The Cancer Professional Podcast

Lymphoedema and body image

Episode transcript

(Intro music fades in)

Paul (00:10)

What does learning to accept your body look like when it has changed in ways that feel so different from what you once knew?

Carmel (00:17)

My relationship with my body has also changed. My body has changed and it isn't, there's lots of it that isn't familiar. And that's true with a massive amount of my cancer experience. I've had a double mastectomy. I've had a you know total hysterectomy.

I've got lots of scars and things, but I've definitely learned to love a lot of my body post cancer and the lymphoedema leg has been one of the hardest things to learn to love because it just feels so alien to me, so different from what I'm used to my body being like

Paul (00:48)

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

Carly (00:51)

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

Paul (01:06)

If you enjoyed 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

Carly (01:24)

Before we dive into this episode, we have a quick favour to ask. We've put together a short survey because we'd really love to know how the podcast is landing for you, what's useful, what's making a difference, and what you'd like more of in the future. And it only takes a few

minutes. The links in the episode description, so when you've got a moment, we'd really appreciate you taking a look. Your feedback genuinely helps us shape the podcast for you. Thanks so much.

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

(01:59)

Welcome to the Cancer Professionals So in today's episode, we will be talking about Lymphoedema and living with lymphoedema and also more specifically focusing on the impact that it can have, physically, emotionally, But today we are joined by two amazing guests, Carmel and Becky. So welcome Carmel and Becky to the Cancer Professionals podcast. And shall we start with you both introducing yourselves and telling us what is your connection to this topic that we're talking about today of lymphoedema?

Beccy (02:33)

Thank you very much Carly. My name is Becky, I'm a lymphoedema advanced nurse practitioner. I've been working with lymphoedema since 1997 and my role currently is the director of national clinical services at Accelerate Community Interest Company Social Enterprise in North East London and we look after people living with lymphoedema of all causes.

Carly (02:55)

Thank you, Carmel.

Carmel (02:57)

Great, hi I'm Carmel. I'm a researcher and a consultant and a trainer and I had breast cancer in 2017 and ovarian cancer in 2019 and as a result I've got quite a complex set of lymphoedema diagnoses and I've been living with it since 2018 in total but it's kind of changed and morphed over time.

Carly (03:21)

Lovely, thank you so much. So lovely to have you both on the podcast. So perhaps a good place to start would be with you Carmel, if that's okay. And that lead up to you being diagnosed with lymphoedema and what that kind of journey was for you.

Carmel (03:38)

Yeah sure. So I was diagnosed with breast cancer in 2017 and my treatment was chemo, lumpectomy, I just had a sentinel node biopsy, I only had a couple of lymph nodes removed and

then radiotherapy and then at the time I thought that was it. It wasn't but at the time I thought that was it and I remember my breast care nurse talking a little bit about lymphoedema risk but because I hadn't had all my lymph nodes removed they didn't really think it was a very high risk.

And I kind of went on my merry way thinking I was all done. And then the following year, I remember really vividly, because it quite a hot day and I was at Kew Gardens with some friends and then all of a sudden my right hand started looking a little bit like, you know when you have a glove and you could blow into it and it gets all puffy? And my hand started to look like that and I was kind of quite shocked. I don't think I really registered what it could possibly be. Anyway, it turned out that that was lymphoedema and I got referred to Becky's clinic and saw some people for my upper limb lymphoedema and managed it quite well. And now I actually don't have that at all. I mean, very occasionally I will get some swelling in my hand, but I got some compression garments and it all kind of went down quite well. Then in 2019, I was diagnosed with ovarian cancer and had quite extensive surgery, including all my pelvic lymph nodes removed. And I don't recall at all any of my ovarian cancer team talking about lymphoedema or the risk of lymphoedema at all.

But luckily had already been referred to the clinic for my upper limb lymphoedema so then when I very quickly almost immediately I think after that surgery developed lower limb lymphoedema only in my right leg and in my pelvis I was already seeing the team so then I could kind of speak to them about it and manage it straight away but that has progressed and I think you probably would call it stage two and but I do manage it you know try very hard not to let it get to the next stage or let it get worse. But that hasn't that won't go away, like my upper lymphoedema has.

Carly (05:31)

Yeah.

Yeah. Wow. So, going back to that moment, like you said, when you were in Kew Gardens and you noticed your hands swelling, how did you feel in that moment? I guess you didn't know what it was. And how did you feel?

Carmel (05:42)

I didn't and I remember laying on the floor with my hand in the air thinking, oh if I elevate my hand maybe it'll all drain away. then coincidentally as I was walking around one of the glass houses I saw a woman with two compression garments on her arms and she obviously had kind of significant upper limb lymphoedema and I thought that was a weird coincidence of kind of seeing her and that was what made me make the connection because I saw her and thought, oh that's probably what it is. Which is why I then spoke to my team. But yeah, at the time I didn't know, and it just felt really uncomfortable and a bit weird.

Carly (06:16)

Yeah. Becky, can we bring you in there? Because I know, Carmel, you mentioned about stage two. Could you talk a bit about kind of lymphoedema, I guess, an overview and actually about what Carmel was experiencing?

Beccy (06:27)

Yeah, sure. So lymphoedema is more than just swelling, actually. It is failure of the lymphatic system and that failure can lead to swelling, skin and tissue changes and a real risk of infection. So it is a very serious set of symptoms and it is incurable. So unfortunately, it is a case of having to manage it and that's extremely onerous, which I'm sure we'll hear more about. But for me, the stage part is something that is useful for outcome measures and useful for observing the progress of the condition, but it's not particularly helpful in thinking about the severity to the individual because you could actually have quite mild swelling, but it have a very significant impact on the way that you feel and the way that you portray yourself. So I think that it's very important that we don't necessarily assume that the size is equal to the burden of the condition because that's not necessarily the case. I think the key is that any patient undergoing treatment for any type of cancer is at risk of developing.

Developing lymphoedema, but particularly female and male pelvic cancers, head and neck cancers, and skin cancers, particularly melanoma, and then breast cancer, as we've said. And even with the sentinel lymph node biopsy, as Carmel mentioned, it doesn't mean that lymphoedema doesn't exist anymore or is now something of the past. And we do see a lot more ladies with breast swelling rather than swelling within their arm as a consequence of treatment and the way that treatments have changed and developed over the years so it is definitely something that I wouldn't want us to rely on the staging to marry up with the impact of the condition.

Carly (08:13)

And it sounds like in Carmel's situation, obviously, is something that she'd noticed and then was able to go and contact the relevant teams to kind of flag that. That kind of early recognition is, I'm guessing that's very important in actually the outcomes and how it's then picked up.

Beccy (08:30)

Absolutely. We know categorically that the earlier lymphoedema is detected, the earlier treatment is implemented, the more successful the outcomes. And as Carmel said, she's actually been able to manage her upper limb lymphoedema now that she doesn't have to wear compression or carry out all of the self-management strategies that you would need to employ generally. So that early intervention, that awareness, that recognition that she had and her healthcare practitioners had imparted that information, however, it did take, you know, some time to think what that might be, because when something happens like that, your mind goes everywhere thinking what on earth is going on, what's happening. But actually, that is so important and so key. And the organisation I work for Accelerate, we've put together a series of education for healthcare practitioners to try and improve recognition of the condition to allow earlier prompt correct treatment every time.

Carly (09:28)

Yeah, absolutely, I was interested to know do you have any sort of stats or figures about actually the prevalence of lymphoedema when it comes to people with a cancer diagnosis receiving cancer treatment?

Beccy (09:41)

We do know some of the site specific data. So we do know that it's around about 30 % of women who will develop arm swelling after breast cancer treatment. And then that reduces significantly in those who've had sentinel lymph node biopsy to around about 5%. However, as we've heard, that doesn't exclude anybody from developing lymphoedema. And we believe that the incidence for other cancers is very high from sort of 5 or 6 % up to about 70%. So the studies have not been particularly helpful, but we do know that there is a very high number of people living with lymphoedema that haven't been able to access lymphoedema care or lymphoedema management and that people believe that this is a natural side effect or consequence of treatment that they've just got to live with or they've got to manage.

And people tell us about how they feel guilty talking about having a long-term side effect of cancer treatment because they should feel lucky or grateful to have had the treatment and to be living their life. And so we do believe that there's a lot of people out there who aren't actually obtaining the right treatments and interventions for their lymphoedema.

Carly (10:38)

Mm-hmm.

Paul (10:59)

I think, you know, you've really talked about how kind of that recognition and early intervention can make a real difference. And Carmel I can kind of come to you and kind of with that in mind, what does day-to-day management of this actually involve? What does it look like?

Carmel (11:17)

Yeah, it's interesting. There's no kind of one thing that you can do to kind of wave a magic wand and manage it. It's like a kind of jigsaw puzzle a little bit and there's loads and loads of little things that I do that all add up to helping to manage it and helping it reduce the impact it has on my life but also kind of prevent the risk of infection and prevent it from getting worse. So on a practical level these kinds of things look like I wear compression garments every day so it's like a kind one-legged pair of tights where on my good leg it just stops at the thigh but on my other leg it goes all the way down to my feet. And they're very thick and obviously tight. That's what they're doing their job. But in the summer, as you can imagine, that's quite challenging. I have to drink loads of water. I drink several litres of water a day. I have to move regularly. I can't really sit for

very long periods of time. I can't stand for very long periods of time. And that impacts my life in terms of kind of if I'm going to a gig or if I'm trying to write my PhD as I am now or if, know, all sorts of things, I have to move often. I elevate my legs a lot. So I have like a foot rest that allows me to elevate my legs horizontally. And I have to do that several times a day as well. There's this thing called MLD or manual lymphatic drainage, which you can do, which I've been taught how to do. My partner's been taught how to do, which is about kind of helping to drain the lymph manually in your limb, your leg, or in my leg. And I've also been taught how to do that in my arm as well, in my hand.

I actually have this contraption that's kind of like, my family jokingly call it the wrong trousers after the Wallace and Gromit film. And it's like a big pair of blue trousers that is basically like a kind of an air-filled, it's kind of like a massage trouser. I don't really know how to describe it, but anyway it kind of does that manual lymphatic drainage but using air pockets. So I sit in that I lay in that for an hour every night. I do regularly bandage, so I usually do a bit of a reset once a year and that's where you bandage your entire leg with foam around it and you do that every day for about five or six days and that helps to kind of decongest you a little bit. I usually do that after the summer when I'm particularly swollen.

It's really hard in the summer, like I say, I carry a little water bottle with a spray around everywhere and I spray my leg regularly to keep it cool. I have to keep cool, I have to always make sure I've got air conditioning in any hotel I stay in and just be really conscious of that. I moisturise daily, you've got to make sure that there's no breaks in your skin and I'm very, very conscious of any bites or cuts. You know mosquito bites can basically cause cellulitis, and you end up in hospital and that's a real risk. So I'm very conscious about kind of maintenance of any cuts and antiseptic and things like that. And then I regularly go to the clinic because it's really important to get remeasured for garments every now and then. The garment sizing is really important. If they're not the right size, they're not going to do their job. And then I often wear a sort of ridged bandage at night

Ad

(Music fades in)

Carly (14:15)

You know how much really listening, properly listening, can make such a difference when someone's going through a cancer diagnosis. It's not just hearing the words, it's understanding the impact it's having on their life and their care experience. It's hard when you're stretched, time poor and carrying the weight of difficult communication.

And that's exactly where the Macmillan Learning Hub comes in. It's packed with resources for health and social care professionals to build their communication skills from listening well to building strong relationships. They're there on your terms, ready when you are, with no pressure to do it all at once. So if you'd like to learn more, check out the episode description for all the details. And now, let's get back to the conversation.

(Music fades out)

Paul (14:57)

What's the kind of emotional impact of that on you?

Carmel (15:01)

Yeah, I think it's really interesting when you think about the emotion, when I think about the emotional impact, because I think a lot of it is also really wrapped up with my sense of identity. You know part of what my identity was, was someone who was very fit and active, someone who's very well. So, you know, for example, I would do multi-day hikes or go for big bike rides and things like that.

I sort of can still do a lot of that stuff, but there's also a lot of stuff that can't do. It limits me in terms of my physical abilities. And that really has impacted my sense of who I am and my sense of identity. And My relationship with my body has also changed. My body has changed and it isn't, there's lots of it that isn't familiar. And that's true with a massive amount of my cancer experience. I've had a double mastectomy. I've had a you know total hysterectomy.

Carly (15:50)

Hmm.

Carmel (15:52)

I've got lots of scars and things, but I've definitely learned to love a lot of my body post cancer and the lymphoedema leg has been one of the hardest things to learn to love because it just feels so alien to me, so different from what I'm used to my body being like

Paul (16:07)

And as you say, it's not just the kind of the physical side. There are kind of the wider implications as well. And Carmel if you're comfortable, are you happy to talk about some of those kind of wider implications, such as body image, intimacy, sexuality, if that's okay?

Carmel (16:24)

Yeah, sure. It is very linked to the physical side as well because I have pelvic lymphoedema. It can also cause that area of my body to swell. including like the labia and the vulva can swell as well and become really, really unrecognizable. And that's not permanent, but it's also very, very hard to manage. It's really easy to bandage your leg, not quite as easy to bandage your vulva.

So that can get quite distressing for me and it's a lot worse in hot weather as well, which is why I now avoid holidaying in hot countries. But yeah, that then makes me just really want to kind of hide away from the world. And I think, you know, I feel ungainly, I feel not as nimble and that includes in the bedroom. And that can really affect my enjoyment of things in the moment if I feel like, you know, past Carmel would have been able to have done this, that and the other and now I'm being a little bit more, I'm struggling a little bit more physically. I mean, my partner's

been amazing and all the way through my cancer treatment has never made me feel any lesser because I've got lots of body changes. But I still think for me, it makes me very self-conscious. makes me, I'm more self-conscious about being naked because of my lymphoedema than I am bearing a chest with no breasts on anymore, which I think... It sounds shocking to some people, but it's just that's my relationship with that side of my body, that part of my body. But I think a lot of it is also just about being with each other and having that intimacy and intimacy being something that becomes a priority and that is something that, you know, my partner and I have always kind of made that a priority, carved out time and space and talked really openly about it all. And I think that all really helps as well.

Paul (18:06)

Thank you for being so kind of open and honest around some of this because this is kind of the conversation that doesn't necessarily get talked about and people might be afraid to ask some of these questions.

Carly (18:18)

Mm.

Carmel (18:18)

I think so, yeah. And I think there's definitely a really, a real prevalence within medical teams and things that, you know, the focus is very much on the disease when you have cancer. And rightly so, you want to get rid of that disease. But then I think you don't always think about the wider person and their quality of life. And a lot of patients feel really uncomfortable moaning about these things.

Carly (18:35)

Yeah.

Carmel (18:39)

And I'm incredibly lucky that I've had a referral to Becky's clinic and that I regularly see a lymphoedema nurse. There are lots of people in the country who don't have access to that or can't access that kind of support. And I do think that, you know yes, it's important to get rid of the cancer, but it's also really important to have a good quality of life in, you know, for hopefully the rest of my long life. And I don't want to feel bad about bringing it up. it's and sexuality in particular, mean, cancer and its treatments impact sexuality a lot. It's such a taboo subject in in oncology care. People feel really uncomfortable bringing it up. And if it's not brought up with them, they're not necessarily going to bring it up. And people still feel really awkward about it, you know, especially in the UK. And so I kind of feel like. You know, it's good to talk about these things. It's good to talk about them and normalise them in a way.

Carly (19:30)

Yeah, can I ask, you mentioned about the kind of challenges, like you said, around body image, you mentioned your partner and intimacy. What support did you reach out and get, if any, around that to kind of help with not just the physical symptoms of your lymphoedema,

Carmel (19:51)

I don't necessarily think I've had specific support about that, but I have found communities of care around, specifically around cancer and sexuality. There was an Arts Council funded art project called Sex with Cancer that I was a part of and they made a documentary and they really talked about it openly. And I think feeling comfortable about talking about it openly really, really helps.

I myself have started a research project where I'm working with people who've had breast cancer and specifically talking about sexuality and the impact on people's experiences of pleasure. And again, like everyone who's joined my research project says, no one talks about this. And because I really think it's important that people feel comfortable to talk about it and share it and you feel less alone.

Carly (20:16)

Yeah. Yeah.

Carmel (20:35)

when you find that other people have had similar situations or have had similar experiences. So yeah, I don't necessarily think that there has been a lot of support out there existing. again, it's kind of people feel very awkward in those situations.

Paul (20:49)

And Becky, I could bring you in. Just to talk a little bit about what healthcare professionals can do with some of this and to support with some of this in terms of the emotional support or the physical support.

Beccy (21:03)

I think a lot of the time that we're asked, you when is the right time to talk about sexuality? Is it as part of survivorship? Is it as part of diagnosis? I think it's really hard and people feel that there isn't a right time to discuss these things. I think that's one of the things that I hear a lot. And then also we have a number of patients, as Carmel said, who have genital lymphoedema and therefore that's conversations that we have very readily and very openly when we are aware that patients have genital lymphoedema. But if somebody has leg lymphoedema like Carmel said or

arm lymphoedema, are those conversations happening in the same way? Because actually what she pointed out was that she's more comfortable with some of her altered body from her cancer treatment rather than the lymphoedema, which is the bit that actually affects her confidence and the way that she presents herself in her intimate moments and within relationships. And I think that's a really shocking thing that healthcare practitioners will probably think from this, that actually the lymphoedema is as big, if not bigger, at impacting someone's body image than devastating scarring or other side effects from treatment. And we do hear patients say that they would have chosen different cancer treatment options if they'd realised that

Carly (22:08)

Yeah.

Beccy (22:21)

Lymphoedema was going to affect them in the way that it does. And I think that for men and women, we need to be much more informed and engaged in asking about their sexuality, their intimacy, and the way in which they feel about themselves post treatment and specifically with lymphoedema when we know that it can be so catastrophic to quality of life and to the way that one views oneself. So I think it's really important. We're talking about breast and gynaecological cancers today and we do need to be mindful that it's all types of cancer with all types of people who will have very different set of feelings and beliefs about themselves and their requirements and their dreams and hopes and all of those other things. But I do believe that lymphoedema has such a devastating impact on an individual's ability to present in a way that they would want to.

Carly (23:19)

Hmm.

Yeah and it really does, hearing your experiences Carmel, really highlight the scale of it and the and the role that healthcare professionals can play. Carmel, when you were sharing about some of those types of conversations that maybe people are worried to have or don't know how to bring up those sensitive conversations I wanted to ask you, Becky, do you have any sort of top tips to start those types of conversations and to open up those conversations which maybe they might be a bit worried to have?

Beccy (23:57)

I think it's really difficult because it tends to be down to our own ability and our own culture and our own belief set around sort of talking about sexuality, talking about intimacy, talking about relationships and sex.

Carly (24:10)

Yeah.

Beccy (24:12)

I think with genital lymphoedema, it's something that I really want to advocate for healthcare practitioners to ask about, because I think that if patients say, my leg swells, then there isn't usually the question to ask, does anything else swell? Does anything above the tops of your legs swell? Do your buttocks swell? Does your tummy swell? Do you get genital swelling? Where is that? What's that like? Is it there all the time? Because I think that it's so important that as healthcare practitioners, we broach that conversation because it's very likely that patients will just think, oh, I can't say about that. That's not appropriate for me to ask if it's there or not. So as healthcare professionals, we must examine patients and ask for their permission to talk to them about the swollen areas and where does that extend onto the body.

Paul (25:00)

Becky, is it the same kind of for men and women or is there a prevalence where it occurs more in men or women

Beccy (25:08)

So it depends very much on the cancer site really. So we know that the prevalence of breast cancer is well researched. Breast cancer related lymphoedema is probably the best known of all causes of lymphoedema. And female pelvic cancers, as Carmel said, are something that hopefully is growing in recognition and understanding, although is still not perfect across the for male pelvic cancers, so testicular cancer, penile cancer, bladder cancer, prostate cancer, all of those, urology and male cancers, there is a high prevalence of lymphoedema in the lower limbs and genital lymphoedema particularly has its own set of complications for people living with. And then with skin cancers, we know there's an increased risk and increased incidence of skin cancers and that can affect men and women fairly similarly. So there will be incidences of men who will have upper limb swelling.

So often that's mistaken as being breast cancer related, which of course a small number of men can have breast cancer, but actually quite a lot of underground auxiliary node clearance for malignant melanoma. And then vice versa, we'll see ladies with lower limb swelling as a result of melanoma as well. And that can be mistaken as a result of gynaecological cancer. And then the head and neck patients can be more readily seen in male patients, but we do have female patients with head and neck swelling as well as a result of of lymph node dissection or radiotherapy. So I think it is a fairly equal split across the cancer groups and you can't ever really compile how many people will have the effect because as I said earlier, the size does not equal the burden

Paul (26:54)

So Carmel, if I could just come back to you as well, during your experiences, there any, or can you share some positives, you know, the positive support that you got from professionals or other interventions?

Carmel (27:01)

Yeah, when I was, I'm not really much on social media anymore, but when I was a few years ago, when I was kind of first grappling with the different kinds of garments and, and, know, part of my struggle with wearing the compression garments is I then feel really self conscious about what I wear because, you know, who wants to go to the beach with a pair of tights on people just think you weird. so I started following a lot of Instagram influencers who have lymphoedema and, know, some of them were rocking like pink garments and dresses. And I just thought, okay, so this is a thing. I mean, I have to wear these. So I may as well go for it and wear turquoise garments and really kind of embrace it. And that really helped normalize it for me and really helped me feel confident to go out wearing my garments in public places a lot more. And also not just wear long skirts all the time, because I cycle everywhere and so that's not always very practical.

And because my leg's swelling, I can never find a pair of trousers that fit me. So now I'm like, I'll wear cute little skirts and cute little dresses. Nobody really notices anyway. They don't really pay any attention to you when they're doing their own thing. But yeah, I found that there was a really, really beautiful community on Instagram of all sorts of people, you know, men, women, all sorts of people with different, you know, some with primary lymphoedema, some with cancer related lymphoedema, and just normalizing wearing all these funky garments and, and, and, you know, actually treating it like a fashion accessory. Well, if I've got to wear this, it's going to be a fashion accessory. That was really helpful for sure.

Carly (28:26)

Yeah. Yeah, that's so nice and it's a nice example of social media being used in a positive way.

Paul (28:47)

And from a kind of when you were going through treatments were there any kind of, I suppose any small, thing makes a huge difference in terms of, you know, the support. And I know you've mentioned the support you've got from Becky and the organisation. What about in those, you know, early days

Carmel (29:08)

One breast care nurse was amazing. She was like, absolutely no, no worries at all talking about it and said, you know, you could do this and how about this and you know, you can get this specific kind of vaginal moisturiser on prescription and don't you let them tell you no. You know, sometimes you kind of do get those amazing people who just come up into your life and really

give you the right pointers or the right help. I had an amazing GP when I was first diagnosed. She was really, really good at working in partnership with my treatment treatment team and kind of, you know, filling in some of those gaps.

Carly (29:30)

Hmm. Yeah, absolutely. Can I just take the conversation in a slightly different direction? I was just thinking about something that you'd mentioned a little bit earlier, Becky. We were talking a bit about the day-to-day management, but actually when it goes beyond that and actually becomes, it can become something that is a risk. Could we just touch on that a little bit? I guess a good place to start is actually what are some of the risks and the potential complications of lymphoedema that you could see?

Beccy (30:10)

Yeah, so I think the main risk that Carmel alluded to earlier is around infection and that's the main risk to health and to wellbeing because if you do sustain an injury to the skin, be that an insect bite that we talked about earlier or a scratch or a cut, then that is a port of entry for infection and there is a part of the lymphatic system that is responsible for helping our bodies to fight infection.

And therefore in areas where that's not working and there's failure of that lymphatic system, the risk of infection is very high. And so a number of people with living with lymphoedema do develop cellulitis, a really serious bacterial infection of the skin, which is a rapid onset and can look quite different in managing this condition with lymphoedema than without lymphoedema. And actually the British Lymphology Society and the Lymphedema Support Network, which is the two organisations that support patients living with lymphoedema and practitioners managing lymphoedema. They've put together some guidelines for healthcare practitioners on how to manage cellulitis in patients with lymphoedema because it is so different to the standard pathway for cellulitis without lymphoedema. And the risk is then that people have an impact on their health and wellbeing, but they may end up also losing time from work, losing time from their role in their family because they may end up needing Intravenous antibiotics, they may end up in hospital.

And of course, there's always that very severe risk of sepsis as well. So I think that any patient at risk of lymphoedema, even if you don't have swelling, if you've had treatment for cancer, you must be made aware of the risk of cellulitis. And sometimes it's the cellulitis that happens first and then the lymphoedema follows that and people can have lymphoedema as a result of that infection. And I think having a balance between living your life

Carly (31:39)

Right.

Beccy (32:01)

and not fearing things. And actually things like, you know, we have patients ring up and say, I've cut my arm or I've cut my leg in the garden. I'm petrified now of what's going to happen because there's that risk, that very real risk of infection. So having that sort of travel first aid kit with your antiseptic and your plasters and some antibiotics if you've already had an episode of cellulitis previously to take with you, it's almost a rescue remedy or rescue pack to have with you. But that's the real risk to health and wellbeing is around infection. But there's also the risk around, you know, sort of the impact that this can have on your ability to undertake activity, as Carmel said. So, you know, not being able to undertake your job or your role because that's impacted by your swelling.

So you can't any longer do the walk to school or you can't any longer do your job that might involve running after somebody if you're a security guard, for example, or things like that. there is there can be a loss of role, loss of of income from this condition. There's very real health economics around that as well that's not really ever been looked at or costed as well as the personal costs, as Carmel said, about the way in which this impacts on you. So the risks are great. And lymphoedema is a progressive condition.

So if left untreated and unmanaged, unfortunately it tends to get worse and that can mean that there can be more advanced skin and tissue changes. So people can develop leakage of lymph through the skin. So what we call lymphorrhea, which can be very, very hard to manage and very frightening as well as to why these things are happening. The fear is very great when we don't know why something is happening or what's occurring to us. So there are some very real risks around lymphoedema.

Carmel (33:51)

Yeah, I might just come in with the kind of personal experience of cellulitis. I've had cellulitis eight times now. I've actually been hospitalised in four different countries with it. And I do carry my little pack. I mean, I have this pack that I just never leaves my side. I've got my emergency antibiotics. I've got all my antiseptic. I've got my bite creams. I've got my thermometer. So I take my temperature. Usually for me, a clear sign of cellulitis is that my temperature spikes.

But it has been, it's got a sharpie in that little kit because then I tend to draw around the redness with a sharpie and then you can see how fast it's growing. It has been really scary. A couple of times it's been incredibly scary. I've had to have IV antibiotics, you know, on three of those occasions. I'm now on prophylactic antibiotics. I'm on a six month course of daily antibiotics to try to stop it from happening in the first place.

At first it was always when I was in hot countries, but then I had an, I actually had an incident this February just gone. And that was just completely random. So, the thing about cellulitis is yes, it's got that risk of sepsis, it's got that high risk of it developing into something really dangerous that can be life threatening. And that is an aspect of it. But also it just absolutely wipes you out. I mean, I'm literally no good to do anything for at least a fortnight once I've had it. And that has a massive impact on your ability to just continue to do anything day to day. And you can't stop it from happening. It happens, that's it, boom. I have to cancel everything in my diary for the next two weeks at least, sometimes longer.

You I want to get on with things. I don't want to feel like I'm constantly taking two steps forward and two steps back. So I do try to kind of push through sometimes. So you've kind of got that risk

management, but then you've also got the, if it inevitably happens, what do you then do and how do you manage that?

Carly (35:29)

Yeah.

Carmel (35:38)

And a lot of that for me has been about self-advocacy. I've gone into hospitals where they have not understood it in A &E. They've not understood how urgent it is. They take my bloods. They're like, your bloods are fine. They don't realise that it's about something more than that. And I think a lot of that is the lack of knowledge of the impact of lymphoedema on something like this.

I do think that there is a bit of that education piece as well within an A &E context for sure. And now I self advocate because I know and I brandish my antibiotics and I know the type of antibiotics that I need so they don't have to keep trying other ones that then don't work. So that's very handy, but not everybody has that knowledge.

Carly (36:04)

Becky, what support or signposts in all resources are there for, well, professionals, predominantly healthcare professionals, to understand more about this and learn more?

Beccy (36:27)

Yeah, so there's a number of things. I mean, the British Lymphology Society, are the go-to organisation for anything you want to know, any position papers, any statements, any support. And there's a couple of study days each year and a conference. if you want to learn more, that's a really good way of getting involved. And you can join as a member friend free of charge. again, that's every health care practitioner can do that, regardless of their role.

Accelerate has developed a series of lymphoedema education for cancer related lymphoedema and Carmel is the star of our show and features heavily. So we've got an introduction to lymphoedema course, which is about a three hour program to learn everything about cancer related lymphoedema. But then we have five specific bolt-ons. one for head and neck, one for female pelvic cancer. one for male pelvic cancers, one for skin cancers and one for breast and arm. And then there's also a palliative module or management of lymphoedema and advancing disease module, which again is very helpful because we want then to impact on our management strategies as quickly as possible, which is really important. And then there's also resources related to specific lymphoedema problems. So things like cellulitis, I mentioned the guidelines, very, very important that every healthcare practitioner has access to that and knows how to advocate, as Carmel said, for patients in that situation if they're not able to do so themselves. And then also it's about how do you get people to a lymphoedema service because that really is the key, knowing how to get somebody to your local service. So find out, do you have a lymphoedema service in your area? What is the referral criteria?

Beccy (38:09)

You know, how can you get somebody to be referred where they can access all of the specialist advice that they need? We know there is a lack of lymphoedema services out there, but for cancer related lymphoedema, the provision is fairly good. So hopefully there is somewhere in each area. Accelerate is able to accept referrals from out of areas. So if patients haven't got somewhere to go in their area, then they can travel to see us if they're happy to do so. And we do also have a private service as there's a lot of advice and information out there.

And signpost people living with lymphoedema or at risk of lymphoedema to organisations such as Macmillan, but also the Lymphedema Support Network I mentioned, the National Patient Group. There's a brilliant group called Lymph What Oedema, which is brilliant because lymphoedema is something you get asked, what is that? So Lymph What Oedema. There's also Lymph United, which a really good group who've helped with some research around how men feel with lymphoedema, which is really good as well. So really good organisations out there to support people living with lymphoedema as well as healthcare practitioners who want to learn more.

Carmel (39:18)

And I actually did give the BLS, the British Lymphology Society, guidelines on cellulitis to my GP, which was really helpful when I was asking for the prophylactic antibiotics. And they're just really clear. It's really, really clear laid out. So yeah, that was, they were really

Beccy (39:27)

fantastic.

Carly (39:29)

That's great.

Paul (39:33)

Some great tips there, Becky and Carmel. It's so great to hear you being so positive about everything that you've been through and your experiences. I'm going to kind of move us over to the our last question, our regular feature, what would you like listeners to take away from the episode? And Becky, I'll come to you first.

Beccy (39:55)

I think I'd really like the listeners to understand that lymphoedema is much more than a swelling. I think it's so important to understand that it is failure of the lymphatic system and that it is catastrophic on someone's quality of life, someone's body image and their ability to live well

with this long term condition. So I think that's really important. t's really important to ensure that we have a good skill set around identifying and recognising lymphoedema and being able to refer on or signpost on because

If we can pick up on these things and make sure that we get the treatment right at the right time, we can make a real difference to the way that people live.

Paul (40:39)

Thank thank you, Becky. And Carmel What would you like listeners to take away from the episode?

Carmel (40:45)

I think for me it's about seeing the patient as an active member of their treatment team and treating them as that because there's a lot that we can do to manage our lymphoedema, to prevent it from getting worse, to keeping it stable, to maintaining it. But we can only do that if we're treated like an active member of the treatment team. So think that's for me the most vital part of this.

Paul (41:08)

Lovely, thank you.

Carly (41:09)

Lovely, wow, thank you so much. To say thank you both, Becky and Carmel, for joining us on the podcast today. has been, I've learned loads. And also thank you so much to you Carmel for sharing and being so open with your experiences. And also to you Becky, just so much expertise there in talking about the topic. And I'm sure listeners will take loads from this episode. So thank you for joining us on the Cancer Professionals Podcast.

Beccy (41:36)

Thank you for having us.

Carmel (41:36)

Thank you for having us

(Music fades in)

Paul (41:39)

You've been listening to the Cancer Professionals Podcast, which is brought to you by MacMillan Cancer Support. If you are a health or social care professional working in cancer care, visit membership.macmillan.org.uk to find out more about Macmillan membership, which includes a range of education and training resources and access to our learning hub. For links to the resources mentioned see the episode description.

Carly (42:03)

If you enjoyed this episode, follow us so you don't miss our next conversation, where we'll be joined by Caroline Tweedy and Alison Thompson to talk about treatable, not curable cancer.

Paul (42:13)

We'd love you to rate our show and share with your colleagues. Get in touch with us by emailing professionalspodcast @ macmillan.org.uk. New episodes are released on the first and third Wednesday of each month.

Carly (42:26)

I'm Carly

Paul (42:27)

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