Transcript

From knowing to doing: Cultural responsiveness in cancer care

Intro music

Liv (00:10)

Why should we see the human being first and ensure culture informs care?

Israel (00:13)

So meaningful cultural responsiveness is about understanding the person in front of you. This is the person. This is a human being, first of all. Not a black person, not a white person, there's a person. And that person needs our care.

Liv (00:30)

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

Carly (00:32)

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

Carly (00:47)

Every 75 seconds someone is diagnosed with cancer in the UK. Wednesday the 4th of February is World Cancer Day, a day to come together to rewrite the future of cancer care and put the needs of people and communities first.

Liv (01:00)

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

Carly (01:18)

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

Liv (01:26)

Welcome to the Cancer Professionals Podcast. Today we're exploring the critical intersection of health inequities, cancer care, and the power of storytelling. Our guests Judith co-founder of From Me To You- The Art of Survival, and Israel Eguaogie, founder of iAssist Northern Island, joins us to share the vital work their organisations are doing to bridge gaps in understanding, access, and support for people affected by cancer.

We'll explore the importance of cultural responsiveness and by this we mean respecting every person's right to high quality personalised care regardless of background and respecting each individual's unique cultural identity and lived experience and the persistent barriers that continue to impact communities. From advocacy and empowerment initiatives to practical steps that listeners can take, this conversation highlights how awareness can and must lead to meaningful action.

So yeah, thank you so much Judith and Israel for joining us today, I'll start by asking you both to briefly introduce yourselves if that's okay. And Israel, I'll start with you please.

Israel (02:25)

Thank you for having me, Liv. My name is Israel Eguaogie and I am the founder of iAssist Northern Ireland. Our organisation is based in Belfast, Northern Ireland and our core mission is to fill the gaps in support for people from the Black, Asian and minority ethnic communities who are dealing with long-term illnesses, including cancer. So the organisation was founded 2015. When I started, it started from a very personal place. When I saw friends and community members struggling to navigate the healthcare system, facing isolation and feeling unheard. It began with me simply supporting a friend, but I quickly realised the systemic nature of the problem. We provide befriending services, personal assistance support, and crucial advocacy to ensure people's voices are heard and their needs are met.

Thank you.

Liv (03:23)

Wow, yeah thank you so much what a brilliant, brilliant thing to set up. And Judith, I could come to you and ask you to introduce yourself please and also your organisation.

Judith (03:32)

Hi, my name is Judith Neptial and I'm the co-founder of From Me To You- The Art of Survival. Predominantly, our main objective is to support black and ethnic minority groups who have received a diagnosis of cancer. The organisation was birthed from my illness. I was diagnosed with terminal cancer in 2018 and it was a direct result of some of the inequities that I faced along my journey in trying to live.

Liv (04:07)

Thank you so much. And can I ask you both as well, why do you feel that this episode and kind of the talking about the topic of health inequities, why is it so important right now?

Judith (04:17)

I think it's extremely important. think, you know, the disparancies in relation to different ethnicities within healthcare, I think might be at the widest that it's been for a considerable amount of time. And we are actually paying that price. People from marginalised communities are paying that price, literally, with their lives. So I currently feel that there is no better time than to have this conversation and to raise awareness around the same.

Liv (04:51)

Absolutely. Israel, is there anything you'd add from your perspective?

Israel (04:54)

Yes, I think this episode is incredibly important because it shines light on the reality that many in our communities faces daily. Just as Judith said, we often talk about health inequalities as an abstract concept. But for many, it's the difference between an early diagnosis and a late one or between receiving compassionate care and experiencing dismissive attitudes. However, storytelling is our most powerful tool to bridge the gap.

Data and statistics are very crucial, no doubt, but it's the personal story of struggle, resilience, and advocacy that truly connects with people and drive a desire for change. When a healthcare professional hears a personal story, it's no longer just statistics. It's a human being, a family, a life that has been impacted. So I agree with you, Judith. It's very crucial.

Judith (05:49)

Absolutely. I mean, we also, just to add, we know that black and marginalised communities are receiving poorer outcomes, not because of biology, but because of the system, because of system level inequalities, and which touches on the things, the very things that you've spoken about, such as late diagnosis, and lack of trust, and limited cultural responsiveness as well, in relation to that. And these are all things that we can actually change. We have the power to change.

Carly (06:18)

Mm. Yeah, you're absolutely right. And I totally agree, Judith, there's no better time. And we are so pleased that you're both joining us here today and picking up on what you said, Israel, about that power of storytelling. That really is where, as you said, the power comes from hearing and understanding the realities. So yeah, we really hope that as we're discussing today that we're able to share some of those stories and really bring that to life. So yeah, that would be great.

So Judith, you mentioned some of the disparities and then you also mentioned about lack of trust, you talked about late diagnosis. And I want to ask a question to both of you. Can you share some examples of some of the barriers, some of those persistent barriers that you see in the work that you do?

Judith (07:11)

What are the persistent barriers? I think, you know, lack of cultural awareness is a huge barrier. And I say this because it has impacted my journey, my fight to stay alive. I believe that I went to my GP and my consultant from around 2015 to 2018 and I was consistently ignored.

And unfortunately, you know, healthcare professionals really need to understand the power that they exhibit when you enter into that room and the effect that they have on people from marginalised communities in that, even though I knew that something was wrong, you know, every bone in my body told me that something was wrong. When my GP and consultant said, you know, it's nothing. I didn't challenge that. I didn't say, well, can we look at this again? There was real case of deference in that I kind of believed at that point in time that healthcare professionals, you didn't question them, you know, and that's a cultural- that's something that's embedded in people from black and dare I say ethnic minority groups. You know, it's embedded in our culture that, you know, not to challenge professionals. I think if they had been more aware of this, then maybe their response and the very outcome of my diagnosis may well have been completely different.

Carly (08:49)

Yeah, thank you. Thanks so much for sharing your experience. sounds so tough to go through that. Like you said, such a long period of time where you knew you felt there was something wrong, but actually that those symptoms were being dismissed. Israel can I come to you from stories that you know of through the work that you do? What are some of the issues and those barriers that you've seen?

Israel (09:05)

Yeah. Thank you, Judith, for sharing your story. I think that is extremely powerful. And these are some of the stories that we hear every day and from people that we support and care for. So basically, I'm going to tell a story of a particular woman who is from Sudan. She was from Sudan and wears hijab. She would constantly go to the A&E to complain, express the pain that she was feeling.

And each time she goes, she will be dismissed and also go to the GP. The GP would not see her because she was constantly coming to the GP. At some point, the GP was like, there's nothing wrong with you. I can't see anything wrong with you. But that was a huge problem because first of all, the language barrier was there. The way she expressed her pain or... how can she better express what's wrong with her without an interpreter? A translator? So dismissing her without providing an interpreter from her background who can actually relate what she's saying word to word. So that was a huge barrier. After nine months, unfortunately, she was diagnosed with cancer. It was stage four.

Israel (10:33)

First of all, her pain wasn't taken seriously. It was trivialized because of the cultural barrier there which Judith talked about. She didn't know how to challenge that being dismissed by the professionals. But at some point, she had to raise her voice and say, look, guys, I'm really in pain. Can somebody please listen to me? You know, we laid her to rest June this year, but that is a legacy there, that cultural responsiveness can have a devastating consequence. How many more will come through that door? How many more will be dismissed? How many more will be regarded as being aggressive when the challenge is systemic prejudice? Before she passed, she said, look, I think they dismissed me. They didn't take me seriously because I was wearing hijab, because I'm a woman, because I'm black. So you see this whole intersectional barriers that she faced, that she had to live through until she passed. Another story is of a man living with prostate issues and he had to undergo treatment. I think he was being encouraged first of all to go for the test but because of his cultural religious beliefs he didn't want to. So we had to intervene and introduce him to another person who is a little bit elderly who had gone through the treatment and gone through the operations to explain to him first of all I think it's okay to get tested this way to get checked this way, it's not the most human way to check I went through it myself but we kept raising that awareness until he went for that. So you can see your culture and religion and languages, these are all intersectional barriers that people from the ethnic minority backgrounds are constantly faced with. Constantly.

Judith (12:34)

Absolutely, I mean it was one of the main reasons after I reached a place of stability within my diagnosis we started From Me to You because we simply started a Facebook page and asked did anybody have similar experiences and the response was that we were inundated.

Carly (12:55)

Mm-hmm.

Israel (12:55)

wow.

Judith (12:56)

With people saying that they had not been heard, not been seen. And we know this to be true because I think there been reports that have come out that have said that, you know, generally people from black and ethnic minority groups, think specifically black go to the GPs about six times or seven times before they are referred on in comparison to somebody who is white, who probably goes once or twice. You know, this is happening in real time. Even within our From Me to You, you know, we work very closely with our community in order to raise their awareness of what their rights are in relation to healthcare, to empower them to have those conversations and to challenge effectively. You know, because also, as Israel mentioned previously, know, challenging is a real area of concern within the black community because you're perceived as being possibly, you know, as I was, I was, frightened, if I'm being really honest about it, to be perceived as an angry black woman. You know, these are real stereotypes. One of the gentlemen in our group when he was diagnosed with prostate cancer after being told repeatedly over the course of a year that there was nothing wrong and then being told that it was terminal, had security called into the room when he merely stated that he was annoyed. These are things that are happening consistently within the system and this directly relates to cultural responsiveness. You know, how are we engaging with each other?

Carly (14:43)

Yeah.

Israel (14:43)

I remember going with my wife for a checkup and my wife is white and the professional was speaking to my wife instead of speaking to me and my wife had to redirect that person and like- Excuse me, this is the person here, can you speak to him? Why are you talking to me about this? He was completely oblivious that I was in the room and had to talk to my wife. And that really made me feel insignificant. So he's just understanding those little cultural beliefs and his excuse was, I thought you could translate or interpret to him.

Israel (15:22)

I'm like, excuse me, I understand English. Why are you assuming? Would you not ask me if I need an interpreter? Why should my wife be my interpreter? Those are just little issues here that we face daily. It's repeated and this happens from the GP surgeries or in the GP surgeries most often.

Judith (15:41)

Absolutely. I mean that's why at From Me to You we created empowerment training for our community to empower them to have those very challenging conversations and hopefully to also tackle the issue of power and privilege within the room with your GP and medical professionals. However we realised that it's a two-fold approach right because a lot of times there's a rhetoric about black people non engaging with medical health services when actually just as much as it's about a lack of engagement because there is mistrust we understand that, rightly so, you know but we have to we have to acknowledge that but it's not just about lack of engagement it's about a lack of accessibility, and you cannot look at one area without the other. So as much as we've empowered our community through training in how to have those awkward conversations and to empower them with the knowledge to navigate the healthcare system effectively, we also produce cultural competency which focuses on the knowledge of understanding cultural differences, communication styles and historical context because we truly believe that healthcare professionals want to help. But a lack of understanding and a lack of knowledge is a real barrier towards this. So we focus on providing lived experience of the inequalities within the system.

Carly (17:06)

Mm.

Judith (17:17)

And we also pride ourselves on ensuring that our training is delivered by people with real life lived experience, in order to enable healthcare professionals to have the tools to carry out their work effectively.

Carly (17:33)

Yeah, that sounds great. I really wanna talk a bit more actually from both of you, from both of your organisations, some of the really great things that you offer. I did wanna touch on though, we've kind of mentioned cultural awareness, we've mentioned cultural responsiveness a few times. What does cultural awareness and cultural competency look like in the context of cancer care? And then secondly to that, what is the impact that that can make if that's something that improves within the workforce?

Judith (18:06)

I mean, cultural competence to me is knowing, understanding what are the core differences and being aware, and responsiveness is in the doing. How do we then, you know, engage with that, interact with that? And it's really about what happens when they engage together and the impact that has on the relationship between healthcare professionals and the community, from my perspective.

Israel (18:32)

Yeah, I think that's a very good one. But then let's talk about the tick box of cultural competence. So where organisations might have translated leaflets or diversity policies that sits just on the cupboard. That's not cultural competence. So you just have in this one most professionals, you see those leaflets now in different languages. But what's that all talking about? Those are all surface, tick box exercises that- oh, we have those leaflets printed. But at the same time, when somebody comes to you and doesn't speak that language, somebody at the front desk is not asking- can we support you? Do you have any language challenges? And then that person is constantly assuming, like the story I shared, it wasn't long time ago, it was last year. But when you go to those places that she went to, are leaflets of different languages, yet she's been dismissed because somebody said, I didn't understand what she was explaining. So meaningful cultural responsiveness is about understanding the person in front of you. This is the person. This is a human being, first of all. Not a black person, not a white person, there's a person. And that person needs our care. We have the culture of care. So there is a culture of care and then the cultural responsiveness. It's about asking what matters to you? Do you need support? And this brings me to the story of the same person when she was being discharged from the hospital.

Carly (20:05)

Mmm.

Israel (20:11)

Nobody took the chance to say, let's go and check where you live to carry out a bit of assessment. Will you be comfortable? And when I asked her, she said she will be discharged in two days. I'm like, where are you being discharged to? You're living in a house that has flight of stairs in your living room to the bathroom upstairs and then further down to the kitchen. How are you going to navigate all these challenges? Have they discussed this with you? She said no.

Carly (20:32)

Mm-hmm.

Israel (20:36)

We had to go back to the nurse in charge. Where is this person been discharged to? This person came in here and you're discharging the person back to a house that is full of barriers. Have you taken the time to ask her questions or even explain to her that she has this metastatic cancer? And they said she said she doesn't need care. Somebody who is an end-of-life care said she doesn't need care. That's wrong. So we had to go back to her and I asked her, did you say you don't need care? She said, no, I said I don't need a man to care for me based on my religion and my culture. But it was misinterpreted and it was written in her care plan that she doesn't need care when she goes home. That was frightening to me. What about if I wasn't there at that moment, at that time. And I ask that you understand what you have. She said, they just told her that she is palliative care so she's going home on Monday. I'm like, what is palliative? Do you understand that? She said, no, but they used the word palliative. And I had to ask the nurse was an interpreter provided to explain to her that she's on end of life care. She said, no, her friend interpreted and her friend doesn't understand English fully well herself. So what does she interpret?

Israel (21:58)

Here is a misinterpretation here. So we had to suspend her discharge and I was very glad that the cancer nurse was present at that time and she said, no, I don't think this woman should be discharged until she fully understands what she's going through. Two days later, there was a multidisciplinary meeting where she was informed she has a couple of time to live on Earth. She was devastated. That was the first time I saw her cry, but she was happy she will be discharged without knowing that this cancer has spread all over her body. So it is about this cultural responsiveness and competence. It's not about the tick box exercises, I attended the training, I didn't attend the training. It's seeing the person in front of you with the eyes of the culture of care that you signed up for. Then other cultural awareness and knowledge can come in. She's a woman, she's black, she wears hijab, she's Muslim. So all those things were then coming. first, yeah.

Judith (22:59)

Yeah, absolutely. I think what you're saying Israel is very true. I think we have to equip professionals with tools to deliver equitable care, trauma-informed approaches, culturally responsive communication and awareness of personal biases, and understanding the role of social determinants in that process. What does that look like? You know, and I also think you're absolutely right- currently we have a system where, you know, cultural competency, I don't believe it's mandatory,

Judith (23:30)

So it really is at the health professional's discretion. But I definitely think we should be looking at that. We should also be ensuring that the training that's provided is more than just a tick box and that it is actually provided. I think what makes our training so effective, again, is that it is delivered from a lived experience perspective and it is co-designed with the community. We have to encourage the Trust and the NHS to move towards working far more effectively with community-based organisations who truly understand the plight of the communities that they engage with, It's a huge job.

Israel (24:17)

And I think this whole cultural responsiveness, it requires- how humble are you? It requires humility from healthcare professionals and willingness to learn. That's number one. We must also appreciate what's been done so far. when you, the last time I went to the A&E, spent almost nine hours. I saw how hardworking these doctors are, the nurses are running and the people waiting to be listened to and cared for. But let's not forget that they are also trying their best. They are doing their very best. You know taking time off work for training is golden. So I think some of them should be willing to learn and embed their learning into practice That is what's important. There's also an acknowledgement of the power dynamics at play because you hold the power, you hold my life. So if you do not understand that this fate, recognising that my personal culture, my faith, my backgrounds are not barriers to care, but an integral part of how and who we are, I am, and how you care for me. Then we're losing it because most people believe in prayers. That prayers works. What about if we add prayers to medicine?

Carly (25:25)

Mm.

Israel (25:36)

It's just respecting those little nuances, which I believe that most people are doing their trust is doing their best, I appreciate them for that because they have also come up with little pocket size translated, I need translator card that most people seeking asylum can take with them. You know, when they go to GPs, that is, personally, they are actually trying to tackle that barrier, language barrier, first of all.

Israel (26:04)

Now when you go to the GP, you can show them the card, I need an interpreter. Instead of just guessing, so that's a step ahead, but there's still a lot to be done. Judith, like you said, the training must be made compulsory. And it's not just going to be like sitting down and no, you have to has to be embedded in daily practice because these are human beings coming in front of you every day.

Judith (26:18)

Yeah.

Carly (26:24)

Yeah.

Judith (26:25)

That's the thing. Absolutely.

Carly (26:28)

Yeah.

Judith (26:28)

I think, you know, as you've just said, I think, you know, training would be it would be a nice add on if it was mandatory. But I think we also have to acknowledge the fact that storytelling is amazing and it has a real place in training and education. But I think we also need to move more towards the, what happens after that, the thereafter. So, OK, we've had the training now. What will you do as an organisation thereafter, how will these be embedded into your policy and procedures that you carry out? Where is the accountability thereafter? Because as think Israel said repeatedly, it can't just be about a tick box. We have to start looking at what happens thereafter in that process.

Israel (27:18)

Judith, sorry, I just wanted to add to that. think it is important to understand having worked with 16 people who were discharged from the hospital into the community, the first arm we are looking at is health professionals in the hospitals. What about the community care?

Judith (27:35)

No, I believe that, sorry Israel, I think that it's something that's, you know, it's an all-rounded issue and I think you touched on it earlier on when you said about going to the GP. I think there was a report done, they looked at all of the, the black community about 80% engaged with their GPs, but the follow-on from GPs to the hospitals, the referral on, was significantly less, you know. So we have to look at primary care.

Carly (27:57)

Mm.

Israel (28:02)

Yeah.

Carly (28:03)

Mm.

Judith (28:05)

Absolutely. And training has to be, we have to look at what's going wrong and what training can be implemented and should be implemented at that point. And also, dare I say it, because communities are not necessarily engaging with their GPs because of fear, and you touched on asylum seekers as well, you know, there's a huge minority of people who are left outside of that system. So maybe there is a model for, you know, taking that initial care and education, some points of it, especially in relation to the community, away from the medical framework, you know, and bringing it more into the community. The people don't feel threatened and they do feel safe to engage,

Carly (28:44)

Mm.

Israel (28:49)

And also this training should be cascaded down because yes, we do work with Macmillan Cancer, but there are other cancer support organisations. Like one of them that we worked with recently, we had to refer somebody to them and they said, we haven't worked with a black person before. I was shocked. Like, okay, so how can we help you? So we had to provide that initial discussion, conversation. I don't call it training, it's explaining to them how best to welcome this person. What are the cultural nuances, the differences, what are the barriers? So it took us about three months to build that relationship, to train some of the staff on cultural competence. How best can you support this individual? And trust me, they provided absolutely robust and beautiful care for this woman, and she loved it. She keeps talking about that, but, you see, the initial barrier was we haven't cared for a black person before, but they were ready to learn. The willingness to learn like, please, can you help us? How do we do that? So it's also understanding that other organisations to, I will speak from the Northern Ireland context, we are living in a divided community, the Catholic and the Protestant, and then the others are us in the BAME context and that community. So you have this organisation supporting in one side of the town, the other side of the town, there is no communication. That lack of communication, that lack of transfer of knowledge, that is what we want to bridge as well with our annual conference. We will bring the support, the community support groups together. Let us share learning- What have you learned? How can we help you? How can we support you to provide that care for people that are newcomers in Northern Ireland who don't belong to the Catholics and Protestant communities who are in the other, who live in your community. Can people who live in the south go to the west? Can the north go to the east? So, they are divided. To be honest, it's complex. And navigating this complexity can be also frustrating to somebody who is eager to survive, to live. You know...

Carly (30:49)

Mm. Yeah. Yeah.

Judith (31:06)

I think Israel, what you've hit upon there is really important component of the training that we provide at From Me to You. And I'm sure that you do as well. It sounds very integral. It's that advocacy is really a core pillar of that for the community because a lot of the times because of we've spoken about, there are inequalities within the system and people do face barriers. And again, initially, obviously, our first point of call is to undertake training with our community members to empower them and to upskill them in relation to navigating the care system. But we have to be aware, you know, that that's not always going to be totally effective. So at From Me to You what we try to do is to provide a branch of advocacy all the way throughout that. So that, if there isn't a further issue and you need us to step into the room with you, then we will do so. Because cancer is a lonely road and isolation and not being understood and not being heard is truly devastating when you're already in the fight of your life to stay alive.

Israel (32:17)

I think we do a lot of advocacy ourselves and then befriending this is exactly what we do most but we also accompany people to attend hospital appointments a lot. We encourage them to speak up for themselves and also support them the best way we can but sometimes you just feel we can do more together if we all work together.

Carly (32:33)

Mm.

Yeah.

Israel (32:44)

One organisation is sharing information or learning with another organisation. What that means is it just continues to provide a hostile environment. Let's not forget about a hostile environment that asylum seekers are also faced with, being in the asylum process. Judith, you mentioned, you talked about that as well, providing training on your rights to health care. Most asylum seekers don't know that asylum, that health care is free. A young man who has passed may his soul rest in peace was told that because he had no recourse to public funds on his visa, so he was denied treatment.

Israel (33:23)

And it's with that, that gives us the impetus now to go to the Department for Health who gave us some money last year to run a of sessions on health is your right. So people should know that healthcare is your right. Most people don't know that and most asylum seekers think if they go to GP so many times, the GP is going to report to the Home Office and that would affect their asylum process. We've had this a couple of times. And we had to encourage them, no, that's not right. Health is your right, knowing exactly that you have, that's your human right. So you have to go and ask. But then they also are afraid to speak up because they believe when they speak up, it's going to affect their asylum claim. Then they just accept everything. So that is wrong as well. So we're trying to raise awareness for people to understand, to be empowered.

Israel (34:16)

No, it's not going to affect your asylum claim. It's not going to affect your asylum status. You just speak up. But don't be rude about it.

Carly (34:21)

Mm-hmm.

Judith (34:26)

I totally agree with you. I think generally in relation to awareness of how to navigate the healthcare system, I think it's a universal problem. You know, I speak to my neighbours and they are unsure as how to navigate the system. They are unaware of basic things like that hospitals have specialities, you know, that you can actually choose what hospital you receive treatment at. These are basic, you know, it's basic information that I think everybody, you know, regardless of race, everybody has a right to understand the systems that they engage with, you know.

Israel (35:06)

I think another element to this is- cancer itself is disease. The treatment is there, the process is lengthy and frustrating, but we live in the element of how it affects mental health. You know, where most cultures don't understand mental health. We raise awareness that there's nothing wrong in asking for help. There's nothing wrong in asking for help. That mental health element also needs to be brought into that. The professionals can encourage them. If there are organisations providing a supportive mentor, signpost them over. Let them know that it's a holistic approach. It's a holistic care package that you provide. So that element is often missed out when we now start talking about them about mental health support. We're like, my doctor never told me about it. The nurse never talked about that. So that's another area of this cultural competence and cultural responsiveness that we are talking about.

Carly (35:56)

Yeah, and I mean, we've touched on so many things. mean, mental health in itself is a huge conversation. Actually, probably could be talking all day, couldn't we, to touch on all those different things. And there's been so much that you've touched on and what really stood out to me through what you were both saying was about empowering people to know their rights, to speak up, to, you know, I suppose listen to their own bodies and really speak up for what they believe is happening to them and what is real. And also I really like what you said Judith about- you said from knowing to doing and I think that's also really important from a healthcare professional point of view. It's how can we support professionals not only to know and be aware of people's, and the differences and the support that they need with regards to that. But how can we then support them to make that change and make that difference and ensure that the care is equitable? So like you say, I really love that from knowing to doing and I think that's so, so important.

Liv (37:13)

The stories that you've been sharing are so impactful. Israel, you made a point earlier about humility and kind of healthcare professionals having humility and you know, it's so important just to ask the question. And yeah, you gave the example of the appointment that you attended alongside your wife and the fact that they were talking to your wife instead of you. And if they just asked the question directly to you in the first place, that wouldn't have occurred. I wanted to kind of ask, what some of the practical steps that healthcare professionals can take are in terms of, they might be quite small things that will make a difference, or we've also spoken about some of the systemic barriers that are in place. What can our listeners be doing to improve their cultural responsiveness in their own roles and communities?

Judith (37:52)

If I'm really honest, it's a difficult one, but I'm going to try and be as honest as possible. I think healthcare professionals have to be aware of where they sit in the room, of their power, of their privilege, and also of your biases, unconscious biases. And we have to have a true and honest, and I would say that starts with having an honest conversation with yourself before anybody else. Are you aware of how those things impact you within your daily life? Are you aware of what happens and if that, where that transference takes on when you enter into the room or you engage with somebody from a different ethnicity? Because to say that I do not see colour, it's not honest. We have to start having honest and difficult conversations, but first and foremost with ourselves.

Carly (38:45)

Mm.

Liv (38:51)

Yeah, that's really important. Thank you. Israel, is there anything from your perspective?

Israel (38:55)

Yeah, Judith, I quite agree with you because most often people say power is dynamic, but not in this context. When you walk into a room and there's somebody sitting down already, you feel prejudged. I feel that way often. You know, I feel when I come into a room here, I don't hold power, I'm already prejudged. So it's understanding. I start looking at ways- What am I going to say? How am I going to respond that I won't be deemed as being rude or aggressive black man. If some of my needs are not met and I have to ask, how am going to do that? So you are right, Judith. It's first of all, being sincere with yourself. You know, the culture of care is what every health care professional sign up to. So there is a culture there. You have to be competent first with that or in that culture of care. Which means you have to treat everybody irrespective of how they look, where they come from, their age. You have to treat everybody equally, but that's not a fact. There is, I think over the last couple of months with the whole anti-immigrant sentiments, there is a rise in that discriminatory practice. People hold different biases. Leave your biases at home when you come to work. I did mention that in one of those workshops, somebody asked, how do we measure attitude? Of course we cannot. I can't go and report and say the way you spoke to me wasn't right, but if we continue to have feedback exercises, we can see from how people, what people are saying as a tool, create a tool for feedback. How did we do? How can we help better? So I'm thinking that If that feedback exercises are provided before they leave, or even a QR code and say, please just scan the QR code, that is another tool for learning. And also sometimes we talk about this cultural competence as if it's a rocket science, it's not. It's just to be aware. I am aware that Liv you are white. I'm aware that Judith, you are black. So I'm aware of where I am. So if I come into a room, I want to feel safe. I want to be able to have a conversation, a safe place for me to have a conversation. I want to be able to express myself and I want you to help me because that is where you are. I came to you for help. So that's my contribution.

Liv (41:30)

Thank you so much. That's lovely. And I wonder, just kind of thinking about the brilliant initiatives that both your organisations are running and the impact that you've had, I wonder whether there are any other kind of success stories that you'd like to share to kind of, yeah, some of the positive impact, that you've had and the difference that it's made to people's experiences.

Judith (41:49)

One of the ones that I enjoyed the most is that we did a class of empowerment with some elderly people from our community. There was a lady in particular, she questioned most of the things that we did throughout the course. And I didn't think that I'd made any headway with her whatsoever. She was, you know, there's no need for this. But then she actually rang me about a week later and turned around and said to me, you know that thing, you know what you was talking about? She said- that, you know, that I can ring up and I can say this and they will give me. She said, I tried it. And the shock that she was like, and it actually worked. It actually worked. was like, I got an appointment. They told me four weeks and then I got an appointment the following day. I was actually, yeah, I really enjoy things like that.

Carly (42:32)

That's so nice.

Israel (42:32)

Ha

Liv (42:33)

brilliant.

Carly (42:44)

Yeah.

Judith (42:45)

because it shows that it's actually happening in real time and it's impacting somebody's life. The other thing that I like to pride ourselves on is that we have community groups in the fact of, you know, and you talked about Israel psychological safety and it's long been a known thing that black men generally have a harder time talking. And we created our men's group because they didn't stop talking in our community group that we have. So we had to give them their own group so that they could have their own conversations. And it was really nice to know that these men otherwise would have been, would have totally been isolated, wouldn't have felt comfortable to have those conversations. But because of the community group, where they engage with women as well, they felt confident in taking that conversation to their wives, partners and families. And then furthermore with engaging with themselves. I think there's a real element that we create psychological safety and empower our community to have difficult conversations to know their rights, that's a huge thing, you know.

Carly (43:53)

Yeah, that must feel so heartwarming to hear the stories and the impact of what you do.

Judith (44:00)

It absolutely does. I mean, we always strive for the point that, I mean, my diagnosis is terminal. And when we started From Me to You, it was always from the remit that nobody should have to undergo what I went through. You know, it was an extremely lonely place and nobody should have that outcome just because of a lack of knowledge. That's unacceptable.

Carly (44:30)

I wholeheartedly agree.

Liv (44:33)

Yeah, is there any other success stories that you'd like to share Israel?

Israel (44:36)

Yes, Judith, it's so nice to hear your story and your journey. And in 1997, I was actually told that I have three days to live. As a young person in Germany, we had a language which was a huge barrier. No relatives, no friends, no network. That was the day I practically died. But touch wood after the third day, my GP was very, very good, introduced me to a treatment that has kept me alive, So that is what informed what I do, befriending, because a lot of people feel disconnected, especially when you move to a new country. And when I came to Northern Ireland, I suffered a couple of illnesses including an enlarged prostate. I truly know how challenging that is for you to be alone, having to navigate the system all by yourself. So anyway, my success story that I'm going to share is quite funny. When I went to see my GP and explained some of the symptoms that I had, my GP then was a female and she said- have you had your prostate checked? Like, what's that? So that was the first time I started asking questions about prostate. How do you check that? And will she explain? I'm like, no, you won't do that. And she said, that's the only way, I'm sorry. She was actually very, very good at explaining it. That one in four men would suffer prostate cancer. And if she's not gonna do it, somebody else is gonna do it, but I should accept that she is here now and I will not see her when she's doing it. She's happy to put a barricade. She was trying to talk me through my cultural and religious background and to accept what she was going to do. And in that process after that, she said- it's quite enlarged. I'm like, what do we do? So she had to encourage me and send me through all the whole processes.

So after going through that process, to be honest, I felt I need to raise awareness because one in four was a scary number, And that was when we started the campaign two years ago. And I went to a particular church. Normally, the African church won't allow you to speak if you're not a pastor, but the pastor listened to my story and gave me the audience, the opportunity to speak to the audience. So when I shared this story, trust me, 30 men from the church went for test.

Liv (47:07)

Well, what an impact, yeah.

Carly (47:07)

Wow.

Israel (47:08)

30 people went for the test and unfortunately about six are living with enlarged prostate like myself which is fortunate because it was caught early. So the next step was the other church, my church that I went to and my pastor and couple of other men have gone for tests but they didn't like the experience. But they actually reported back that their GP understood the cultural differences here and explained to them and was very, very kind to them. So that is what has informed the next campaign for the next three years, which is one in four, it's my personal campaign. We'll be going to churches, mosques and schools that I've had access to and materials translated in different languages because when you come up with prostate cancer, people will be like, no, God forbid it. They will not even want to engage. So we have to devise a different method of having to talk about this. So that itself is a positive outcome for i-Assist, what we do. So having recorded about 36 men that went for the prostate test, I mean, it's a win for me.

Carly (48:22)

Yeah.

Liv (48:23)

Yeah, yeah, that's brilliant. And without sharing your story, like you say, that wouldn't have happened. That's- what a brilliant outcome. If I can move us on to our final three questions. So we end every podcast episode with these and ask all our guests. So the first question is, if you could go back in time to kind of setting up your organisations, founding your organisations, what advice would you give yourself? And Judith, I'll start with you.

Judith (48:51)

What advice would I give myself? I would say to be confident, to believe in myself and in the objectives of the organisation and to never be fearful, to challenge and to have the difficult conversation. I think that's what I would actually, yeah, I think it would want to be one of my resounding points because I believe that very early on. This wasn't something that I came to because I, you know, trained for it or anything like that. So I was quite unsure in the early days. And I think you have to be aware that, you know, when you're doing something that can impact somebody's life in the way of whether they live or die, then you should always have that conversation. You know, so yeah, I suppose that would be it.

Liv (49:45)

Lovely. Thank you so much. And Israel, what advice would you give yourself?

Israel (49:51)

I would tell myself to be prepared for a marathon, not a sprint. I would also tell myself to celebrate the small victories and the small wins throughout the journey because those are the moments of hope that helps us to continue to do what we do.

Liv (50:10)

Wow. The second question is, what change would you like to see to improve the lives of people living with cancer?

Judith (50:17)

from my perspective, I would like it to become, if I had a wish list, for it to be mandatory, that people from marginalised communities have to be included within all clinical trials. Because I believe that that's where it starts from, that would be my wish list. That would definitely be my wish list.

Liv (50:36)

Absolutely. Yeah, that's a brilliant one. Thank you. And Israel?

Israel (50:41)

I want to see a healthcare system where every person's culture or background is seen as an asset, not a barrier. A system where every patient has a story and that story needs to be heard, valued and used to co-create a care plan that respects their whole identity. That's what I would wish for.

Liv (51:01)

Brilliant. And finally, what would you like listeners to take away from this episode?

Judith (51:06)

I would like listeners to, if nothing else, to take away the fact to look at cultural competency and to understand that it really does have a place in every organisation. And also, please work with community-based organisations. Don't let that cultural competency be a tick box. Engage with people with lived experience because it really does make a difference.

Liv (51:32)

Yeah, that's so important. Thank you. And Israel?

Israel (51:35)

I just hope that listeners will take away today that cultural responsiveness is not just a 'nice to have'. It's not just- I have obtained the training or we have the policy. It is a fundamental component of safe and effective health care. And that everyone, whether a patient, a provider, or a community member has a role to play in dismantling health inequalities. And this all starts by listening to a story. It's about listening to people with lived experiences. It's about putting yourself in my shoes, in her shoes, and in their shoes, people who have experienced it.

Carly (52:17)

Yeah, wow, what a way to end the episode.

Judith (52:21)

Can I just say Israel, thank you for sharing your story. It's such a similar story to mine, but you don't think that anybody could have a more challenging story than yourself sometimes, but you definitely did. So thank you for sharing.

Israel (52:34)

Thank you. And thank you for sharing yours too.

Carly (52:39)

And to both of you, we are so thankful on behalf of everyone on the Cancer Professionals Podcast. We're so thankful and we're so privileged for you both to share your own personal stories, but also everything that we've talked about, all of those stories that you've brought to this conversation. And we are so, so thankful that you shared all of those and what an impact it has made to this conversation. Those stories are such powerful reminders of why cultural responsiveness and also community- led organisations, community engagement matters so much in cancer care. So thank you, thank you, thank you. We could talk all day, but thank you so much for joining us on the Cancer Professionals Podcast.

Judith (53:05)

No, thank you. Thank you so much. Take care.

Israel (53:24)

Thank you for having me.

Outro music

Carly (53:29)

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Liv (53:52)

If you enjoyed this episode, follow us so you don't miss our next conversation, where we'll be joined by June Davis, Lead Nursing and Allied Healthcare Professional Advisor at Macmillan, and Laura Massou, Consultant Anaesthetist and Medical Lead for Prehabilitation at Royal Berkshire NHS Trust. We'll explore the newly published Macmillan guidelines on prehabilitation for people with cancer and what they mean for the future of cancer care.

Carly (54:10)

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Liv (54:22)

I'm Liv

Carly (54:24)

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