where you actually get diagnosed with cancer before you realise you should have been checking yourself every month.

**50:47 Paul**

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

**50:53 Helena**

Representation, representation, probably some representation thrown in there with a little bit of extra representation. That is what I would like to see. You know, I would like to see focus groups. I'd like to see healthcare professionals really trying, I know that they don't have a lot of time, which is, you know, one of the biggest barriers really there. But having the opportunity to kind of learn about people from different backgrounds more deeply. And I would like to see the availability of mental health care widened.

**51:40 Paul**

And lastly, what would you like listeners to take away from this episode?

**51:45 Helena**

I think, take away from the episode really that, cancer sucks. OK, we know this, but it isn't the be all and end all of life. Whether that means you're looking at the end of your life or you are able to enjoy a light nice long life after a cancer diagnosis. Being positive, understanding where to set boundaries, cancer treatments can take their toll on you, and it's very important to make sure that you rest and take time out.

**52:25 Paul**

Thank you. I think that awareness piece is always so important. So thank you for sharing, sharing those last points and thank you so much, Helena, for talking to us today about such an incredibly important topic. It's been really inspiring to hear about the work that you do and how we can all get involved. It's been great having you on the Cancer Professionals podcast.

**52:47 Helena**

Thank you very much

**(Outro music)**

**52:49 Paul**

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 the resources mentioned, see the episode description.

**53:11 Lydia**

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by Lisa Nel, practicing therapist, clinical supervisor, and independent trainer, and Dr Karen Campbell, President of the UK Oncology Nursing Society and associate professor in cancer nursing. They talk to us about vicarious trauma, how to recognise it, and practical tips of how you can best support yourself.

**53:37 Paul**

We'd love you to rate our show and share with your colleagues. New episodes are released on the first Wednesday of each month.

**53:43 Lydia**

I'm Lydia.

**53:54 Paul**

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