The Cancer Professionals Podcast

Living well with HIV and cancer

Episode transcript

(Intro music fades in)

Carly (00:09)

What does shared decision making look like when a person's reality is shaped by so much more than their clinical needs?

Emma (00:16)

Walk alongside somebody to understand where they are in their world because their HIV and their cancer might not be their priority. And unless we're holistically treating people and engaging in shared decision making, we will never ever treat people effectively.

Paul (00:31)

Hello, I'm Paul and my pronouns are he/him

Carly (00:35)

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 (00:49)

If you enjoy this episode, please subscribe, rate, 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 a short survey linked in the episode description.

(Music fades out)

Carly (01:11)

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

Paul (01:20)

Hello and welcome to the Cancer Professionals Podcast. In this episode, we're exploring HIV and cancer and how we can provide the best support to people navigating healthcare systems during diagnosis and treatment. We're joined by two amazing guests, Roland Chesters, who shares his experience of living with HIV and cancer, and Emma Davey, a clinical nurse specialist in palliative care and HIV oncology.

So please introduce yourselves and your connection to this topic. And Emma, I'll start with you

Emma (01:51)

Thank you Paul and thanks so much for inviting us. We're really pleased to be here. I'm Emma. I'm a Macmillan Clinical Nurse Specialist in Palliative Care, a job I've been privileged to do for the last 25 years whilst working in a voluntary capacity lifelong in HIV care. And then more recently over the last five years, I've worked as an HIV oncology nurse as a separate role alongside my palliative care job based at a tertiary cancer centre in Liverpool.

Paul (02:17)

Thank you Emma and Roland.

Roland Chesters (02:19)

Morning Paul, as you already said, I'm Roland Chesters. I am by no means a medical professional. I am a lay person, the person on the Clapham Omnibus who 20 years ago was diagnosed with HIV and more recently had a cancer diagnosis.

Paul (02:36)

Thank you, Roland, and we'll certainly be coming back to hear more from you shortly in the conversation. So we wanted to really start by talking a bit about where we are now for people in cancer care, perhaps who don't work in HIV day to day. And Emma, I wanted to come to you first to perhaps give us a little bit of that picture.

Emma (02:57)

Yeah, it's wonderful to be able to share the great news of HIV care that's really revolutionised over the last 40 years. So we've got about 113,000 people living with HIV in the UK. Living with, thriving with HIV as we work hard to get towards the UNAIDS target of zero new HIV acquisitions by 2030. And the UK are making good progress in that direction.

We know we've got 95 % of people living with HIV diagnosed. Of that 95%, 97% are engaged in care. And of that 97%, 98% have an undetectable viral load. So that means that they're taking antiretroviral treatment and can't share their HIV with anybody else. It's a huge success story. You live with a... better than normal life expectancy now as somebody living with HIV that's engaged with care. And treatment options have evolved and developed hugely, very often meaning people take maybe one tablet a day or potentially might now be on injectable antiretroviral treatment as well that they have once every eight weeks. So huge progress

Paul (04:05)

Thank you, Emma. I know in the kind of conversations leading up to today, we talked about which cancers tend to be more prevalent among people living with HIV. Can you maybe explain a little bit about why this is?

Emma (04:19)

So historically, people living with HIV would be diagnosed often with what were called AIDS-defining cancers. So these were three main cancers, Kaposi sarcoma, which people will think of as the skin lesions that often can affect internal organs also, diffuse non-Hodgkin's B-cell lymphoma and invasive cervical cancer. And in the time prior to effective antiretroviral treatment, these were AIDS-defining cancers many, many people would have lost their lives as a result of. Now, since we've had great ART antiretrovirals, numbers of these cancers have dropped by two thirds in people living with HIV.

apart from cervical cancer and we're still doing a lot of work to try and increase cervical screening for our population. But what we are seeing is an exponential rise in other cancers for people living with HIV and the reasons for that are multifactorial. The statistics around this are difficult and it's not to scare monger but I think knowledge is power isn't it and if we can educate that's always a good thing because we know that cancer when it's caught early is incredibly treatable and curable, but we know that 50% of deaths in 2023 of people living with HIV expected deaths were due to cancer. And if I'm telling you that numbers of AIDS-defining cancers are reducing so significantly, why is that? Well, there's four main reasons. Firstly, cancers of ageing. We've got a population of over 50% of people living with HIV over 50, which we celebrate.

You're not at increased risk of certain cancers, but as we age, we're all at increased risk. So your HIV isn't necessarily the risk factor, but we know that things like breast cancer, prostate cancer, ovarian cancer, our chances of developing these are greater as we age. We know that for many, not all of our HIV population, there are lifestyle factors that can contribute things like smoking, alcohol use, obesity, other issues that can affect us.

We know that there's significant sort social economic challenges for some of our population of people living with HIV. So, you know, if people are living maybe below the poverty line, if people are living with English as the second language, if people are living with poor mental health,

are all things that can make accessing timely cancer care more challenging. And as a result of that, we're finding that people living with HIV are tending to be diagnosed with cancer at a later stage and also at an earlier age.

But the biggest factor really for increasing rates of cancer in this population of people is due to other oncogenic viruses. So commonly people won't just acquire HIV, they'll acquire other viruses, not necessarily at the same time, which we know can increase people's cancer risk. So as examples of that, we know that the hepatitis virus can increase your risk of liver cancers.

We know that EBV, the glandular fever virus, can increase your risk of gastric, laryngeal, and certain types of lymphomas. And certainly within my clinical practice, what we're finding is that HPV is a huge, huge risk factor for people living with HIV and for people without. But we know that if you live with HIV, your chances of developing an HPV-related cancer are far, far higher.

So we're seeing that very much in vulval, penile, head and neck, and anal cancer. And certainly anal cancer is a cancer I support most greatly within my clinical work.

Paul (07:53)

we'll probably come back to some of the things that you've mentioned as we go through the conversation. But Roland, ~ could we perhaps bring you into the conversation you could share some of your experiences and your story so far.

Roland Chesters (08:07)

Thank you Paul. So as I said in my introduction, I was diagnosed with HIV almost 20 years ago now and at the time I was diagnosed I was also told that I had what was then called an AIDS defining illness which was progressive multifocal leukoencephalopathy which is a brain disease and in my case had affected the cells at the base of the brain, the ones that govern your motoring skills. So I was essentially paralysed.

unable to use arms, legs, unable to speak and my husband became my carer. 20 years on, I am mostly able to walk and talk and sometimes even speak at the same time. Although actually, when you're not able walk and talk at the same time, you find that it's incredibly difficult to do. However, my HIV is really well controlled.

My HIV consultant even tells me that I am HIV boring, which I take as a great compliment. The more exciting bits, as far as my consultant is concerned, is the fact that some five years ago I had a heart attack, which was followed some months later by a stroke. And middle of last year, my lovely HIV consultant asked if I would like to volunteer to do some medical research. And of course, I said yes.

and this was research into anal cancer amongst HIV positive men. So I went off to have a screening done and they took some biopsies which perhaps a little undignifying but at a certain age who cares anymore and they eventually came back and said oh yes, we think we found something.

So I had to go back for more biopsies and they came back and oh, no, yeah, that's definitely something that needs to be looked at seriously. So in early January this year, I went off to Homerton Hospital and underwent the laser ablative treatment, which is basically a fancy way of saying they went up my bum with a laser gun and shot out all the bits of cancer. whilst that might sound daunting,

It was actually not that daunting. When they say local anaesthetic, they gave me a cream to put up my bum, to numb it. They then did an injection, which numbed it even further. And they fed me with pain killing tablets to the point where I could see on a big screen all that was happening. And I actually found it really interesting seeing how the consultant managed to manoeuvre the laser gun at my bum hole to actually attack the bits of skin that needed to be removed. And they said it may be painful for a week or two after. It was slightly uncomfortable for a couple of days and then nothing. They told me I need to go back in six months just to make sure that it's all clear and I will keep having to go back every six months for a couple of years to make sure there's no recurrence.

Obviously this is only my personal experience other people may experience it in different ways. But I think part of my message is it's nothing to be scared about. Receiving a cancer diagnosis can be devastating. And when I received the news, I thought, I'm not going to say any rude words, but I thought, really? After all of this, I get this as well?

Obviously in a previous existence I'd done something really, really bad and I was being punished for it. But as always, I am hugely grateful to the medical professionals, hugely grateful for the care that I received and I feel incredibly lucky because if my consultant hadn't even asked me if I would volunteer for research, my cancer would probably not have been discovered at such an early stage. I haven't had any symptoms, so I didn't know.

Paul (12:07)

Thank you for sharing that. And I suppose, you know, there are certain aspects of what you talked about, which perhaps people don't feel comfortable talking about. So it's great that we can actually start the conversation as part of the episode today. And Roland, I wondered if you could perhaps also share a little bit about...

navigating across different teams, know, navigating the different healthcare teams that you had to kind of keep talking to about all of these things.

Roland Chesters (12:37)

Absolutely. When I was diagnosed 20 years ago, my lovely consultant then had the power and the authority to refer me to other specialists to get other things done. And obviously the structure of the NHS has changed over that period of time. And I now have about five or six different consultants looking at different things. And the NHS, from my perspective,

is sadly not fully connected. So it means that when something happens like this cancer diagnosis, it's then up to me to inform all the other consultants of what has happened. I'm a lay person, so the wonderful consultants tend to talk in medical terminology. I did train as an expert patient about 10 years ago.

Most times I'm able to say to the wonderful medical professionals, I don't understand a word of what you're saying to me. Can you please tell me that in language that I can understand? Because now it is up to me to relay that information to the other medical consultants. And I interpret in my mind what I'm being told and I give that interpreted version.

to the next medical professional who takes from it what they think I'm trying to say. Whether what I'm saying is correct or not, I don't know. So I'm really quite concerned about this. My wonderful GP is supposed to maintain all of these records, but even he is sometimes astonished that I've had an appointment or some kind of treatment done that he hasn't been informed about. He has no knowledge of.

It is a concern. What can be done about it at this stage individually, I think is quite difficult. But every time I speak to medical professionals, I urge them to make sure that they are using a language that can be understood by the person being treated and that their message is one that can be easily conveyed or that they contact my other consultants directly themselves.

Carly (14:52)

Yeah, that's tricky isn't it when the responsibility seems to fall on you to be able to translate that information between the was interested to know kind of talking about that more joined up services that you would want and you would want to see different and you touched on a few elements of what that could look like. Is there anything else in your experiences? What would that true joined up sort of collaborative services between the different teams that you were working with. What would that look like? How would that feel for you in an ideal world?

Roland Chesters (15:29)

Well, when I first started treatment, I was quite seriously unwell. So I just kind of went with the flow of what I was being told and what I was being told to do. But as I became more well, I suppose, and now obviously in hindsight, as things have changed,

Carly (15:36)

Yeah.

Roland Chesters (15:48)

the way the system worked then, that my then consultant was completely in charge of all of my care, not just HIV, but anything else that was going on in my body, that consultant could refer me to other people, they could prescribe me medication, which now my specialist can only prescribe me the antiretrovirals, everything else has to go through the GP. And again, my GP receives a letter from a consultant saying, please prescribe this for Roland. A GP calls me up and says, why? What do you need this for? What's happening? And I am fortunate in that I am retired because all of this can be really time consuming and energy consuming. So one has to have a degree of resilience and perseverance to make sure that as far as I can I'm trying to join up all those little bits of string that keep unravelling.

Carly (16:52)

Yeah, and lots of people don't have the time, do they? And Thank you for picking that up. think that's really important for listeners to hear, particularly because we talk a lot on the podcast actually about living with cancer and other long-term conditions. And kind of encapsulates one of those big challenges about that, about those kind of perhaps lack of the joined up services and what professionals can do more of. So. Yeah, thank you for sharing that from your experiences and I think that would be really helpful for people listening to No, no.

Roland Chesters (17:22)

Can I just add it's also to do with self-confidence. And this was part of the Expert Patient Programme training. Feeling that you are equipped, I am equipped to have a conversation on a par, on a level with consultants. And my consultants, on the whole, have been pretty wonderful,

Carly (17:25)

Absolutely.

Roland Chesters (17:40)

So it's having that self-confidence to be able to say to a consultant, are you sure about this? Are we getting this right? Because I think we should be trying something else.

Carly (17:45)

Mm. really important.

Emma (17:49)

That's such an important point that though, Roland, that I think sometimes in medicine, we listen to respond, we're already thinking of an answer to a challenge or a situation. And actually, we need to really be vigilant in listening to really hearing, you know, to really hear what someone's saying, because as you say, you are the expert, And your reflections there really, I don't think you're alone in that at all.

having done quite a lot of work within this area, these are the key themes that sort of come out from, you know, the research and the literature. But actually, we know that collaborative working is one of the biggest challenges for people with a dual diagnosis. for many of the people I support, because of stigma around HIV diagnosis,

many people still don't share their diagnosis with the GP. So they almost haven't got that advocacy to back them up. And it seems a huge responsibility that somebody themselves has to collaborate services. You know, that seems an unfair pressure from which many people wouldn't actually be able to do. I think, you know, we really need to focus from an oncology point of view at working collaboratively. And that's not just tokenistic copying each other in on letters. It's really

Carly (18:49)

Yeah.

Emma (19:02)

active dynamic multidisciplinary work. We know this is a cohort of patients with additional complexities very often. We know there's a number of interactions between antiretrovirals and our oncological treatments and people often have broader complexities in their support. So we need to really be thinking about how we can engage as a multidisciplinary team with our person at the centre of that. They need to be leading that.

to see how we can work better. You know, equity in care is difficult. People living with HIV are largely still excluded from oncological trials, which should not be the case in this day and age.

we have inaccessible healthcare. And it's sometimes thinking about how we can take our care to the people that maybe are apprehensive to come into oncology care or maybe just can't afford their bus fare to get there. Their cancer diagnosis might not be their biggest priority. So we need to work creatively to try and address some of these barriers that I feel.

(Music faces in)

Carly (20:08)

This conversation really shows how living with more than one health condition like HIV and cancer can be overwhelming, not just because of physical symptoms and side effects, but the emotional and psychological impact too.

Paul (20:19)

That's where self-management can help. It's about having the confidence, knowledge and support to take an active role in your care. Did you know that Macmillan and Hope for the Community offer the Help Overcoming Problems Effectively programme also known as the HOPE programme.

Carly (20:37)

Yes, and it's designed for people living with or after cancer to develop techniques and strategies to manage aspects of living with cancer, such as dealing with setbacks, fatigue and stress management, challenging unhelpful beliefs, goal setting, self-compassion and more.

Paul (20:52)

Professionals, volunteers and support services and communities can also get involved by training as Hope Facilitators and helping to run courses in their local area.

Carly (21:02)

So if today's episode has got you thinking about how to support people living with cancer, including how you can become a facilitator and deliver the HOPE programme, head to the episode description to find out more. Now let's get back to the episode.

(Music fades out)

Carly (21:16)

Health inequity spans so many different elements, doesn't it? It's so multifaceted, whether it comes to, like you said, financial barriers, whether it comes to lack of trust or engagement in the healthcare that's a whole other topic in itself, isn't it, that we could talk about. I wanted to pick up on something that you said, Emma. You mentioned about stigma and the stigma around HIV.

And I wanted to talk about that a bit more. And wanted to bring up here the People First Charter. And I think it would be good to talk about this as part of the conversation, perhaps a little bit later on. But we know that something that is included in the People First Charter is about language and about the use of language and actually the fact that we know that people living with HIV can experience that kind of stigma and actually that the language that is used by professionals can actually perpetuate that. Are you able to kind of elaborate on this and actually how people supporting people living with HIV and what is it around the language that... can be used to provide that better, more positive experience.

Emma (22:25)

Yeah, I'm thrilled to talk about it, Carly, and could talk about it all day long, because I feel really passionately about it. Stigma has changed, but stigma is absolutely definitely still there. And I think stigma comes in in many different guises, doesn't it? You know, for people that remember historical HIV campaigns, many people will carry stigma about HIV as a virus. I think

You know, there can be professional stigma as well. There's been some research in America done that showed that sort of up to up to a third of oncologists undertreat people with a cancer diagnosis living with HIV because of perceived misconceptions about immunocompromisation or potential toxicities of treatment. I'm really pleased to say I've never found that within my clinical work.

And I think that self stigma, which I Roland touched on there, is also really, really significant. And Roland talked about that feeling of what have I done? Is this something that I have done to cause this cancer? And self stigma can disable people from engaging with care very commonly. So it's something we really need to think about and keep the conversation going about. As health professionals, we're the magnifying glass that the general public see health care services through.

So it's so important that we get it right. And I know we can't get it right all of the time, but we need to be vigilant, I guess, to our own learning. You mentioned the People's First Charter, which is incredible work, And this is around destigmatizing language. So.

You'll notice through our conversations today, we've talked about people living with HIV rather than the HIV patient because you're not defined by your health conditions. We think very carefully about, you know, we talk about HIV acquisition rather than infection because that can sound deliberate. We talk about vertical acquisition rather than mother to baby transmission. So

It's important that we're using language as health professionals to destigmatize this. Historically, HIV and AIDS were sort of lumped together and talked about together and we still talk about AIDS and we still recognize events like World AIDS Day. We've got the UN AIDS targets that we're working towards. From acquisition of HIV left untreated, often seven to nine years later, people would develop opportunistic infections. this was a time that historically people would receive a diagnosis of AIDS. And at that time, before antiretrovirals, for many people that would be a terminal event. Now,

Since the introduction of really fantastic treatment, we don't talk about AIDS so much. We still notice its historical importance. Absolutely, we do, particularly for the long term survivors who have lived with this for a very long time. But actually, now AIDS is not a terminal event. We talk more about people being diagnosed with late stage HIV. So if they're diagnosed at a point where their blood counts are

Carly (25:19)

Mm.

Emma (25:37)

or maybe they have opportunistic infections, we now make that a diagnosis of late stage HIV, get people engaged with care when they're ready to do so, and on effective

antiretrovirals, and look to reverse that. So the face of this has changed very much, but we don't talk about AIDS patients. I think for people who have lived with 40 years with an HIV diagnosis, that can be really, really triggering.

I'm interested to know Roland's thoughts.

Roland Chesters (26:08)

Thank you, Emma. Excuse me. I have mixed thoughts on this. As I said earlier on, I was diagnosed with what was then an AIDS defining illness and I don't want the impact of that to be minimised. I am of an age where I remember very clearly the ~ government campaign.

to inform people here in the UK about HIV and AIDS and the slogan Don't Die of Ignorance. And it was a campaign of fear deliberately created in order to make sure people were fully aware. And as a result of that, here in UK, the pandemic was much more limited than in other parts of the world. But there has been no other government campaign of updated information since that time.

And so that is the only, for some people, that is the only information they know that AIDS can be a killer. And it certainly, as you said, Emma, it certainly was at that time, but also, as you have clearly said, is no longer necessarily the case. But the stigma still exists and certainly, as as the health professionals are concerned, I have been on the receiving end

Only a couple of times, I have to say, and I've been in connection with many, many health professionals over last 20 years, only a couple of times where clearly I am being treated differently because of my HIV status. And on both of those occasions, I was able to say, you need to be better informed about this because HIV is covered under the 2010 Equality Act Can I also go back to the self stigma bit slightly in that, again, I'm of an age where people didn't dare to talk about cancer. It was not socially acceptable. People would talk in whispers about the big C.

Carly (27:57)

Mm.

Roland Chesters (28:06)

You know so and so has got the big C. Obviously we talk more openly about cancer these days but talking about anal cancer takes you to another level of stigma and certainly as a gay man my internalised stigma was saying to me when I was first diagnosed people out there may think that when I share this information with them it's as a result of sexual activity.

that I have acquired this kind of cancer, which isn't the case. But yeah, you have to develop a little bit of a coat of armour to be able to say openly and upfront, actually cancer that I have is anal cancer and people will either respond out of curiosity or with a degree of ooh or will not wish to engage in conversation with you on that topic any longer.

But I have always seen living with these conditions and being public about these conditions, it's my responsibility to educate and inform. Not everybody else will feel the same, absolutely. But because I can do, I will do.

Carly (29:00)

Mm-hmm. Thank you.

Emma (29:18)

We're so grateful to you for that, and to have the opportunity to shine a light on, you know, cancer like anal cancer, which is a really rare cancer, but for people living with HIV the chances of developing anal cancer are up to 19 % higher than the general population. And for the population of men that have sex with men living with HIV, that rate can be higher again. So we really need to normalise this conversation because nobody talks about anal cancer. And certainly in my clinical practice, know, Roland shared that he was asymptomatic from his anal cancer.

And it was his involvement in a research trial that picked it up and thank goodness it did. What I see clinically in my practice is often people have maybe had vague symptoms, but because symptoms of anal cancer can be things like bleeding, can be things like itching, know, commonly people have been diagnosed with haemorrhoids or they are being given the opportunity to have other STI testing, which, you know, is still important, absolutely. But because of that,

and the rarity of this cancer. And maybe the fact that actually in primary care, understandably, unless you work in HIV care, you wouldn't necessarily know that people living with HIV are increased risk of this particular malignancy, which can often mean, unfortunately, that people are diagnosed late. Now, up to 90 % of anal cancer is HPV related. And you know,

Emma (30:49)

It's not, as Roland says, it's not necessarily related to people's sexual identification whatsoever. This affects men and women, you know, in whatever relationships they're having. But women, obviously, we are screened for HPV if we're engaged with cervical screening, whereas men unfortunately aren't. Currently, there's not routine screening for HPV within the UK.

Carly (31:11)

Mm.

Emma (31:14)

HPV is the most commonly acquired sexually transmitted infection. Most people who are sexually active will acquire HPV within their life and their body will naturally eradicate it. But there are a couple of strains of HPV, strains 16 and 18, which over the long term can potentially become malignant. And as we now have this aging population, we know that the chance of developing these cancers are higher. As Roland's touched upon, living with HIV can be a stigmatized illness. Anal cancer, there's a lot of stigma around that on

its own. So when we combine the two, this can be really, really challenging for people and we really need to normalize the conversation around anal health.

Roland Chesters (31:59)

Emma, is there a HPV vaccine available?

Emma (32:02)

There is, yeah. So anybody living with HIV is entitled to the HPV vaccine up to the age of 45. If you're over 45, I still implore you to discuss it with your HIV team. Men that have sex with men are also entitled to the HPV vaccine and that can be given at any sexual health clinic or GP clinic. So ask the question because we know that it will considerably reduce the risk of some

Carly (32:30)

Thank you. I wanted to move on just slightly, just more around support or any services for you Roland, that were available to you for people living with HIV and cancer? And that could be perhaps related to the self stigma that we've talked about or anything else or with HIV and cancer.

Roland Chesters (32:42)

I didn't really look into it that much, how to admit, Carly, because I have an immensely supportive husband who, when I told him about the diagnosis in his usual manner, said, okay, well, we'll deal with that as well. And that matter of fact and common sense attitude for me is what is absolutely needed, because otherwise I could be quite a drama queen. In terms of support for people living with HIV,

I do volunteer myself as a peer mentor, I'm a positive voices speaker for Terrence Higgins Trust and so on and so forth. So there are lots of resources now for people living with HIV, whether newly diagnosed or not. In terms of specifically people with HIV and cancer, I have to admit I am unaware of what support services there are available. I'm sorry I've let you down on that.

Emma (33:47)

I can try and fill the gap a little bit. can happily try and fill the gap.

I think there is a paucity of information for people with a dual diagnosis and I think it's something that would be really beneficial to be evolving going forwards. Terrence Higgins Trust have some fantastic resources for people living with HIV that are diagnosed with cancer.

Carly (34:02)

Mm.

Emma (34:09)

And certainly George House Trust, Manchester and Liverpool based charity supporting people with HIV equally have been doing a lot of work in this area. But I think there is a

lot of work still to be From a personal experience, peer support is something that's been central to HIV care for many years.

Often when people receive a diagnosis of HIV, we know as health professionals that you will go on and thrive, know, engage with care, you will live a great and normal life. But actually hearing that from somebody who is living and living well with an illness has the greatest impact.

And I think that lived experience from people who have walked that journey, although it won't be the same, is really, really powerful.

Paul (34:53)

Yeah, that's great. And Emma, think just touching on kind of resources, about what else might be available for the health and social care professionals who might be listening to this episode. What other resources can people go to to help guide, practice? ~ or language.

Emma (35:15)

Yeah, definitely is Paul. There's, I think, three main things. We've talked about destigmatising language and the People First Charter. It's a really accessible web page and can be received as a document, which is fantastic. As oncology professionals or as any health professional supporting people with HIV, it's really, really important that we're accessing the HIV drug checker. And I know you're going to provide links to that.

Antiretroviral therapy has revolutionized HIV care, but it does have a number of interactions with other medications. And certainly within oncology care, where we're not effectively checking people's antiretrovirals with the treatment that we're planning on giving, that can cause problems. It can mean that people do experience increased toxicities or develop opportunistic infections related to their HIV.

which can often mean there's breaks in oncology treatment, which we don't want because that will affect people's longer term outcomes. So certainly cross-checking any medication prescribed on the HIV drug interactions checker is really, really vital. That will be linked to many health professionals prescribing platforms, but I know certainly in certain areas it's not, so it's important to be vigilant with that. There are also the European AIDS guidelines, so the EACS guidelines and there are specific guidelines which are supported by the British HIV Association for Treatment of People with Cancer Living with HIV and these are set of guidelines that really identify as oncology professionals our responsibility for supporting people living with HIV. So this is around checking the drugs as we've talked about, it's around prescribing for opportunistic infections.

So commonly when people are having chemotherapy or radiotherapy, we should be prescribing irrespective of somebody's blood counts for certain opportunistic infections. So this is things like oral candidiasis, these sorts of things, and the guidelines are there. And it also gives us guidance about what blood tests we should be doing when. So that's a really third valuable And if in doubt, ask your HIV team. They are so skilled, knowledgeable, approachable, helpful. You know, we have not expected to know this as oncology professionals, but it's timely collaborative working that we take

responsibility for not expecting a person who is juggling a dual diagnosis and think of the, you know, the psychological, the financial, the emotional, the sexual impact for that for many, many people. We need to take responsibility for that to try and alleviate some of the pressures that Roland has there talked

Roland Chesters (37:56)

may I just reiterate, thank you for all of that Emma. You've already mentioned the interactive chart, Liverpool HIV Chart. And whilst my GP is wonderful, it's a surgery that has got multiple doctors in it. So when I have an appointment,

I say to them, have you checked interaction? And they're not aware of the chart. And so again, it's a learning process for them. And I'm the one that has to say to them that you need to look at this and make sure there won't be any interaction. And I'm happy to do it because it's in my best interest as well as their best interest. But at the same time, it does create a certain degree of resentment that I have to do this.

Carly (38:24)

Yeah.

Roland Chesters (38:41)

Not every time, but certainly quite often.

Emma (38:44)

I imagine that can affect the feeling of trust as well, Roland, when your health is in this person's hands, you want to feel trust in their knowledge, which I imagine can be difficult. From an oncology point of view, I think we need to be mindful that very often when people come with their oncology appointments, they often attend with a friend or relative. And we must be mindful of people's confidence around all health conditions, not just HIV confidentiality.

Roland Chesters (38:47)

Absolutely. Yeah.

Emma (39:14)

But certainly we see frequently people will come into clinic and actually they won't share their HIV diagnosis with us. So I think that in itself can be quite challenging for health professionals to have that open, honest dialogue with people to make sure we can provide safe

Roland Chesters (39:32)

about My understanding has always been, and unless this has changed, that medical records about sex health issues are kept separate and confidential to the ~ clinic that you are attending and will not be available to other medical professionals.

Emma (39:53)

No, that's absolutely, it is absolutely the case. Usually people are asked if they're able to share their HIV diagnosis with us. And certainly in terms of taking a medication history, that is often the point that we'd recognise those medications and think, okay, we need to talk more about this. Sexual health records are completely private. You are absolutely right. But certainly if somebody is diagnosed with a cancer,

the individuals are very much encouraged to share that because of the interactions with our oncology treatments. I'm really mindful, there will be people living with HIV who maybe aren't aware of it themselves, or maybe who are aware and have declined data sharing, which we respect entirely. And I guess that's a whole different challenge and that's tricky, isn't it, within healthcare?

I know some, I believe in Ireland, that actually routine HIV testing for people coming into oncology care is something that's in place. And I guess that could well be a consideration for the future in that we know we will be able to give safer treatment for people if they are agreeable to that. We have the opt out HIV testing rolling out nationally through the UK to try and help.

find that undiagnosed 5% of people living with HIV. So people going into A&E who are having blood tests for whatever reason will now also be tested for HIV and other blood borne viruses like hepatitis. And that scheme has been hugely successful in new diagnoses but also re-engaging people who have maybe for whatever reason and there's never any judgement, you know, we are always here to support you, there's never any judgement if you've fallen out of care for whatever reason.

But we know that actually on effective antiretrovirals people do well. So it's trying to normalise that. Historically, and I've seen this working for 25 years in this field, and I can reflect on cases of people who may became, were being investigated, maybe they had raised lymph glands and night sweats, certain symptoms.

And as a result of those symptoms were offered an HIV test. And I reflect particularly on somebody who was diagnosed at the same time with an HIV diagnosis and a lymphoma. But he was very clear. He felt he'd been offered that HIV test because he was a gay man. And he said, if I was a 75 year old woman, professional retired woman, would I have been offered that HIV test? So actually we don't.

you know, we need to normalise testing for everybody because everybody is at risk. Illness does not discriminate.

Roland Chesters (42:36)

story is more than 20 years old, but from what you were saying, not much of this has changed. before I was diagnosed, I was becoming progressively more and more unwell. As I said, I was losing the use of my arms and legs, the ability to speak. I saw so many different consultants, had so many different tests. Nobody could give me a definitive diagnosis. My husband,

now my husband, decided to come with me to see a chest specialist in our local hospital. They thought they found something wrong with my lungs and this was the first appointment that he had come to with me. The problem with my lungs turned out to be chickenpox, of course, so nothing serious. But because this consultant recognized that

we are a same-sex couple, he asked me about a HIV test. The first time I had been asked, and subsequent.

The result of that was, as you know, the HIV and AIDS diagnosis. So again, I consider myself incredibly lucky. But for two and a half years before that, because I turned up all by myself nobody, nobody thought to suggest or invite me to take a HIV test. Yes, that's partially my own responsibility as well. But at the same time,

They should also be aware of their responsibility, those medical professionals.

Carly (43:55)

Mm.

Emma (43:57)

it's not, you know, it's stigmatizing in itself, isn't it? When people are particularly targeted for a request to take an HIV test, we need to make this normal conversation for everyone. Because certainly around new diagnoses, although there's only 5 % of people undiagnosed, diagnoses that are being made late, 40 % of those people diagnosed now are made, diagnosis is made of late stage HIV, so they're really sick.

Roland Chesters (44:23)

people who are diagnosed late then have to be treated in a different way to people who are diagnosed early. And nowadays, the saying is that if you are diagnosed early on after you have become infected, you will, as Emma said, have to take one pill a day or something like that for the rest of your life.

which means that you will not become unwell and because as HIV positive people we are so medically well cared for and scrutinized that the slightest thing that's going wrong is usually picked up on fairly quickly. But

Carly (45:03)

Mm-hmm. Mm-hmm.

Roland Chesters (45:05)

people who are late diagnosed, who have got some other what I still call AIDS defining illness, it is more difficult for them to be treated. I myself at the moment take something like 18 tablets a But I'm grateful that they are available to me and that they keep me alive.

Carly (45:27)

Yeah, absolutely. Thank you both. So I'm going to move us on to our regular feature, which is...

one question that we ask of all of our guests and they're designed to be kind of short and snappy questions. So the question I will ask you both and I'll start with you, Roland, for you to answer is what is the one thing that you would like listeners to take away from this episode and our conversation today?

Roland Chesters (45:52)

Be bolshy, be vocal, stand up and say, this is my body. I know what's happening inside my body. I'm the one that feels this isn't right somehow. So do you, medical consultants, do something about it and do it now.

Carly (46:12)

Thank you. Yeah, that's great advice. That's a great suggestion. And that's actually something that really came through for me when talking to you. You mentioned several times about that advocating for yourself. So that was great. Thank you. And Emma, same question to you. What was the one thing that you'd like listeners to take away from this episode?

Emma (46:31)

Thank you. Personally, for everyone, get tested. Really crucial. Professionally, listen. Listen to understand.

Walk alongside somebody to understand where they are in their world because their HIV and their cancer might not be their priority. And unless we're holistically treating people and engaging in shared decision making, we will never ever treat people effectively.

Carly (46:55)

Absolutely, and a brilliant way to end the episode.

Paul (46:56)

Thank you.

Carly (46:59)

Thank you. Thank you so much to both of you. Thank you so much, Emma, for sharing your expertise. And thank you, Roland, for just being so open and so honest in sharing your experiences. And like we said, it's the importance of having this conversation and normalizing this conversation as well. So thank you both so much for joining us on the Cancer Professionals podcast.

Roland Chesters (47:22)

Thank you for inviting me.

Emma (47:23)

Thanks

(Outro music fades in)

Paul (47:25)

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Carly (47:46)

If you enjoyed this episode, follow us so you don't miss our next conversation

Paul (47:50)

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Carly (48:03)

I'm Carly.

Paul (48:03)

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

(Outro music fades out)