

The Cancer Professionals Podcast

Larger bodies in radiography

Episode transcript

(Intro music fades in)

Carly (00:09)

What are the realities of accessing imaging services as a person in a larger body?

Carolyn (00:13)

The staff weren't rude to me or anything like that, but it was the way they handled me, I suppose, during an appointment. So I'd kind of be pushed and pulled into position. The staff wouldn't communicate with me. You kind of feel like your body's a burden.

Carly (00:29)

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

Paul Middleton (00:31)

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.

Carly (00:46)

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.

(Intro music fades out)

Paul Middleton (01:06)

This episode includes discussions of body size, obesity, weight stigma and lived experience of cancer, which you may find upsetting or triggering. Listener discretion is advised.

Carly (01:18)

In this episode, we're exploring the experiences of people living in larger bodies within radiography and the importance of this within cancer care. We know that radiography plays a central role across the cancer pathway from screening and early diagnosis to treatment planning, monitoring response to treatment and follow-up imaging. However, individuals living in larger bodies can face significant barriers. There might be challenges such as inadequate equipment, accessibility limitations, discomfort during procedures, and also experiences of stigma, which can contribute to reduced screening attendance or delayed presentation, or even avoidance of healthcare and ultimately poorer outcomes. But we are delighted to be joined by two guests bringing very incredibly valuable perspectives to this discussion. We have Dr. Amy Hancock, who is Director of Medical Imaging at the University of Exeter and Carolyn Graham who will very kindly share her lived experience of radiography as a person living in a larger body. So thank you both Amy and Carolyn for joining us on the podcast. Let's start with you telling us a little bit about you and also what brings you to talking about this topic today. Carolyn, should we start with you?

Carolyn (02:31)

So I'm Carolyn Graham, I'm a patient partner and that is I help researchers with their studies using my lived experience of the topic. Back in 2007 I was diagnosed with Hodgkin's lymphoma and as part of my treatment I received a course of radiotherapy. At the time I was living in a larger body. Over the course of my adult life my weights fluctuated a lot so I've had a lot of different experiences of imaging appointments depending on what size body I was in at the time and when I saw the call out for Amy's research I felt that my experiences could be really useful.

Carly (03:09)

Lovely, thank you so much. And thanks so much again for coming on the podcast to share those experiences. And Amy, over to you.

Amy Hancock (03:17)

Hi everyone, I'm Amy Hancock. I'm a therapeutic radiographer by professional backgrounds. I'm now the Director of Medical Imaging down at the University of Exeter. My background interests pretty much around person-centred care. And my interest in this project came about because we were working with our students and sadly we were hearing reports from them that some of the practices that were occurring during their training placements weren't exactly person-centred towards people living in larger bodied. So we were really interested in trying to understand what was happening and look at how we could perhaps enhance services if we needed to at that point. Obviously getting to work with people like Carolyn who provide that lived experience and that voice has just been really important throughout all of this.

Carly (04:05)

Thank you. Yeah, thanks so much. So Carolyn, you talked a little bit in your intro about your experiences of with cancer and also you touched on some of those experiences of

radiography. Could you tell us a bit more about those experiences and what was happening for you during those times as a person in a larger body?

Carolyn (04:27)

Sure, I mean I've got a complex medical history so I have osteoarthritis, fibromyalgia, neuropathy, so I've had a lot of scans and x-rays and ultrasounds over the years.

Prior to my cancer diagnosis and after all my cancer treatment was over, my experiences during those times were pretty much the same. So I would go along to an appointment and I was a lot bigger then than I am now and I would be, generally, the staff weren't rude to me or anything like that, but it was the way they handled me, I suppose, during an appointment. So I'd kind of be pushed and pulled into position. The staff wouldn't communicate with me. They just... It's kind of hard to describe.

It's more of the feeling that you get. You kind of feel like your body's a burden. It's in the way. It doesn't fit the machinery or it's causing the staff to have to spend more time with you or kind of put more effort in. Interestingly, when I had cancer, so my diagnostic CT scan for that didn't go well at all. But after the end of my chemotherapy treatment, I was sent for a course of radiotherapy and the experience was just completely different. The staff engaged me at every point. So whether it was in the changing, getting changed, getting onto the equipment. I had radiotherapy to the chest. So obviously, you know, it was, I felt quite exposed. The staff were chatting away, friendly. They talked me through every single thing that they were doing. They checked that I was comfortable. They checked that I was okay. And these are experiences I didn't get prior to having cancer.

Whenever I've been to for radiotherapy or for any kind of imaging. There's issues with the cubicle sizes and also with the sizes of the gowns. And I don't know why it is this way, but it seems to be that the gowns are only one size. And so when you live in a larger body, you either take one gown and then risk being exposed as you walk from the waiting area ~ down to the imaging room, or you then, like I do, you have to then ask for a second gown. I do remember feeling like, my goodness, this experience is completely different to what I usually experience on the NHS. And it was as if having cancer kind of negated having a larger body. So that was no longer a burden because now we had a cancer to treat. So I was definitely treated more respectfully with more dignity and kind of treated like a whole person. Whereas I think when I've been for scans and x-rays before, I've been, it was almost like the staff just see the body part or the disease. They don't really see

Carly (07:25)

Hmm.

Carolyn (07:34)

all of me and that was the biggest difference. I know not everybody has a positive experience during radiotherapy but certainly you know I couldn't have been treated better by the staff at that point.

Carly (07:48)

Yeah, that's so great to hear that you had a positive experience, particularly when you compared it to prior, you you receiving that cancer treatment. Comparing your experiences previous to when you were diagnosed with cancer to your more positive experience, what were some of the other differences that you felt really made an impact, a positive impact on your experience?

Carolyn (08:11)

Yeah, I would just say it was really the way that the staff spoke to me. So they had more time. That was, you know, I know that that's just the way the system is. Staff don't have a lot of time to spend with patients. It's kind of in get it done and back out the door again. So they had more time. They felt like nothing was too much trouble.

I could ask anything I wanted. They told me every single thing that they were doing along the way. When I've had imaging done before, it tends to be they'll just move bits of you around and you'll just feel a hand on a shoulder or they'll grab a hand and move it to another place. And there was none of that. And also...

During radiotherapy, there was a lot more people around about me, so it could have been a very daunting, you know, nerve-wracking experience. And I was a bit nervous, especially on the first treatment. I didn't really know what to expect. And the staff were absolutely great.

Carly (09:13)

Yeah, that's really great to hear. And you talked about seeing the whole you and seeing you as a person and that kind of person-centered care, which really is so, so important and actually just something that should happen consistently. Can I ask, of touching on some of those experiences that maybe weren't as positive, what impact did that have on your willingness to perhaps engage with healthcare at that time.

Carolyn (09:41)

I'm the type of person that I think because of my complex medical history, I know the importance of having to go for imaging studies and I've had more than a fair share of them over the years. So I kind of I felt like I made myself go. So I would be a bit anxious what to expect. no, is the gown going to be big enough? Will somebody be around? Will I have time to ask the person for a second gown or will they just kind of there's a gown and you go and they'll wander off and also quite conscious of where is the cubicle in relation to where the imaging room is because nobody really wants to kind of wander around, when they're, you you've not got your clothes on and, you know, especially when you're in a larger body. I mean, a lot of people feel quite confident in a

larger body, but you know, not everybody does. And I certainly fell into that category. And ~

Carly (10:30)

Hmm.

Carolyn (10:42)

you're not just aware of the way that staff might think, but also other patients and visitors in the area as well.

Carly (10:50)

Yeah, yeah, of course. Yeah, thank you so much for sharing, And I think it's really interesting to hear what really made a difference to you in terms of what made that positive impact to help you, you know, in a time where you really need that support and you need people to kind of, you know, provide you what you need in that moment. So yeah, thank you so much for sharing.

Paul Middleton (11:12)

Amy, if I can bring you into the conversation, what kind of what stands out about Carolyn's experience and are there things that kind of resonate with what you've seen in the research and also what you've seen in practice?

Amy Hancock (11:28)

Yeah, and I think the most striking thing to me is, know, Caroline speaks about imaging from years ago and experiences from years ago, but yet they're so pertinent to her now that she recalls and she remembers how it made her feel at that time. just think that just shows what an impact, you know, our behaviours and our practices have as healthcare professionals on patients, you know, weeks, months, years, decades down the line really and sadly you know the experiences that Carolyn had not in isolation you know from the research we found that patients are still you know experiencing or have experiences and it's just obviously disheartening to understand that you know patients are still perhaps being stigmatised or alienated from services because they live in a larger body.

Paul Middleton (12:23)

And we heard a little bit about how it impacted Carolyn and as Carolyn said, you you kind of forced yourself to go to the appointments, but what can the impact be on whether people continue to engage with, you know, the healthcare system?

Amy Hancock (12:40)

Yeah, so the research we did is we wanted to, you know, hear and understand about the lived experience of people living in a larger body. we specifically made it for, you

know, the diagnostics, the medical imaging strand of radiography, as well as the radiotherapy, because, you know, there's an interconnectivity. You need the imaging in order to get the diagnosis, in order to be able to go for the treatment. And it's just around how before people attend that appointment, Carolyn was saying about those experiences, makes people sort of fear and dread about next appointment. Am I going to be treated the same? Is there going to be a gown big enough? Am I going to get this disrespectful language or stigmatisation? And if you're entering an appointment which is you know, you are going because there is potentially something wrong or you already know something is wrong. So there's all that anxiety around that appointment anyway, you know, knowing what the outcome of that imaging is going to be or, you know, the side effects of that treatment. To then add that kind of fear of, this going to be an interaction that is going to leave a negative kind of impact on me.

Carly (13:55)

Mmm

Amy Hancock (13:56)

You know, that kind of builds that anxiety for patients even before they've attended department. Obviously the interaction itself, you know, the behaviours of the staff. Sadly, we found, the language used by some staff wasn't, wasn't respectful and wasn't inclusive. We've got examples of patients talking about, ~ not necessarily radiographers, obviously when patients recover, experiences are talking across healthcare.

But you know, things like we've got a big one here, you know, being said in front of patients, in front of other medical professionals, things like eye rolling, things like, huffing and things under the breath, which is sort of like Carolyn says, it's not actually something done directly. You can't actually put your finger on it and say they did this, but it's just that sort of atmosphere around the how they sort of engaged with the patient, you know, what did their body language signify, how did the sort of hesitation or being made to feel like I'm a problem or a burden, obviously has a consequence of that interaction, which then sort of reinforces the message of, don't want to go to my next appointment if that's what I'm going to be facing every time. And sadly, within the research, you know, there were patients that turned around and said,

~ Obviously not specific to cancer in this example, but you know, we had people saying, I'm not going to get pregnant again. I'm not going to have another child because that experience was so horrific that I don't want to put myself in that situation. But we also had patients where, because of the situation and the way they made me feel, they said they wouldn't go back even if they needed more diagnostics, you know, there's perhaps potential for patients to be misdiagnosed, later diagnosis around this just because of that sort of the way they were made to feel in that interaction.

Carly (15:51)

Gosh.

Amy Hancock (15:52)

You obviously talk about these things and it's never meant to be a bashing of a profession or anything like that because there's so many amazing examples of healthcare professionals that are working and are being person-centred but we just need to consider that there are a subsection of society that are facing these barriers and these challenges to care.

Carly (15:58)

Mm. Yeah, I think that's so important to highlight and that's obviously why we're having this conversation to really think about healthcare professionals and their role within this.

Paul Middleton (16:23)

And can I ask, and I know we've kind of talked about maybe the what, when people are going off for a one-off diagnostic imaging or something like that against maybe some treatment where people are perhaps seeing the same people. why is there such a difference between people's experiences between the one-off and the repeated treatments,

Amy Hancock (16:45)

Yeah, I mean, it's what was interesting again in our research is we asked the patients, the respondents to say whether they'd got a lived experience of medical imaging and or a lived experience of radiotherapy. And there was 15 patients that had received radiotherapy, but only eight of them chose to speak about that experience. The rest of them picked the medical imaging, to talk about and across the sort of patient experiences, medical imaging sadly did, there were more instances of negative sort of behaviours. But also I think because of the imaging itself, the equipment, there's a lot more restrictions. If you think about CT or MRI scanners, you've got a lot more restrictions with what they call the bore size. So that's the hole that you go through as part of that imaging. So I think that naturally the equipment side of it sort of creates a more challenging environment for people who are larger bodied, know, to be able to be, you know, accessibility of equipment, let's say. However, things around like, waiting room type equipment, chairs, cubicles, obviously things like that are pretty much the same and standard across both sort of professions.

It was more the let's say the behaviours or the interactions of the professionals across the diagnostic strand, that sadly that patients reported were more challenging or more negative for them. And again, I don't think that's necessarily because of the radiographers themselves. I think it's because that environment is more restrictive for people with larger bodies, let's say. So perhaps these are occurring more frequently.

So it's not necessarily a lack of respect or rapport building. It's probably that environment. It's more of a challenging environment than the treatment side as well. But on saying that, think, you know, reflecting on what Carolyn was saying, there is a

diagnosis. There is, you know, you know these people are here because they have cancer, you know, be it still in situ or if, you know, following surgery or something.

So actually the focus is on more about them and that cancer and being sort of holistic in that care rather than the, you know, there's a potential problem when they're coming for diagnostics.

Paul Middleton (19:13)

And does that kind of reflect some of what you've experienced?

Carolyn (19:18)

Yeah, my experience absolutely reflects what Amy was saying. In fact, it wasn't until this opportunity to work with Amy on this research came up that I... consciously realised that I had been treated differently during my radiotherapy. So I think because I was so overcome with the cancer diagnosis and I had CT, MRI, PET scans, know, chest x-ray, there was just so much going on and it was only when I had time to reflect because I was thinking, yeah, I've had a lot of ~ imaging studies done, I can help with this. And it was during one of the focus groups.

Carly (19:35)

Huh.

Carolyn (19:56)

When I was talking, suddenly thought, wait a minute, I actually was treated differently. just when Amy was mentioning there about the bore size and the equipment, I remember having an MRI scan and it was a lengthy one because it was a full torso scan down to my pelvis. And when I was in the machine, this was when I was probably at my largest size and they strapped me in and they were starting to push the

sorry I don't know the correct terminology but they kind of the bed into the machine and it was obvious that my arms were a bit wide they kind of brought the table out and then just grabbed my arms and crossed them over me tighter and strapped me in and then put me back in without a word. So obviously I'm not stupid I was aware like I can feel that touch in my arm so I kind of knew why they were doing it but it was just

It was literally like I was a body on the bed. I wasn't a person. yeah, that's, yeah, not great. That wasn't a great experience. I mean, luckily I'm not claustrophobic or anything. I was able to have the MRI scan without any issue. But still, you know, I have other health conditions and to just...

Carly (20:53)

Hmm.

Paul Middleton (20:54)

Gosh

Carly (21:01)

Mmm.

Carolyn (21:15)

I've never really, I've never been able to understand why the person just wouldn't talk to you. Like, oh, I'm just moving your arms out the way to make sure they don't get, you know, you don't get hurt by the machine. you know, there's no reason why a few words.

you know, it would really make all the difference to your experience. And with that, it does make you think, ~ is this going to happen the next time I go? And you kind of start to dread having that same procedure done again.

Paul Middleton (21:41)

Yeah.

Carly (21:46)

It's that lack of communication, isn't it? Like you said, there's no explanation as to what they're doing and why.

Paul Middleton (21:46)

Mm hmm.

Carolyn (21:50)

Absolutely. Yeah, I mean, if I try and put myself into the staff perspective, it's just they know they've only got a certain amount of time, they've got to get the procedure done. And so I think maybe it's not intentional. It's probably just that they maybe go into autopilot, just go in, do this, do that, get it done and then onto the next patient. But from a patient perspective, especially as Amy was saying, you you either know you have something wrong with you or you think you have something wrong with you.

So from our perspective, it can be quite a nerve-racking time. When we come along to these appointments, we don't just turn up on the day like a blank slate. We're bringing with us all our conditions, all our life experiences up to that point. So when we encounter a member of staff and they have a simple interaction with us, we've got all that history that we're bringing.

you know with us and it could even be we might have had a really bad day up to that point you know it could be something as simple as that so a few words of kindness it really does make all the difference.

Carly (22:54)

Yeah.

Amy Hancock (22:56)

Yeah.

Carly (22:58)

Yeah, it really does.

Paul Middleton (23:00)

Thank you for sharing that, Carolyn. That's, you know, really, yeah, it's kind of difficult to hear in places. Yeah. And thank you for kind of sharing your own experience.

Amy Hancock (23:11)

So I think Carolyn makes a really important point there. know, we don't think any of the radiographers or the healthcare professionals that these patients with you know experiences reported were purposely purposely being non-compassionate or disrespectful. It's just sometimes that you know we're restricted by time pressures are restricted by the equipment and sort of that situation that they're in. But it is exactly as Carolyn says about remembering there's a person there, there's a person who is coming for an appointment that needs holistic care in that moment and needs that kind of consideration, respect, being treated with dignity,

Carly (23:55)

So Amy, I wanted to go back a little bit about the research that you mentioned you'd carried out. Could you tell us a little bit more about the background, where it came from and what it entailed?

Amy Hancock (24:07)

Yeah, so there's a team of academics and researchers from the University of Exeter. I'm working side my colleagues, Dr. Christine Heales and Dr. Fay Manning. And I mentioned at the start of the podcast around sort of hearing students experiences of the clinical training that they were, probably not experiencing the best, you know, examples of person centred care. And it got us talking as a group of people who were really passionate about, patient experiences and making sure that, you know, not only are they person-centred, but also they're, you know, appropriate for what they need at that time. You know, if people are getting, if they're having delays because they can't fit in the bore or they're having to be delayed and go to, another centre where they can have an MRI scan or something, we're obviously very, you know...

interested in whether this was having a longer term effect and we mentioned earlier about healthcare avoidance. So what we looked at was a survey with patients, with people ~ outside of the NHS asking them to talk about their lived experiences, I say, of either medical imaging or radiotherapy. And we had over 100 responses to this survey.

and the patients reported about their experiences of the sort of general, like I say about the equipment in the waiting rooms, about the behaviours of staff, about the impact of those experiences as well and talking about that kind of pre-appointment, know, that anxiety, that anticipation about what's going to happen at the next appointment, will I face the same barriers.

thinking about that actual appointment and the limitations and the challenges that they're facing. But we also found out, we got to understand about that kind of long term. And it's almost that cycle that we mentioned earlier about because they're anxious and nervous about going again. It then reverts them back to that first stage where they're kind of thinking, do I really need to go for this? Should I be attending that appointment?

What we were sort of surprised about was some of the patients were, you know, not only saying I'm not going to get pregnant again, but also things like the patients would be delayed or deferred for the treatment. And sadly, if there isn't the right size equipment locally at their hospital, they were having to be referred ~ bariatric or even animal centres in some instances.

So you can imagine the stigma around, you you are too big to have standard imaging. You are going to go to a specialist centre. So that kind of stigmatised them all over again. And, you know, we had patients that were reported that they had delays in cancer diagnosis. Someone had a brain tumour that took another four weeks to diagnose because of...

the delays in getting an appointment at a centre that could accommodate their body shape and size. And obviously if we think about the importance of timely diagnosis, it's really key that these delays aren't happening. And another thing was around the, you know, we don't kind of consider how we communicate with patients after that appointment,

We all have access now to NHS apps. We can pull up our own results without even having to speak to a healthcare professional. How that's recorded on that document, on that online app, can be quite distressing. So thinking about that sort language used in there.

Carly (27:52)

Yeah, yeah, absolutely. And kind of picking up on that sort of language and you mentioned earlier about the language that is used in communication and actually the

importance of the language that is used. And I guess firstly, I was interested to know about the term that you use in your research and that of course we've used throughout this conversation about people living in larger bodies.

What was behind choosing that as the kind of preferred term?

Amy Hancock (28:21)

Yeah, so we before Carolyn came on board as part of the patient public both work we did later on in the projects, we did some with four individuals who are patient representatives and we were just so mindful of what terminology to use. It's such a sensitive and emotive topic and this

a real sort of disparity in the language that people use. You some people will happily call themselves fat. You know, there is very much a body positive movement where people are reclaiming that negative term and will be happy to use it. Whereas there's people that will be deeply offended by that term. We also didn't want, you know, medical terms like obese or BMI or anything that sort of...

gave a label almost and there's a lot of negative connotations. So we worked with our patient representatives and find a neutral phrase, term, you know, that we could use and they came back with this larger bodies. And there's almost a bit of a sort of a strap line behind this, which includes anyone who's wide or tall or broader than the average, not limited to those who are plus size.

and we felt like this was a nice, you know, neutral way to sort of address this group. And I will, I'm going to bring Carolyn in at this point because we did some further work later on about the term and you know, went back to the group and this is where Carolyn became part of it.

Carolyn (29:58)

I think myself and the rest of the group, we really like the term larger body because it didn't single out people living with obesity. It included tall people, athletes, like Amy said, just people who are kind of taller and broader than than the average. And so it fell more inclusive and it kind of took the stigma away from it.

Carly (30:19)

Yeah.

Carolyn (30:22)

And we were all, like Amy said, there were some people that were just quite happy. They were saying that they didn't mind being referred to as fat. But most of us were like, well, it is a kind of derogatory term, especially it's used quite as a derogatory term

in the media as well, which means that it kind of gets used by a certain section of the public. to use the term larger bodies,

just seemed kinder, more inclusive. And actually I mentioned earlier that I do other patient and public involvement work and I have actually heard the term being used in some of those projects. So it does look like that term, don't know how, if it's as a result of the work that Amy's done, but that term is slowly starting to filter through and it always makes me smile.

Carly (31:09)

Yeah.

Carolyn (31:15)

Yes, at last we're starting to use more inclusive language and hopefully one day there will be a lot less stigma around people in larger bodies.

Carly (31:27)

Yeah, yeah, absolutely. And I think kind of thinking about language more generally and reflecting back on your experiences, Carolyn, in terms of the interactions that you've had in your experiences with healthcare professionals and the language that has been used, what would you say to a healthcare professional who perhaps is listening, isn't sure what to say or what is the right thing to say, what is the correct language to use?

What would you say to those people?

Carolyn (31:55)

I would say if you're not sure... Imagine the person standing in front of you is a family member or a friend. How would you speak to them? You would speak to them with kindness and compassion and you would treat them with dignity and respect. And that's all that anybody wants regardless of their body size. Don't treat us as just a body shape or a body size or whatever our disease is. Just speak to us the way you would speak to someone you care about.

It can really make all the difference for somebody and it can actually change. And I think, Amy, I think you uncovered this in the work that you did with your surveys, that having a positive experience, can actually change the trajectory of a person and think, well, maybe my next appointment might actually be, that person might be kind and respectful and it really can make the world a difference.

Carly (32:44)

Yeah. Yeah. Yeah, absolutely. And it sounds so simple, you saying it, but actually it makes the world of difference to treat people with kindness and with a person. And as

Amy talked about earlier, actually what a massive impact it can make, it can ultimately change someone's health outcomes just through the things that we've talked about. So yeah, really, really important. Thank you. Thanks so much for sharing and kind of touching on that.

Carolyn (32:57)

Mm-hmm. Yeah.

Amy Hancock (33:11)

Yeah. Yeah, and we found that, know, radiographers, healthcare professionals can break that cycle as well. where, you know, they had a good positive experience, it was, you know, a neutral experience.

It made people think, actually, I'm not as worried now for next time. You know, it was putting him at ease almost as well.

Carly (33:31)

Yeah.

Paul Middleton (33:34)

And that's a nice kind of segue. Again, just going back to the research, Amy, what's starting to change and kind of what's been recommended following the research?

Amy Hancock (33:47)

I mean, a key thing was about, again, related to language, was quite often we blame the patient rather than the equipment. So things like instead of you're too big for the machine, it's actually the machine is too small. And it's about sort of reframing that we need to think about. Patients don't always understand the limitations of the machine.

the bore size, the hole that patients go through has to be a certain size to do with all the the image quality. But that's for us as healthcare professionals to deal with and look at. That's not governed by the patient. So we need to sort of be depicting this is the reasons why it has to be this shape and size. However, let's work with you to look at.

how we can accommodate that. know, like Carolyn says, if the work's referring to people who are taller, actually what can we do so they're not hanging off the edge of the bed? What can we do to make, there's some level of comfort be there in terms of the equipment? these, things that need to change that are really, really simple. Have a supply of all sizes of gowns in your changing cubicle. That's just such a small simple thing that we can do in clinical practice.

You know, chairs that are, without arms or, wider chairs, wider wheelchairs. If we do these sort of inclusivity measures, it will fit the whole population, not just a subset of the population. So there's some of the more like practical things. And as Carolyn mentioned, we're starting to see a change in language and but it does, you know, have to start with sort of education.

Paul Middleton (35:36)

There's lots of practical tips you've shared there. And a lot of them, don't necessarily require lots of resource or lots of equipment. You know, it's just some of those simple practical changes. And like Carolyn said, the difference that it can make.

And Carolyn, you have mentioned some of the work you do kind of around patient advocacy and being involved in the research. How important is that in all of this?

Carolyn (36:10)

It's really important. I can see Amy smiling there. ~ I've been doing this for nearly six years now and I could never have imagined the impact that it would have when I started researchers come up with the idea, like Amy was saying, she, know, her and her team got the idea to do this study, but they don't necessarily have the lived experience. So it's only by speaking to patients and public that they can really get the kind of finer nuances of what it means to be someone that's affected by that particular issue.

Carly (36:49)

Yeah.

Carolyn (36:51)

So I think it's absolutely vital for people to speak up, to get involved, to take part in this research. I think when people think about research, they tend to think about clinical trials. But, you know, a lot of it is studies like this that lead to change in policy and practice. Or even, as Amy said, know, the equipment is, you know, the equipment's too small. Well, how do we get that changed? Well, it takes people to speak up, whether it's health professionals, patients.

Paul Middleton (37:03)

Hmm.

Carolyn (37:20)

And yeah, I would say anyone that has a lived experience, don't be afraid to take part. Your voice really matters and it can really make a difference.

Carly (37:30)

Yeah, absolutely. And actually I've learned lots about, like you said, research, often you think about clinical trials, but all the other ways that someone with lived experience can get involved. And we of course know on the podcast how powerful the voice of lived experience is about talking about topics like this. So I also probably at this point would say thanks again, Carolyn, to you for sharing your experiences. And we know how important that is to really help people learn and help people to understand truly what's going on. yeah, totally echo and kind of agree what you said, so thank So we're gonna move on to our regular feature, which is a question that we ask of all of our guests on all of our episodes.

So I will start with you, Amy, what would you like listeners to take away from this episode?

Amy Hancock (38:19)

Just the importance of their role in either breaking this cycle or reinforcing this cycle. I think we sort of undervalue the impact that healthcare professionals have on not only the patient care during that interaction but also future interactions. So I'd just like people to take that away.

Carly (38:39)

Thank you and same question to you Carolyn, what would you like listeners to take from this episode?

Carolyn (38:46)

I think being kind and respectful to everyone regardless of their body shape or size and that it can have a real positive impact on their healthcare experience and encourage continued engagement with healthcare services.

Carly (38:59)

Lovely, thank you. Both great tips and great takeaways. So really just to say thank you, thank you, thank you so much for being part of this conversation. And it was so interesting. I definitely learned so much from this conversation and really understanding about the barriers and the challenges that people living in larger bodies can face during cancer experiences, but also thinking about those small practical changes that people can make, but also thinking about communication, thinking about the language that's used. And also, I guess the theme that's really thread through this is treating people as a person and treating people with kindness. That's really kind of resonated with me today. So to you both, and Carolyn, thank you so much for joining the Cancer Professionals podcast.

Amy Hancock (39:46)

Thank you for inviting us.

Carolyn (39:46)

Thank you. It's been a pleasure. Thank you.

Carly (39:50)

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Paul Middleton (40:12)

If you enjoyed this episode, follow us so you don't miss our next conversation. We'll be joined by Carmel Cardona, who shares their experience of living with lymphedema, and Becky Elwell, Director of National Clinical Services at Accelerate Health, a community interest company to discuss lymphedema in cancer care.

Carly (40:32)

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Paul Middleton (40:43)

I'm Paul.

Carly (40:44)

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