The Cancer Professionals Podcast

Episode 3: Working together towards inclusive cancer care for the LGBTIQ+ community

Intro Music

00:00:09 Carly Have you ever wanted to know how you can make cancer care inclusive for everyone?

00:00:13 Stewart (Audio clip) I've met a lot of patients who at the end of their treatment feel like the rope is just cut off and they're left free and they feel incredibly adrift.

00:00:23 Lydia Hello, I'm Lydia and my pronouns are she/her

00:00:26 Carly And I'm Carly and I go by she/her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan.

00:00:32 Carly In this series, we chat to a wide range of guests, including health and social care professionals, to lift the lid on current issues faced by the cancer workforce. Expect to hear discussions of clinical practice, personal experience and practical advice to improve your knowledge and skills in supporting people affected by cancer.

00:00:51 Lydia In this episode, we're joined by Stewart O'Callaghan, who is the founder and CEO of outpatients, the UK's only LGBTIQ+ cancer charity. Stewart joins us to talk about the current picture and some of the challenges and issues in cancer care that are faced by the LGBTIQ+ community.

00:01:10 Stewart (Audio clip) How do we lead with that person first approach and make people feel safer and when we do that we allow people to attend their healthcare appointments. If we address those systemic issues that stops people from going or leaves them less informed on what that means is we can get people diagnosed earlier, we can improve their outcomes. We can make sure that they're living longer and healthier.

00:01:34 Lydia We learn from Stewart about the steps we can take to help overcome these barriers and how we can keep up momentum and inspire change.

00:01:41 Carly Perfect. OK. So hello, Stewart, and welcome to the Cancer Professionals Podcast. Thank you for joining us.

00:01:49 Stewart Hi, it's nice to be here.

00:01:54 Carly So can we start by you telling us a little bit about you, who you are, what you do?

00:01:56 Stewart Yeah. So my name is Stewart. I use they/them and I'm the founder and chief exec of outpatients, which is the UK's LGBT cancer charity. It's the only one of its kind that does that sort of span of work all the way through from screening, through to palliative and living with and beyond. We're supporting patients, we're educating professionals and we're trying to raise this topic as a key point of policy in the healthcare system.

00:02:22 Carly So you mentioned that you're the founder and CEO of outpatients. What inspired you to start the charity?

00:02:28 Stewart So it came out of lived experience. So I have chronic myeloid leukemia, which is an incurable form of leukemia and I was diagnosed with that when I was actually living abroad in Germany and I went through quite a lot of issues with trying to get the right kind of treatment and support, especially as someone who's LGBT and and then that sort of led me to think well am I the only person having any struggles? And if I am not, is there a way that I can connect with other people to make this better, and very quickly the want and need to connect with other patients turned into a drive to actually help the healthcare system in general and start to share the kind of conversations we were having in our private spaces with healthcare providers so they could provide better care.

00:03:18 Carly You did touch on a little bit around that lived experience of cancer and how that inspired you, I suppose to start the charity. But would you be happy to talk a little bit more about some of those challenges that you've faced personally throughout that time?

00:03:33 Stewart Yeah of course. So I think obviously one of the big ones was actually being someone who's diagnosed abroad and coming back into the UK and trying to find your support structure there where you have you sort of missed the HNA process. You know you've missed all these kind of things that are in place to make sure that your needs are being met. And being someone who at the time I was diagnosed, I was 29 and CML usually affects people over 60, so already feeling quite isolated in that space. And then not having that support network sort of immediately offered because of how I entered the system led me to sort of independently go and try and find that in local areas and went into things like Macmillan centres and sort of posed the question is, is there anything for someone like me or someone in my community? And at that time there really wasn't, especially in Brighton, where I was for a short while, I now live in London.

Over a couple of years I like sort of came to find there's some really fantastic projects in prostate cancer for gay men, but again, that's not something I fit into. And so anytime I tried to do sort of more general support as well, sometimes the interests or the things that I thought would have been positive for me didn't really fit. So you know, I wanted to do art classes and sort of things like that to connect to other people. And I was told I should go and play sport because arts for old women. And I just, I was sort of shocked by how not just gendered, but age stratified people's views of support is in cancer and I was finding it quite difficult to navigate, and that led me to really pull back finding support at all really, for quite a few years. I was sort of frustrated by going into these areas and being quite vulnerable and coming out and putting myself out there and being told you know there's nothing for you so you just sort of have to make do.

00:05:17 Carly Wow. Yeah. So it sounds like there's a link between actually the experiences that you had and some of the things that were missing and actually OUTpatients mission, which is to transform cancer care into a more inclusive environment for LGBTIQ+ people with cancer so they feel welcome in in cancer services. So, can we talk a bit about the current picture for the community in relation to cancer care? What are some of the things that are happening at the moment?

00:05:46 Stewart Yeah. So I think, you know, LGBTIQ stuff and for anyone who's unsure what the acronym means. So LGB is lesbian, gay and bi so that's sexual orientations. T refers to trans people, so that's to do with gender identity. I refers to a variation of sex characteristics or being intersex and then Q is queer, which is the reclamation of a slur and people tend to gravitate towards that label to be quite broad in their definition of themselves, without having to be too specific but still identify themselves as part of community. And the + is for all the other letters that could exist in there, like asexuality, pansexuality, all those letters that I described have different experiences, to be honest. But there's definitely some similarities between and that's generally what tends to link the queer community altogether actually is there's lots of different people and different walks of life, but the barriers we face tends to be what actually is, is the sort of commonality.

And I think there are there through from screening, you know, all the way through to trans people not being called for the correct screening or not being given the right info. Through to actually the support as well, when you actually do get diagnosed and do people feel safe to bring their partners with them, that they'd be encouraged to do so. Also people's wishes about treatment pathways we've had to support patients who just weren't really being listened to. And also late effects, so psychosexual impacts either during or after treatment is the huge one that people are very squeamish to talk about. So there's all these things and one of the things that I definitely have seen happen over the past couple of years that the charity has been around is we have seen some improvement. You know, we have some people really start to understand that our community is a core consideration for person centered care. You know, it's actually a really positive thing to be thinking about. And you know, it's been there for a while, it's enshrined in the equality act. But how does it really translate into cancer care. And it's moving beyond the idea that we previously had of well we treat everybody the same.

But the analogy I always give people with that is making a cup of tea. It's very British but stick with me. But if you made everyone exactly the same cup of tea, you'd be missing those people who might be lactose intolerant, don't have caffeine, etc. Whether those would be personal needs or whether they also be lifestyle choices. So so for example someone's religious and like Mormon doesn't have any stimulant. By giving everyone the same thing, you're actually ending up creating issues or poor experiences, etc. So the person centered care approach is obviously to actually stop and take an equitable approach and think. OK. Well, what, what additional things are needed here? And and I think that's something that is what needs to be done in LGBT cancer care because I meet people very frequently who, for example, lesbian women being forced to have fertility discussions and almost being forced to sort of preserve their fertility even when they don't want to. And conversely, gay men not being given that conversation because it's considered that it won't be relevant to them. And the commonality faced there is who's asking the patient and who's respecting their wishes.

Carly 00:08:44 That's a great analogy. I really like that, and that really does highlight what we mean by equity being able to have that personalized care approach and meeting their needs as an individual rather than that one-size-fits-all. I know you've already touched on this in terms of the current picture, it's clear that there are lots of challenges and issues and barriers that are faced by the community. Are there any other kind of key ones that you have seen and experienced or noted that people are experiencing?

00:09:12 Stewart Yeah, I think the other barrier goes beyond just the pathways and the way we treat people, but it gets into the geography of where we treat people. So certain parts of the country are more resourced than others, certain parts of the country have more LGBT people than others. You know, and that can lead to sometimes a bit of a post code lottery of care that people have to navigate in order to access care that is inclusive. I mean, I know of a person, a trans person who lives in Wales but comes to London for their cervical screening because that's one of the places they actually feel safe to do so, and that is the amount of distance people will travel. But obviously if you have been diagnosed with cancer, sometimes you don't get that freedom to choose exactly where you're going for these treatments, you might have to go to a certain hospital because it is a specialist or because it's the local one. So, it's thinking about making sure that every facility, every trust is armed with the same level of care that can be inclusive for our community, rather than expecting people to travel. And I must say, to be fair with the way things have been progressing and getting better, nurses really are pushing so much of this. You know, we educate so many nurses in our webinars and it's such a fantastic drive and push. And I think that's the bit that gives me hope for sort of the future of this care is that with their support and hopefully with others in other sort of varying ranks inside healthcare, we can start to think of this as, yeah, that core component of person-centered care.

00:10:39 Carly Great. Thank you for sharing the example about nurses and driving a lot of those improvements. That's really brilliant. So it's clear from what we've been talking about that these health inequalities and these differences in experiences happen across the cancer pathway, are you able to go into a little bit more detail about how people's experiences are impacted at those stages? So from screening for example and how that looks throughout that?

00:11:05 Stewart Yeah, so, so I'll sort of chunk the pathway into various sections. So if we think about screening, for example. Presently, there are some issues for trans patients who re-register their gender in their GP record and that's how those systems work in inviting people [for screening] its done automatically based on a female marker on your records for cervical and breast. So if someone changes that marker, they're not going to be automatically invited to those programs and in cervical there's a way you can sort of go to your GP and request that or you can go to sexual health clinics that may provide that service. And that's why, again, that trans person travelled at such a distance because there was trans specific clinic they trusted.

But in breast, it's a little more complicated because there isn't really a pathway to put that person on. So, my point here is really that sometimes I think we focus a lot on the interpersonal, which true can be a barrier and people do avoid health care for fear of discrimination or they have been discriminated against previously. But sometimes there can be these systemic barriers too, and I think they're important to acknowledge for where that fear of discrimination comes from in the individual because they are navigating a very complicated system that literally often doesn't have a pathway for them in this context. And then also for the healthcare providers who are trying to navigate that system with the patient. And how they can set the expectation in the patient that they're doing their best and This is why certain things might not work out the way that we really want them to.

There is some improvements coming in cervical, for example and some new tests that are coming through. So you know different ways that we can sample for HPV and that is exciting and targeted lung health checks is obviously coming around soon and that's exciting too. But again need to make sure that it's inclusive of our community, as we're developing these systems and I think it's a really important time to be thinking about this in screening because we have the digital transformation of screening. We have a new program being set up. It's really important to think about where all communities can benefit from that.

So if we go from that kind of screening bit into an actual diagnosis, bit despite all of these sort of best intentions of trying to make additional clinics or supporting patients or improving public health messaging, we do see delays and obviously delays in cancer is a very key concern. And I think a key point to point out here is when you look at delays in LGBT health, you actually tend to find that if, for example, we're comparing LG to the B so that's lesbian and gay to bi, you actually tend to find that bisexual people have greater delays and poorer outcomes generally across health. And I think that's something that surprises people because people sort of assume that by bisexual people might inherit some straight privilege in navigating healthcare, but it's actually not what we see in the data, so that's where it's really important to when we take patient history or get to know them to actually understand them completely, not just their current partner and understand what life and context they sit within so that we can support them so we can avoid those long delays, which in the case of cancer could be further proliferation of disease.

And the tricky thing that we have from professionals point of view is the healthcare system we use doesn't really monitor or track these patients for their sexual orientation or trans status. So this can create a lot of issues when we're thinking, OK, I've heard it, great, LGBT issues are something I need to be thinking about. But how do I identify these patients? How do I support these patients? And it's something that I personally push the chair of the NHS and the chief executive, the NHS on and it was a government commitment in 2018 to improve monitoring for LGBT stuff in health. And unfortunately, that commitment got thrown out with the successive changes in in politics and government. So it's something that I think we need to go back to. We do know there's a problem there and it's not just through pockets of small research and anecdotes that we also see as a charity, but this LGBT monitoring is done in surveys by the NHS, so we know that they believe it's a reliable question and it's something that can be used. And we see this in the cancer Patient

Experience Survey, for example. And in that it does show that LGBT people feel less informed about their treatments, they feel less likely to be able to have their cared ones and loved ones around them to support them, and that they often find less support in general, especially after treatment. So there's clearly something going on. But then, because we don't have that monitoring in the actual medical system, we're not able then to match the patient experience with things like outcomes, delays, adherence, all those things that are also are really important clinical markers.

Which then leads into those long term late effects and things like psychosexual Wellness. I meet patients all the time who either don't feel safe to talk about their psychosexual Wellness or they have tried to and have had consultants or or nurses feel very uncomfortable and avoid the conversation or walk out of the room. And we have to think about psychosexual Wellness as a core component of personal health and I have absolutely seen people who have gone through that negative interaction with healthcare providers and as a result, feel that there is no support and end up in a position where their life falls apart. They lose a partner, they lose their job, they lose confidence, they become socially isolated. There's all of these aspects, and if it all just stems to the fact that people are nervous about talking about anal sex, that seems so trivial. You know that something that could really be addressed in in a healthier way.

So the final part to think about is that living with and beyond or on the palliative as well. So in living with and beyond, we are getting better at cancer care. So that is a growing population or we'll see people like myself who are chronic form of cancers who exists in that population at the time. And it's thinking about what support do they get. You know what ongoing support? I feel that I've met a lot of patients who at the end of their treatment, feel like the rope is just cut off and they're left free and they feel incredibly adrift as a result because once you've had cancer, it always stays with you mentally in some capacity. So it's not as simple as going back to the life you had. A lot of patients I meet talk about the life after. So again that living with and beyond, So what support actually do we provide in that. And on the palliative That gets quite complicated for LGBT people in the aspect of what legal rights do our partners have? What legal rights does our chosen family have? What happens if our chosen family being our community that we rely on as family, have a conflict with our legal family? There's a fantastic piece of work done by Hospice and GIRES, which were specifically looking at trans people in palliative care, and there's some really important things to take from that. And again, is the person going to be treated with dignity and death? Will they be buried under the correct name? But also, how do we support those who are bereaved and how do we make sure that their grief is seen as equal or equitable to others grief? And especially if their chosen family and make sure that we don't devalue that and in turn result in disenfranchised of the individual.

00:17:58 Carly Thank you. And that really does highlight lots of issues and challenges across all of those. So thank you for highlighting those. And I know that you have interjected in a few things around some of those improvements, for example, I know you were talking about improvements in screening, but making sure that it's inclusive and other things that you feel have made progress, but what other areas have you seen where improvements have been made and of good progress?

00:18:24 Stewart I think, to be honest, a willingness to have the discussion about the Community, I think you know in the very few years that I've been doing this. You know when I first got started, there've been pockets of work, absolutely. But they often died out and often because of the amount of funding that was available to it or the capacity of the individual running it. It is why in setting up the charity I was keen to set it up as charitable bodies. That we could hopefully build something that has a bit more longevity and can support other people's projects and to help people with their additional work and platform the great things that we do see. So people don't feel so isolated in the work they do. And and I think what that started to do especially with our annual professionals event where we bring in people who are doing fantastic projects and we give them a chance to connect and that's led to really wonderful research and connections and even more recently one of our speakers has been able to set up a PhD for some lucky candidate who's going to get that another to do a PhD in this topic, you know.

And I think that's it being able to move the conversation forward and recognize that in doing so, it's everybody's conversation. You know, it's it doesn't have to just be this incredibly niche topic that people think it's quite complicated because I always remind people that in cancer, we talk about complicated things all the time. Much more complicated than pronouns. So when people say that it's too complicated to get into, is it really complicated, or is it just that you're not confident or that it doesn't feel that important to you? And if that's the real reason, let's let's target that. Let's make you realize that it's not just an interpersonal, you know, zeitgest of EDI. There's actually some clinical indications for gender affirming care with cancer care, for example. There is a real impact on someones mental health if we're respecting them throughout their pathway, including their loved ones. All of those bits that I think make people realise that there is, yeah, a responsibility in all of us to provide that better care.

00:20:26 Lydia Thank you, Stewart. That's really great to hear. And I wonder if you could talk more about the bigger picture. You've spoken a little bit about the things happening across the UK and there's obviously lots of changes being made. But I'm interested in knowing where we are now and where we want to get to?

00:20:41 Stewart So we're at an interesting intersection of LGBT politics and health, I think. And I say that because I think LGBT identities are not inherently political, but we are politicised, unfortunately and our rights and freedoms are obviously subject to law and and we obviously have inequities there. And when you look at health, you can see that there's historically been a lack of involvement and investment in particular points of health that that affect us and that leads to Community Action to try and improve things. So if you think about HIV, AIDS, prep and Mpox. You know all of these sort of actions that we do to promote our healthcare.

For a while, I was sort of I think maybe potentially naively feeling that you know a few years back that healthcare in the regard of cancer and and that sort of area was relatively immune to the sociopolitical landscape and discussion around LGBT identities, because maybe the connection hadn't been made yet, or maybe people kind of understood that we're talking about people's mortality here. We're talking about serious health. This is something that is just something that needs to be done. But as we've managed to forge that connection to be stronger, to understand where these things overlap, I think it's also come at a similar time as to which our communities health has become more of a social commentary. So we see this in relation to trans health and the access to trans health and the incredibly long delays and what that does to people, but we also have seen a rise, I think in for want of a better word, hostility against trans people, even in the healthcare space. So whether that be structural hostility, like those long delays which have been upheld in court because the NHS seems to be doing their best. But is it really their best if it's years before your first appointment, but also when we've had particular political figures who have made a point to discuss LGBT and trans health and not really understand the nuances that it involves, which is I think the most frustrating thing.

So even in our own work, we've worked with the Society of Radiographers to publish guidance to help support trans and non-binary intersex patients who might be pregnant, from being exposed to radiation. And we did this because the law stipulated that that should be done, but it didn't provide a method by which to do it. So we created that and unfortunately it ended up being a commentary piece in the papers at the behest of the health secretary at the time, who said that it was a ridiculous thing to have and it was unnecessary. But the whole piece of work was really brought about because there was a case of a pregnant trans man who was irradiated. So it's this frustrating thing where on my side of my day-to-day job, we're working in reality and lived experiences, and I'm hearing these stories every single day. But the way that they are characterized in the press and have become increasingly so are somewhat devoid of the real experiences that I'm seeing.

I think a lot of people when they talk about trans health, they talk about it in a theoretical frame rather than the impact on the individual and when you get into the impact of the individual, I think it's much more compelling about actually what we need to do to support people and help people, and this is where I think sometimes comments like trying to ban trans women from certain parts of hospital incredibly unhelpful or, trying to remove information aimed at trans people from cancer screening risk indication because surely we should be providing people with as much information as possible so they can make informed decisions about their care rather than removing that from particular pages.

00:24:27 Lydia It sounds like there's so much going on out there, which is great, but you mentioned earlier about certain sort of areas where things are maybe fizzling out. I wonder how we can maintain those improvements and maintain that progress if you've got any advice in that space?

00:24:42 Stewart Yeah, definitely. I think it's sort of a common failing that we all have in thinking that social progress or, you know, human rights progress is something that reaches a plateau and it's self-sustaining and it's just not the case unfortunately. And I think it's much better to and you know, sometimes people think about it as a pendulum, but that's sort of self-propelled in its motion, but again, not really the best example. The best example really, it's more a tug of war you know you are gripping on for dear life in some cases for the health and the rights of your community, and if you unfortunately lose strength in that it will slip back to the other way because the opposition is absolutely pulling the opposite direction. So it's not a neutral state and this is where I think to give it a bit of context when people talk about doing nothing as an action in. In the case of social rights and health rights that's what they're talking about. So are you letting it sort of play out or are you putting pressure in a certain way? And I think to extend the metaphor, it's important to recognize that no one wins a tug of war by themselves. So it's a group action and if you get tired, you rest and someone else steps in and so on. And I think that's where coordination and collaboration are really important because if you think it's all on your shoulders and I've been guilty of this at certain points and you know, I could definitely take more holidays you know it, it's that aspect of you have to remember for your own Wellness to take a chance to breathe. Because if you don't, then you will burn yourself out. And that's again another reason for turnover of projects. So part of it is that individual monitoring to monitor your Wellness and keep up the pressure. But to coordinate is the other part and the other part is for those who are able to Commission work is to actually make sure that we're able to provide multi year funding and commitments to some really fantastic projects because you can't get a lot done in 12 months and all the progress you make can sometimes then be hard to sustain if there isn't a long term plan.

00:26:47 Lydia Great. Thank you. I mean, that's so much useful information there and you know hopefully something that our listeners can get on board with and be aware of and definitely take forward. I'm also interested to know how you have worked with other organisations such as Macmillan to keep this as a central issue.

00:27:03 Stewart We've done a bunch of small bits together, which are really great, so if someone was to go to the Macmillan Learning Hub we've done some webinar content. We've also been grateful to work with Macmillan really from the start actually, and Macmillan was one of the organisations that gave us a little bit of money to buy our first laptop, you know, to get the kind of ball rolling and it's been really great to maintain that relationship the whole way through. And I think the other thing that Macmillan has done really well with us there is allow us the freedom for us to set the path and the pace. And that's been really good for maintaining that Community Trust as well. We were able to maintain our independence and that's been really important for people who really access our services and want to believe that we are providing something new to the sector. And in doing that Macmillan's also being really good at giving us platform, I think in my perspective it's for those allies who do really care, it's not then a case of trying to convince them anymore. It's a case of giving them the tools in which to really act upon their allyship. You know, what can I do? What insight can I give? What resources are available to me to make it easier for someone to make that change in their immediate circle?

00:28:11 Lydia And just for the benefit of our listeners, if you're interested in accessing our e-learning or listening to our webinar, you'll be able to access that at macmillan.org.uk/learning. Just another question, is there any sort of work that you've got coming up in the pipeline that you're particularly excited about or it's particular innovative?

00:28:32 Stewart Yeah. Actually we are about to publish and sort of start sharing a whole new info hub that we've put on our website about sex and cancer. So this is something that is specifically about if you're having this treatment, there might be these impacts and this is something we've worked with professionals on is something we've also had reviewed directly by patients and it doesn't break it down into, you know, if you're gay this and if you're bi that, it's more a case of if you have this anatomy and this is the sex you have, these are the impacts you might expect. And it really I think gets at the heart of that issue of that squeamishness that people might have so people can go away and look at it themselves and get informed, but also hopefully for professionals. I hope it's enlightening. And I hope that it's a way to also learn how to approach that topic without putting labels on people as well. So you can talk about anatomy and activity without assuming something in someone. And that's also then a hopefully going to make that resource available to people who aren't LGBT, who might feel that they want some more information too. You know, we're not trying to ring fence what we do. We're a charity, so we have to talk about a certain community and that's what we're here for but others can absolutely benefit and my hope is to expand that into a project that actually has some more resources that come out of it too. Likewise, our webinars and education just keep growing and we are working on a bit more of a curriculum. So a bit of a longer course that will become available. So those people who are, for example listening, are interested in being someone who might be taking the charge in their local trust really wants to be seen as someone who's an expert in this area can get that additional knowledge and start to leave a change in in their local patch.

00:30:10 Carly Sounds very exciting. And where can people find information about those projects or when they're launched?

00:30:16 Stewart Absolutely. So our website is outpatients.org.uk and you can have a poke around on there and you'll find everything. The best pages when you're going in, especially as a professional, is head to the Resources tab, and in there you'll have patient resources which you should absolutely take a look at because that's got our campaigns and all of that stuff in it to. But then there's also a professionals page where you can find some additional information and how to get trained up.

00:30:38 Carly Thinking about our listeners and things they can maybe put into practice. What thoughts or suggestions do you have for those working in cancer care on how they can help to reduce these inequalities and start to remove some of these barriers for their LGBTIQ+ plus community.

00:30:55 Stewart Yeah, definitely. I think one of the biggest things to do is that shift in perspective about this issue, right? So I think a lot of people think well, this is a minority community. It's a small consideration and I think that's the first thing to unpick, because if we look at it from a proportion of the population, right, so people sometimes will look at these numbers of, say, you know, there's 5% LGBT people we forget that actually is an average of all age groups, and in those all age groups, there's an older age group who probably don't feel safe in coming out. So if you look at those younger age groups who are much more likely to have grown up in a socially increased environment or have the ability to tell us who they are, you can actually see on surveys including NHS surveys that about 14% of 16 to 24 year olds identified as LGB so that's Lesbian, gay or bi. And then 16 to 24 year old trans people is about the rate of 2.4%, so these are notable numbers. So you can really read that two ways. One, it's either this is a population that we are going to see in the future. We should therefore prepare healthcare for their arrival. Or, recognize that again that older population might also be at these rates, but just not have the comfort to disclose that in our surveys or methods. So once you've kind of got that in mind and realised that, you know, we're thinking about at least 15% of the population in this community, it's quite a notable amount.

And I think that's where the next step is, well, what do I know and what don't I know? And do I know what I don't know? So, how can I sort of be aware of the gaps? If this is a topic that's completely new to me and that's where that piece of work we did together on the education is really useful for people just to sort of start to explore this topic. Again, we do webinars specifically that are more in depth and we get a lot of feedback all the time. When people say, you know, I had no idea that it was this detail or there were this many barriers and issues. And I think that knowledge is the first step, because otherwise you're not going to know what is going to make the impact. Also, everyone is stretched. No one has really enough capacity. So how do you prioritize the effort you can make? How do you prioritize your energy and your staff energy, or how do you pull these factors into existing work plans and action plans to make them more equitable?

There's another project I was on to give you an example where they were going to make flash cards on certain topics related to child and adolescent cancer care, and they were going to have a separate EDI work path and card, and my recommendation was them is EDI is not a silo thing. It's cross cutting. It goes through everything and the sooner we're able to do that and learn how to embed it in our separate work streams it's going to improve healthcare for a lot of people. Although I talk about LGBT people specifically, we have so many commonalities in those from ethnically diverse backgrounds about what we think is important in relation to data, person centered care, privacy, etc. So it may seem insurmountable when you first get into the topic, but the more you actually get entrenched and the more you actually get to know other people and you go back to those networks we were talking about and you start to realise that there's a really exciting and collaborative world over here. The more you start to realize actually, maybe I can make a change and and maybe there's an overarching commonalities that we can tackle first.

00:34:32 Carly And so going back to what you said about that knowledge, it's the first step and you sharing some information and really great resources on your website for example, what other resources or information do you know of or you could highlight and can share that could be helpful for listeners that would support them in this in this first step in understanding more and finding out what they don't know or what they need to know.

00:34:55 Stewart Absolutely. So obviously dig around our website and there's that report from Hospice I mentioned Hospice and GIRES I think it's called I just want to be me and that's really fantastic for palliative stuff. Marie Curie have done some stuff in the past as well, prostate cancer UK did some stuff. Obviously, Macmillan has the pages we've written together and now you have those booklets they're available too, and they're available nationally, so there's no excuse not to order them and have them in. And again, that's another example of a patient resource that can still be useful to a professional, so if you're completely new to the topic, those resources are just as useful.

And I think the other thing that can be quite useful as well is also consuming the entertainment media from a certain community. It's sort of a bit of a example off piste, but it doesn't always have to be about cancer. If you just want to hear pronouns in context, if you just want to hear how queer people talk about their identities and lives, if you want to hear how trans people talk about themselves, there is a wealth of information out there. There's a million podcasts. There's all these TV shows, and there is something quite profound I think, about listening to those points of media where the community is speaking within the community and your given the privilege to listen. Because you can learn so much about what is important to a community, how things are phrased, how things flow, and I've definitely benefited from that from different events and different media points.

I mean, there's that fantastic conference, the black women with breast cancer conference that happens every year in London and it's a privilege to be in that room. And I think in this day and age where there's so much media around, you know, it's really important to use that asset, of course, always making sure that we are going to things that are made by the Community for the Community because there can obviously be some things out there that obviously are not so healthy in relation to certain topics, especially to do with LGBT health. But I think that's definitely something that can make it feel less like homework and maybe make it a little bit more enjoyable.

00:37:04 Carly Thanks. So I really like that suggestion of going beyond just looking at information that's specifically about cancer care or specifically about healthcare and going broader. So yeah, thank you. And if everyone made these changes and and these steps and these improvements that we've talked about, what difference do you think this would make to people with cancer?

00:37:26 Stewart I think a lot of what we see is people have this sort of medical mistrust, right? They sort of feel like I'm not going to be taken seriously so much so, especially in the trans community, they have a whole label for it. They call it trans broken arm syndrome. Where they feel that they could genuinely walk in with their arm hanging off and still be told like, oh, it's trans health, we don't understand it. So being able to embrace people, understand people, and then provide that really person-centered care from the off is just going to radically change people's experiences. I mean, we've also heard from people who, for example, again a trans person who avoided their cervical screening for seven years because their voice broke from testosterone. Because they were so afraid of calling up and then unfortunately, when they did call up they were laughed off the phone. So it's those things of how do we nip that in the bud, really? How do we lead with that person first approach and make people feel safer. And when we do that, we allow people to attend their healthcare appointments.

If we address those systemic issues that stops people from going or leaves them less informed on what that means is we can get people diagnosed earlier. We can improve their outcomes. We can make sure that they're living longer and healthier, and that's the primary goal, right? So again, it adds to that living with and beyond group and our community should absolutely be in there too. And again, that's where those living with and beyond considerations that are LGBT specific is so important on why the charity exists of all parts of the pathway, because once someone goes through that experience, you know you, you are sort of forever changed and someone living with cancer day in, day out. It is on my mind every day whether that be a good thing or a bad thing. Obviously I've built my life and job around it, so maybe I've sort of made my own bed at this stage, but it's something to recognize that I think someone challenged me a couple of years ago on well, why do you need it? Why do you need to have support that's specific to you and your community? I think where we find comfort and and support is a really integral part of the patient experience and it can often be overlooked when we think about mortality and adherence and outcomes and all of these things. But there's a quality of life factor that we're missing if we don't think about that person's mental state and emotional state going through it. And I experienced that first hand where I was going through all the medical stuff that didn't have the support and I felt incredibly isolated for years until starting to build this thing and actually getting to meet other people, and that's turned my life around and I'm really, really proud to say that we get to provide that to other people who join the charity. And you can visibly see the relief on their face when they enter our peer support because they finally get to be somewhere without having to explain who they are, and that relaxation that that sort of weight off the shoulders is something that comes from community and I think it really, really is an integral part.

00:40:32 Lydia I think you've highlighted so wonderfully there how important the work that you do is. You know, we should all be sort of striving to make sure that anybody with cancer, I guess anybody with a long term condition or anyone who's struggling, really they should be put first and anything we can do to help them live better live longer should absolutely be integral.

Just to wrap up the episode today, we have a regular feature called what three Things, which is something we ask of all of our guests.

So the first question to ask you is if you could go back in time. What piece of advice would you give yourself?

00:41:10 Stewart So as you've probably gathered, I'm a bit of a workaholic, and I've built my life around this, so I think the thing I would tell myself is to breathe and take breaks. So I'm I'm very impatient and that is a blessing and a curse. And I think absolutely just as I said before, it's OK to take a holiday and it's a lesson I think I'm still working towards.

00:41:33 Lydia And what change would you like to see to improve the lives of people living with cancer?

00:41:38 Stewart I think I really want to see it embedded in the change that we're seeing elsewhere, so I want to see it embedded in person, centered care. I want to see it embedded in pathway design and I want to see it embedded in new health technologies having it as that cross cutting concern.

00:41:55 Lydia And finally, what would you like listeners to take away from this episode?

00:41:59 Stewart I think don't let your discomfort get in the way of you providing good patient care. It's human nature to feel that we don't feel confident when we are not informed or it's something that's new to us and we're afraid of making mistakes. And I think the thing I hear a lot about LGBT related health is people are very afraid about saying the wrong thing. So don't say the wrong thing. Just go in with an open, honest approach and say I'm not sure what to say. Like, what do you want me to say? What would you like me to call you? Let patients lead you, and then you're less likely to say the wrong thing. And if you enter into a conversation with an open heart and genuine support. Even if you make a small mistake, it won't be the end of the world.

00:42:39 Lydia I think that's a perfect ending to the podcast. That line. I love it. So thank you so much for talking to us today, Stewart. It's such an incredibly important topic and it's been really inspiring to hear about the work you do and how we can help to improve things for the LGBTIQ+ community. It has been great having you on the Cancer Professionals podcast.

00:42:59 Stewart It's been a pleasure. Thank you for having me.

00:43:02 Carly You've been listening to the Cancer Professionals Podcast, which is brought to you by Macmillan Cancer Support. If you work in health or social care, visit macmillan.org.uk/learning to find out more about our learning hub, where you can access free education and training. For the links to the resources mentioned see the episode description.

00:43:20 Lydia If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by Helena Boyce, Anti-Racism and Racial Literacy Educator, business owner, and 3x Breast Cancer Survivor. Helena talks to us about racism in cancer care and her own experience of cancer including the challenges she faced.

00:43:44 Carly We'd love you to rate our show and share with your colleagues. New episodes are released on the first Wednesday of each month.

00:43:47 Lydia I'm Lydia.

00:43:50 Carly And I'm Carly and you have been listening to the Cancer Professionals Podcast by Macmillan Cancer Support.

Music fades out.