Transcript

Inside radiotherapy: Treatment, experience and compassionate care

Intro music

Carly (00:10)

Why is it so important to understand not only how radiotherapy works, but what the experience is like for the person receiving it?

Roy (00:16)

I just remember, you know, every session I had when I'm laying there having the treatment when the machine is moving around me, that there's a psychological element of me saying, get rid of those cancer cells, kill them off, get rid of them. And I'm just thinking every moment that machine is moving, I'd like to, my take away that it was doing a great thing,

Carly (00:39)

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

Paul (00:41)

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

Carly (00:58)

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Paul (01:14)

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

Carly (01:23)

Hello and welcome to the Cancer Professionals Podcast. Today we are talking about radiotherapy, which is a common treatment for cancer. We will explore what radiotherapy is, how it works, what people might experience when going through radiotherapy treatment, and also importantly, some really practical ways that healthcare professionals can support people before, during, and after treatment. So joining us are two amazing guests. We have a lead radiotherapy clinical nurse specialist and also someone who has experienced radiotherapy firsthand to share some insights to really help us better understand some of the challenges and the experiences and also the simple ways that we can really provide care that's informed, compassionate and truly person-centred. So welcome Jane and Roy, thank you so much for joining us on the podcast. Can we start by you introducing yourselves, telling us a little bit about you and also what brings you to the podcast?

Jane (02:27)

Thank you for having me. My name is Jane. I am the lead radiotherapy clinical nurse specialist at the Harley Street Clinic in London. I've been in this role for seven years now. And the primary, kind of clinical purpose of my role is to support patients going through cancer treatments, helping them manage their side effects, educating them on how to look after themselves prior to treatment, during treatment, and also after treatment as well.

Roy (02:57)

Hi, yes, my name's Roy and I'm just a regular guy. My profession has been in broadcast sales and selling technology, but my encounter with radiotherapy was I was diagnosed with prostate cancer back in 2021, and radiotherapy was part of my treatment which I had in January and February 23.

Carly (03:25)

Thank you. And it would be great to hear a bit more about your experiences, personal experiences around your radiotherapy, Roy. But can we start sort of quite generally around- what is radiotherapy in terms of what is it and how does it work?

Jane (03:42)

So radiotherapy essentially is high dose x-rays that we use to treat cancer. These high dose x-rays are generated usually from a machine called a linear accelerator, although there are other types of radiotherapy. The treatment is often divided up into treatment doses. So a patient might come in for five days of treatment or such as Roy, they might come in for, I think it was 37, was it? Or was that right, Roy?

Roy (04:16)

33, yeah. Not that I was counting.

Jane (04:18)

Yeah, 33, sorry. And that's to make sure that as we deliver the dose of the radiation each day, that it's safe for us to do that for the patient without causing too much harm or issues in the future as well. So we call that fractionated treatment. So that means that we've just divided up the dose into safe, manageable doses for the patient to receive each day. And that allows us to be able to deliver the radiotherapy and not causing too much damage to the normal cells, but be able to give enough so that we're being effective to the cancer cells that are in that area. And a lot of these decisions are based on some of the characteristics depending on the patient. So it might be around the staging of the tumour, the size of the tumour, where on the body we're delivering that treatment, but also some other factors such as age, performance status, quality of life, and essentially the aim of that treatment, what are we trying to achieve? So all of these things will be taken into consideration when prior to a patient starting treatment.

Carly (05:28)

Could you talk a little bit about the different types? I know you kind of referred to that very briefly, but could you talk about the different types of radiotherapy people might receive?

Jane (05:38)

Yeah, so radiotherapy is a bit of an umbrella term and it does incorporate lots of different types of radiotherapy and I touched on external beam radiotherapy just then when I was talking about what radiotherapy is. External beam radiotherapy is the most common type of radiotherapy used. We use it to treat lots of different areas on the body and as I said, we use linear accelerators to generate the radiation. However, within radiotherapy, there are also other techniques that are used to deliver radiation. So you might hear the term stereotactic radiosurgery, which is where we are delivering slightly higher doses of radiation, but in shorter fractionations for patients.

And within that, there are lots of checks and quality control techniques that we have to use to ensure that that's safer, that type of treatment to be delivered.

There are also things like proton beam therapy, which you may have heard about, has been in the news not so long ago. Brachytherapy, which is more of a localised internal radiotherapy, but also things like molecular radiotherapy or selective internal radiotherapy and possibly intraoperative radiotherapy. So there are lots of different types of radiotherapy. But primarily we do use external beam radiotherapy for the majority of cancer patients, depending on a lot of those characteristics that we talked about previously.

Carly (07:04)

Absolutely. And is it also the different type is around what the reason that it might be used for? Could you say a bit more around that?

Jane (07:12)

Yeah so, if we think about where on the body we're going to be delivering the treatment, as an example, one of the lesser used treatments might be something like selective internal radiotherapy and actually that's primarily used for patients receiving treatment to the liver and so it is very much dependent on where we want to deliver that treatment and what our outcome, what we hope our outcome to be as well.

Carly (07:37)

Mm-hmm. I'm interested to know a little bit more about the role of the radiotherapist could we talk a bit about what does the day-to-day work or role look like for a radiotherapist and also, how they support people living with cancer or people coming into having radiotherapy.

Jane (07:56)

So I have to obviously caveat I'm a nurse by background, but I work really closely with the radiographers and have worked in radiotherapy for a very long time. We work really closely together and actually there is a very strong multidisciplinary team working, that happens within all hospitals, and especially in oncology settings because of the complexity of the disease. Primarily radiographers roles, the way I kind of describe it in simplest terms is that they're the ones who deliver the treatment. They're the ones who will do the technical side of controlling the radiation, the radiotherapy machine and physically bringing the patient into the room, setting them up on that machine, making sure that any images or scans that they're taking are appropriate, ensuring that actually

from a safety aspect, it is safe for us to deliver the treatment to that patient on that day. They do also, within that there are some caveats as well, because the radiographers role has progressed and developed exponentially over the years. You know, now we have people ranging from junior radiographers to consultant radiographers who are able to plan treatments which are often done by consultants, doctor consultants, but also consent patients for treatment and do some of that more advanced work. So there's a lot of advanced practice that happens in radiotherapy as well with the radiographers.

Jane (09:28)

We work really closely with them from a different aspect. So I lead the radiotherapy review team and within our team we have myself and then we have another clinical nurse specialist and we have a review radiographer. So we have a bit of a multidisciplinary approach from a review aspect, so supporting patients through that treatment. And that's another arm of radiotherapy that radiographers can go into as well. So it's quite varied and I think the roles can be quite varied. But essentially, we work closely to educate the patients prior to treatment. The technical side is obviously done mostly by the radiographers. However, with us from a nursing perspective, we do have some knowledge in that too. That helps us to be able to better support patients throughout their treatment as well.

And so, you know, the radiographers will be doing their assessments also and assessing patients each day, ensuring that they are fit enough for treatment and well enough for treatment, and then escalating as appropriate, whether that's to us or to the medical team to say, you know, actually, maybe we need to just review this patient and check that they are fit enough for treatment that day.

Carly (10:38)

Yeah, absolutely. So it sounds like there's a team around a patient. You talked about the oncologist, the radiographer, the work that you do. Are there any other roles that sit within that team that are really important part of that for someone?

Jane (10:43)

Yeah, yeah, I mean, there are a lot of roles within that. We also have, so as you mentioned, we have the clinical oncologist. We have in the background, a team of physicists who help to support with kind of maintenance and looking after the radiotherapy machines. We also have people called dosimetrists who also helped with the planning process of the treatment.

Jane (11:18)

We have engineers as well who help if there's a problem with the machine because obviously this machinery is really complex and does sometimes break down, which does happen. I'm sure Roy can probably attest to that. And then we obviously have the nursing team and lots of support staff as well. So we have lots of, you know, where I work, we actually have a Macmillan Centre where we have volunteers but also support workers who can help guide patients through, whether it's referring to psychology, dieticians, physios, all those AHPs, so our allied health professionals as well, are really there to support patients and make sure that they are living life as best as they can and their quality of life continues throughout treatment and afterwards.

Carly (11:44)

I'm interested to know, so your role as a nurse what was it that led you to this role and to being a nurse? Could you talk a bit about that? I'm really interested to know.

Jane (12:15)

Yeah, it's hard question to answer, I would say. Because I don't remember a time when I wasn't a nurse, I suppose, which is quite nice. But I've been a nurse for over 10 years now, probably 13, 14 years. I've always worked in oncology, initially worked in surgical oncology, and then kind of moved into that kind of oncology outpatients. And I suppose I just took the opportunities that came to me or that were presented to me at the time to kind of develop and grow. I've sort of landed in this kind of, I guess, a bit of a niche area because not all radiotherapy departments will have nurses. Some of them have a team of review radiographers or advanced practitioners who do a very similar role.

Jane (13:02)

But I've always worked in alongside those sort of roles. I've been lucky enough in my career to do that and to learn a lot from the radiographers or the advanced practitioners that I have worked with and really enjoyed that. I think I've, you know, loved working in oncology and I can't see myself working anywhere else. But, you know, I think as well, it's just opened up quite a lot of doors.

Jane (13:24)

You know, the reason that I've managed to be a part of this today as well is because I do some work with the charity called the UK Oncology Nursing Society, which support the development and education of cancer nurses across the UK. And so, you know, being involved in that and being part of providing those opportunities for other cancer nurses coming up in their careers and supporting them through educational opportunities and just mentoring. And- we have a conference every year as well that's really well attended and just networking. I think growing that network and talking more about cancer. And I

think that that can be really powerful, not only for the nursing profession, but also our patients and our other healthcare professional colleagues as well.

Carly (13:58)

Mm-hmm. Absolutely. Yeah, absolutely.

Paul (14:16)

Thank you Jane and that was a really kind of useful overview of what radiotherapy involves. And Roy, if I can perhaps come to you, would you be happy to share your story and can you tell us about your experience of being told you needed radiotherapy?

Roy (14:34)

So I was originally diagnosed with prostate cancer back in June 21. So before we get to the radiotherapy part, my primary treatment initially was going to be surgery. So I had the prostate removed through a prostatectomy, again, through one of the other specialists at HTA.

So, yeah, so they removed the prostate and my phraseology back then, this was in September 21. When I woke up from the operation, all of the things that you've been prepared for was, okay, yep, they've got to break me to fix me, basically. It was a weird experience waking up from having the surgery. And after that, it was learned that the capsule, the prostate that had been removed, the histology report just showed that the, unfortunately, the cancer cells had gone on the outside of the capsule. But my initial blood test, my PSA blood test was fantastic, was negligible. So the PSA level in my blood was excellent. And, you know, my surgeon just said look, if the prostate comes back, sorry, if the cancer comes back, if we haven't got it all by removing your prostate, then don't worry because there are other treatments that we can do. So nine months passed with a good PSA result, which was negligible, but then nine months on, the PSA level started to rise again, which obviously indicated not all of the cancer, had gone. I was referred to my oncologist, and then it was combined with hormone therapy treatments. So hormone therapy treatment and radiotherapy treatment was to be, I think they call it salvage treatment. I think when, as I say, the most upsetting moment was when we realised that not all of the cancer cells had gone, it was on the outside of the prostate and then that's when your confidence starts to dip a bit and you kind of think, okay, we've got to have another go at this. And that's when the radiotherapy treatment was prepared and begun, as I say, in January 2021, sorry, 23. So yes, already at that point, as I say, my confidence was quite low, but I did feel that I was in good hands. You know, but it's like, okay, let's carry on this. Let's get rid of this. You know, I don't want it in me. I don't want the cancer in me anymore.

Paul (17:11)

Thank you for sharing that and you you come across so positive from going through that and just thinking about you know back about how you felt at that time, did you have any kind of initial fears or expectations and how did they kind of compare to the reality of what actually happened?

Roy (17:29)

I think, as I say, the initial fear, because we thought that the surgery would have got rid of all of the cancer, think by the cancer obviously not being completely eliminated, the fear is, I think you start to doubt things and you think, you know, is this really going to get rid of it this time? Yes, because you've had a really good surgery. We tried that. It didn't completely go. But the way I looked at it was like, OK, let's just think of it little bit of debris that was left behind. The cancer didn't quite go. We're talking microscopic. I think from the scans that I then had, didn't show anything. So I think my initial questioning was like, if it's not showing anything, but my PSA level is high, so we know something's not right. How do you know where to treat? But I think from years of experience, and the oncologists explained that very well to me, is we know it's where the prostate used to be. We know around that area and your lymph nodes is what we're going to treat as well. Just for good measure, we just want to make sure that we're going to get rid of this once and for all. And I think that's my trust in the specialists around me. At that point, I hadn't quite met you Jane, from when we spoke earlier on, just before starting the radiotherapy treatment. about three days before beginning the radiotherapy treatment, which, as you said, is 33 fractions.

I still had remnants of COVID from the Christmas before, the couple of weeks before. And my biggest fear was, believe it or not, that I wouldn't be able to start treatment because with all these things, you just want to get on with it. You don't want time to lapse where the cancer is still there and not being got rid of. I do remember calling up and saying, look, I've got COVID, quite expecting to say, well, we'll wait till that's gone and then contact us again. But it was the way I took it, was like, you're not getting out of the treatment that easy. So, and what was great to hear is like, look, and I'm sure I wasn't the first person with COVID and I wouldn't be the last person with COVID. It's like, we can deal with that. We can manage that. You know, come along to the clinic as planned. And we, you know, but we will shift your time so you can come at the end of the day so we can clean everything, can mask you up. And I think the first time I met you, we were all wearing masks because I had COVID. It was a weird experience. And then a few days later when we could take the masks off, COVID had gone. It's like, ah! That's what you look like.

Carly (20:06)

So that's what your mouth looks like. Yeah. Yeah.

Paul (20:16)

There was a big person behind the mask.

Jane (20:21)

Yeah.

Roy (20:25)

So absolutely. So yes, it was a... Yeah, you just want to get on with the treatment, as I said, you just want the cancer got rid of.

Carly (20:30)

Yeah, that's just such a great sort of example and story that really shows that having that care that's truly meeting what you needed. You were talking about the sort of fears and anxieties you've had of just wanting to be able to go through with it and then maybe the worry that it's not going to happen because you weren't very well and just then being able to meet what you needed and make the changes in order for you to make it happen. I think that's such a great example care that's just centred around you and being able to meet what you needed in that time. it's great.

Roy (21:04)

Yeah, absolutely. I think one thing I was going to add to Jane when you asked her about her job, why did she choose it? All I was going to say is because she's fantastic at it. So it's your great strength. And the whole team, actually, think I made. Yeah, everyone was brilliant.

Paul (21:21)

So just thinking about when you started the radiotherapy and perhaps, if you were talking to somebody who was about to start radiotherapy tomorrow, what would be helpful for them to know and what was helpful for you in that time?

Roy (21:38)

There were a few things. I think it was before the treatment begun was to understand all of the potential side effects. That's obviously very important with any treatment is to clearly understand what could happen. It may not happen and they may happen to a greater or lesser extent. So you don't know what might happen, but it's good to understand what possibly could happen. So I think, so that's important that you've got a good understanding of all of that or, you know, sometimes people have different treatment options. So again, you've got to weigh up all of those. I think what was also important was in terms of, I just remember my first session when I went along for the tattoos, three tattoos I had, that's my first tattoos.

Jane (22:31)

They weren't that exciting though Roy, sorry.

Roy (22:32)

No they weren't, no.

Carly (22:34)

Did it make you want to get more- are you completely covered in tattoos now from that experience?

Roy (22:36)

It hasn't, no, no. Just, they're just three little dots. I thought we could do something more of that, but I felt a rebel, you know, I've got three tattoos, there we go. So when we went along for the, you know, to be prepared with the dots and lining up with the machine, at that moment in time, my partner, you you could talk about what's important. Having a partner, my partner's been great through the whole experience with being diagnosed and going through the treatment. What was good is for him to, the more he understood, I think he could help me too. So when we went along for that session to be measured up on the machine and aligned, he was asked, would you like to come in and see the machine, you know, just to see where Roy is going to have his treatment. And that was great because it wasn't his imagination what's going on in that room. He could see it for himself. So all of that, I think, was important. And he also joined me in my sessions with the oncologist and also he met Jane and all the way through before the treatment began and during the treatment and after, he's been part of that. So think the more that he understood or more any partner or friend that anybody has going through treatment can understand. I think that helps, certainly helps the patient definitely.

Paul (23:55)

Wow, Are there any any other moments or people from that period? Because obviously you know 33 elements of treatment there. Any other people who made a difference for you?

Roy (24:09)

Very much so. think Jane certainly did. And also the other, the whole team of the radiography team, you know, was getting me on prepared and on the machine every day. Yeah, I got to know them very well. And that makes me, we use humour now and again. You've got to have a bit of humour. You've got to laugh at things. The dignity goes out the window a little bit- there was one particular moment, a couple of things, many things happened, I think it was for my treatment, we had to go through preparing your bladder and preparing your bowels every day. Okay, so let's just put that out there. So that's part of the preparation process that you have to go through.

Roy (24:58)

The bladder prep in particular, you've got to a certain amount of fluid in your bladder before the treatment, but not enough that you need to go for a pee. And there was one particular day and we have, I think you've got the ultrasound machine out to test, know, see where the level is in the bladder. And I'd overshot the runway, I got too much fluid in me. So it was the first time it happened and somebody just said- Can you go and partially empty? Having had surgery before and trying to get control of my bladder back, somebody goes going, can you go and partially empty? I just said, that's easy to say. That's really easy to say. But it's having a laugh about that, having a bit of fun about it and saying, don't worry if you can't. We'll just start again and you start the fluid coming in. But I think I did manage it.

Roy (25:53)

I did manage to partially empty. Partially empty and then stop it. It's like,

Carly (25:53)

Wow, I think that's pretty tricky for anyone.

Paul (25:56)

Yeah.

Jane (25:56)

Yes, I have to say as well Roy, you did go through one of the longest treatments that we have. Sometimes we do 37 treatments for some prostate patients as well, but you did Monday to Friday for six and a half weeks. It is a really long time. It's tedious. It's monotonous. And you were so patient with us as well. And I think, as you said, like building that relationship between yourself and the team who are looking after you is really important because it allows us to be able to look after you better. And you really did listen to the advice that we gave and you did follow that advice. And I think that that's what really did help you through the treatment as well as having, you know, your partner for support and all those things as well. And you had treatment during a tricky time too, it was Covid. was, yeah, that was that I think added an extra complexity to it as well.

Carly (26:52)

Yeah.

Roy (26:58)

Yes, that's so true. Yeah. Yeah. Build up a good relationship with all of the team.

Jane (27:03)

Yeah.

Ad

Paul (27:05)

Before we jump back into the conversation with Roy and Jane, if you're listening and thinking you'd like to deepen your understanding of radiotherapy beyond what we're discussing in this episode, don't forget that we've got lots of additional learning on the Learning Hub.

Carly (27:20)

Absolutely. This episode is a great introduction to the topic, but we know that radiotherapy is a huge area. So on the Learning Hub, you'll find a range of really practical resources.

Paul (27:30)

Things like the introduction to external beam radiotherapy e-learning course, best practice webinars.

Carly (27:37)

and an expert webinar on developments in cancer care, including what's new in radiotherapy.

Paul (27:42)

So if you're enjoying the conversation and want to explore radiotherapy in a bit more depth, head over to the Learning Hub after the episode. See the episode description for more details.

Carly (27:53)

Okay, let's get back to the conversation.

Paul (27:56)

And I was just going to ask, there were 33 points of treatment and how long did each of those sessions last, Roy?

Roy (28:06)

The actual session was probably the smallest part of the day really. They lasted, Jane, I'm sure you'll keep me true here, five, 10 minutes, 10 minutes. You're in the treatment room-ish. Yeah.

Jane (28:18)

Yeah, about that. yeah. It's often the preparation. In Roy's case, obviously, we treated his prostate. And as he was talking about, we had to do bladder preparation as well as bowel which meant that minimum that probably took about an hour before the treatment actually started. And that is the case for some patients when we're treating different areas. for example, a lot of our gynaecology patients will have a similar process.

Our bowel patients as well might have a similar process with the bladder filling. And obviously lot of the prostate patients will also do that. And in some centres, they may not do that process. It's dependent on where you're actually having that treatment. But for a lot of people, they will have to go through that. So it means that if all goes well, you might be in the department for maybe an hour and 20, hour and 30 minutes.

Jane (29:10)

If your bladder isn't filling quick enough or if your bowels are a bit full and the enema hasn't worked, then there may be a process of actually that takes a little bit longer. So I think it's just managing the education piece for patients from our aspect and also their expectation as well and just making sure that they're fully understanding of that process and why we're doing those things.

Carly (29:34)

Yeah, yeah. And I think that goes back to what you were saying, Roy, also about your partner and that being informed and understanding actually what's happening at each stage and like you said, Jane, why they're doing that and the difference that can make.

Paul (29:47)

And I think, you know, Roy, it sounds like you've had a really positive experience, you know, from, what was quite a horrible thing to start with. Is there anything that you can think of that you wish professionals perhaps had understood more about? Either your position or the information giving you along that journey that would have been helpful.

Roy (30:09)

I think personally, think the advice and everything and the support that I got around me was great. I cannot fault it at all. And I think as Jane also mentioned, for example, through the process, I also then was signposted to a dietitian, so had a dietitian helping me because that was important for the bowel preparation stuff. Then I did have a bit of psychology, you know, one-to-one counselling, which did help me. So that was more post-treatment, I think. So as I say, that was signposted to other support along the way, not just the various disciplines of the clinicians, but also Macmillan's. I used to go into the Macmillan's room pre-treatment and sometimes after the treatment there were a couple of volunteers that worked in the clinic where I was going. So having access to them was really, really helpful. A number of things. It would take my mind away from things, but equally we would talk about the cancer, just, you've got to exhaust it and

you know, keep going around things. And I remember the Macmillan team, the first day I met a particular lady called I was sitting in the waiting room, I think it was about my first or second treat, no, I wouldn't be sitting in the waiting room because I had COVID at that moment in time, it must have been about the fourth treatment session. I was sitting in the waiting room and she just came up and spoke to me , and I didn't know who she was. There was no, you know, and from that moment onwards, I was talking to her virtually every time I was in the clinic. was very, very helpful. So, as I say, there's a lot of people around me at the time, and it's tapping into that. And I wasn't aware of all of that support upfront, I think. Maybe because you don't know if you're gonna need it. So it depends how things go.

Paul (32:19)

Just kind of a bit of a side step thinking about support but kind of prior to the support, did you have any side effects of the treatment?

Roy (32:32)

Yes, it didn't come with zero impacts, unfortunately. But they're manageable, I think. And also, it's very difficult to draw a line which the side effects were from the surgery, initially, which were from the radiotherapy and obviously the hormone therapy as well had its side effect as well in different ways. So the lines blur because it has been different treatments along the way, it's not just a radiotherapy on its own. One side effect for example, I know my bowel movements have not returned to what they were before.

Roy (33:17)

It's not 100% of what it used to be like, but it's manageable. Through my oncologist, who I still see on a regular basis, we can manage it. It hasn't prevented me from living and getting on with my life, with touchwood, without the cancer.

Paul (33:36)

Yeah, brilliant. And Jane, if I can kind of maybe bring you in there, what are some of the common short and long term side effects of radiotherapy?

Jane (33:47)

So the side effects of radiotherapy are really based on where we're delivering the treatment to. Unlike chemotherapy, radiotherapy is very localised. So for Roy, you know,

having prostate treatment or prostate bed treatment, should I say, the side effects would have been primarily in his pelvis. And if you think about the structures within that, you know, the prostate sits very closely to the bladder and the bowel. And there's like, you know, muscle and sphincters and things, lot of things incorporated in that. However, if you were a breast patient and we were treating your breast, actually, depending on specifics of that treatment, actually, we would just be affecting the breast itself and very minimal to the surrounding tissues. The reason people get side effects from radiotherapy is because we often will treat an area which will incorporate healthy tissues as well as cancer cells. And then we will also treat what we call a margin around that to ensure that actually if there are any like microscopic cells within that, that we are using the radiotherapy to that area to give us that assurance that we have delivered effective treatment.

Now, the aim is that we, based on lots and lots of research and hundreds of thousands, millions of people prior to this point now, we know that we can give certain doses of radiation to different areas of the body that will allow us to effectively treat the cancer, but not damage the normal tissues enough to hopefully cause too many issues in the future for patients such as Roy.

So the aim is that actually those healthy tissues will be able to regrow and recover from the radiotherapy, whereas the cancer cells won't be able to do that. Side effects tend to come in a bit of a wave. So what we tend to see is that depending on the course of treatment, it might be within sort of two weeks roughly that patients might start to experience some side effects in the area that we're treating.

Jane (35:51)

And then they can gradually build up towards the end of the treatment and for up to two weeks after as well. And then they will start to recover. that recovery is really those healthy tissues improving and regenerating after the treatment. So side effects can range from lots of different things. One of the most common side effects that most patients regardless of where we're treating on the body, will experience is really around fatigue. And the reason that people get that is because of that cell damage and that cell regeneration. So it takes a lot of energy for our bodies to be able to manage the damage that we're doing with the radiation. It's controlled damage, so, but that energy resource that it takes from the body is quite significant. So a lot of people will feel fatigued as they go through the treatment. But then if we look more at sort of the site specific areas, as I mentioned with Roy, we treated it very deep within his pelvis. So he probably experienced, as he mentioned, actually some bowel changes. Things like going more frequently, possibly some diarrhoea, so loose stools. Some people experience bleeding in that area because of the blood vessels in the bowel, becoming a bit weaker through treatment or inflammation from the radiation. And then similarly to the bladder, if we're giving radiation and it's causing inflammation, that could also cause what we call radiation cystitis, where it feels like there's burning when you're passing

urine. You can get increase in frequency, nocturia, which is when you're waking up in the night more frequently to pass urine. And just some people do lose a little bit of control with that as well. A lot of these are, we obviously educate patients as much as we can around the side effects and they are consented by the consultant prior to treatment. And there are certain percentages in terms of risk of the side effects happening short term. So I've just kind of talked about those, what we call acute side effects, which are those short term side effects. But there is also a possibility for longer term side effects, which can happen months or even years after the treatment has finished. And that's around again, that cell regeneration and possible scarring in the area that we've treated as well, which can affect the functionality of the area that we've treated. But a lot of the techniques that we use now in radiotherapy that the radiographers use on the machines are really geared towards making it as safe as possible and trying to reduce that damage where we can.

Paul (38:26)

What kind of practical advice do you give patients around things like maybe skin care or diet or something like that during treatment?

Jane (38:37)

So similarly, if we think about perhaps a treatment that people talk a bit more about, things like surgery, there is a lot of information given about preparing yourself for surgery and making sure that you're in the best possible condition, your body is in the best possible condition as well as psychologically before you even start the treatment. And the same goes for radiotherapy. So there's a lot of work that's being done as well around prehabilitation prior to these treatments. And I think that's really important. We do see that actually if people can be fit and healthy and their best selves before they even start the treatment, actually they tend to have less side effects or they tend to have less severe side effects, should we say, and they tend to recover quicker also. So just looking after themselves. So, you know, eating regular meals, exercising regularly, staying really well hydrated, and possibly linking in with psychology if you feel that actually from a psychological perspective you need to kind of look at that aspect too, or just making sure that you have people around you to be able to support you from a psychological aspect too. So I think that that's really key and we do see that those people do tend to fare a bit better through the treatment because of that.

Skin changes are quite common as well through treatment, again, depending on where we're treating you on the body. Roy probably didn't experience much of that, no, because the dose of the radiation was quite deep in his pelvis, that meant that the radiation that was affecting the skin wasn't very much at all. Whereas if we were treating a breast patient, actually the dose of radiation is very close to the skin, which means that we can affect the skin cells too. Skin advice will vary from place to place. There's

not one product that will stop you from getting a skin reaction. There is not enough evidence to say that one product does that. But the national advice is actually that patients should moisturise with a generic moisturiser twice a day throughout treatment and for a short time after until those side effects recover. And that moisturiser shouldn't contain a chemical called SLS, which is sodium lauryl sulfate, and it shouldn't contain zinc oxide as well. So as long as that is the case, then that's fine. You know, as long as patients are using something, that is the main thing.

Carly (41:01)

Yeah.

Paul (41:02)

Yeah, thank you. And it kind of comes back to that real, personalised care and personal advice for patients as well. And I think just touching on maybe some of the longer term, because Jane, you said some of these side effects could come back at a later date. When should maybe professionals signpost back to perhaps specialists like yourself or teams like yourself, during a person's treatment?

Jane (41:30)

I think any time really, you know, as I said, we expect the acute side effects to really have settled down by maybe roughly about six to eight weeks after the treatment, but the radiation can still be working after that too. It's just knowing your patient. And I think it's if they feel that something is different or something has not improved, then that's really important to monitor that over months and making sure that actually if things haven't gone back to how they were prior to the treatment, that actually they're escalating that. And I think Roy touched on it earlier. He's very kindly mentioned that his bowels aren't back to their normal routine. And that would have been, you know, an effect, a late effect of the radiation treatment that he's had. So it may well be that, yes, it's manageable, but, you know, maybe now he's going three times a day instead of once of what he normally do, you that kind of thing. And these things do happen following this type of treatment. There are in some areas in the UK, there are what we call late effects clinics, which are clinics that patients can be referred to to manage some of these late effects from cancer treatments. And they're often led by a multidisciplinary team.

Jane (42:45)

And we've seen some really good outcomes from patients who are referred to those, but that's not available to everybody. So it's more about the patient being able to tell us how they're feeling and for us to be able to react to that and refer them on to the appropriate person. And that might not be someone like me, that may well be a gastroenterologist, it might be a dietitian, you know, and I think that that's important to be able to, for healthcare professionals to be able to recognise that, and then escalate to the appropriate person.

Roy (43:16)

Yeah, I think, and you know, my bladder control hasn't exactly come back to where it was. And as I say, it isn't just down to radiotherapy, it could be down to the surgery as well. But there are products, you know, wearing a pad now and again, and most of that's for confidence. think, you know, my bladder control, I would say is probably 99.5 % back to where it was but doing my pelvic floor exercises is quite key. I do, I I try to and yeah but hey I wear a pad and now and again certainly when I go out in a social environment it's just for my confidence and yeah.

Jane (43:47)

Good.

Carly (43:49)

I saw Jane's face super happy about that, knowing that. Yeah. Yeah.

Jane (43:51)

Yes! I told you Roy has followed our advice which is good.

Paul (43:53)

Yeah. Yeah.

Carly (44:06)

Yeah, yeah, it was really interesting to hear the different side effects and actually, like you said, depending on where the treatment is, the side effects might be different. And just before we move on away from side effects, I wanted to touch on what you said around skin side effects and some of the things that you can do. And I wanted to sign

post that we actually recorded an episode that was released maybe it was about a year ago now, and it was specifically around skin side effects of treatment. So yeah, if anyone wanted to hear more kind of in depth about that specific side effects on skin, yeah, do listen listen back to that one, to kind of go into that.

Jane (44:53)

Just on that as well, Carly, sorry, just to mention, I don't know if this research would have been out when that episode came out, but there has been a bit more research into assessing patients' skin and skin tones as well. So a lot of the assessment tools actually will be based on kind of white Caucasian skin, whereas now actually they're looking at how do you assess someone with darker skin or black skin or brown skin and actually how those side effects look quite different. So that's quite interesting. And I'm sure that probably over the coming years, they might find that actually different products work slightly differently for different types of skin. So that will be quite interesting to see when as that kind of research develops as well over the years.

Carly (45:29)

Yeah, yeah, that sounds great. Thank you for adding that on, Jane. I wanted to touch a little bit on, so one of the main focuses that we like to talk about and make sure we include in these podcasts episodes is really helping healthcare professionals not only to raise their awareness and understanding and knowledge about certain topics like radiotherapy, but also thinking about things that healthcare professionals can practically take away and actually do and integrate into their own practice day to day. So I wanted to touch on that, thinking specifically about what healthcare professionals can take away, some of the things we were thinking about were things around how can a healthcare professional explain radiotherapy to patients in a way that makes sense or perhaps helpful questions that you liked being asked to maybe check in. Is there anything on that side from your perspective, Roy, that you would want healthcare professionals to take from that, thinking about your own experience and what was helpful and perhaps not as much?

Roy (46:40)

I think as I said, lot of the information and the way things are explained to me is very much listening to Jane just a moment ago, you know, the way the radiotherapy works, you know, it affects good cells and bad cells, but the cancer cells can't repair themselves. That information was told to me at the time and explained to me at the time. And I think that's so very important to understand. I just remember, you know, every session I had when I'm laying there having the treatment when the machine is moving around me, that there's a psychological element of me saying, get rid of those

cancer cells, kill them off, get rid of them. And I'm just thinking every moment that machine is moving, I'd like to my take away that it was doing a great thing, right? And I think that's so that explanation, very simple explanation, did help me perfectly. I think in terms of other takeaways, think I did mention it. I think two things. One is- look at radiotherapy. It could be in the round of treatment. It's not just maybe radiotherapy on its own. It could be other treatments that you're going through. So for me, as I say, it was combined with hormone therapy treatment at the time. I'm still recovering from the surgery, but the hormone treatment, wow, that's a there's a big impact on itself. And I do remember Jane, as you might remember, I did have a blood test along the way, which showed some negative indicators on my liver function. And that came from the GP surgery. I got a phone call saying, no, your blood tests have come back. You've got a problem with your liver. And I'm thinking, wow, I don't need this at the moment.

Roy (48:29)

So, the first thing I did was virtually pick up the phone and spoke to Jane and you know I just wanted to get into the clinic that day and it's like we can do some blood tests, let's come on, you're on your way up for your radiotherapy treatment, let's take it, let's take a look at it, let's go from there and lo and behold everything is fine but it could have been a combination of hormone therapy.

Roy (48:55)

Maybe the COVID, who knows, we're not exactly sure what was going on, but everything's fine today. But at that moment in time, it's a panic. It's like, whoa, I don't need anything else. So as I say, it could be to look at it in the round of all the treatment that's going on. It's not just radiotherapy on its own. And the only other one takeaway is buy some hand warmers for some people.

Jane (49:23)

The rooms are cold.

Roy (49:23)

The rooms are cold, that's fine. No, no. At the end of the whole thing, I was going to buy some hand warmers. And we've to take this, it was really funny because you're moved into position and sometimes they have to move you a little bit and shift you a little bit. Wow. And some people have some really cold hands.

Carly (49:49)

For them to wear, I thought that makes sense. Yeah. Yeah.

Roy (49:49)

Yes, for the clinical staff to wear. yeah, and I'm not mentioning any names, but I did at the time. I said, you need some hand warmers. But it was just funny. I was going to give an award for the coldest hands. You've got the coldest hands.

Jane (50:06)

Sure that's not helpful especially if you need a wee as well, you know, lying on the bed.

Roy (50:08)

That's so true. It shocks. It's like, wow.

Paul (50:17)

And again, that's probably something that maybe people don't think about. So again, that's a really great piece of advice. And thank you for sharing that.

Roy (50:24)

Yeah. But in the round of everything, it made me smile.

Paul (50:32)

Yeah, and we definitely need those smiling moments, I'm sure. We're kind of coming towards the end of the episode and we have our usual feature where we ask our guests three questions to just help bring the episode to a close. So I'll start with you, Jane. If you could go back in time to the start of your career, what piece of advice would you perhaps give yourself?

Jane (50:56)

I think not to think too far ahead. I think healthcare is constantly developing and moving. And I think over my career, it's changed exponentially, not only just in oncology care, but in healthcare in general. And I think because of that, there have been so many

opportunities and doors that have been opened that I wouldn't have even been able to think about you know 13, 14 years ago when I first started my career. I think that I would just try and go for every opportunity that came to me at the time and really just try and enjoy it in the moment.

Paul (51:23)

Thank you. And Roy, if you could go back in time to when you were first diagnosed, what advice would you know, what advice or what would you tell yourself?

Roy (51:44)

I think it'd be along the lines that everything's gonna be okay. Tapping to the resources that are around you. There's a lot of resource.

Paul (51:57)

Lovely, thank you. And Jane, back to you. What change would you like to see to improve the lives of people living with cancer?

Jane (52:05)

I think I would just love to see people talking about it more. You know, today we're talking about radiotherapy and a huge proportion of cancer patients receive radiotherapy, but they often come to us quite anxious and scared because they don't know much about it. We talk a lot about chemotherapy and we always have for a long time and surgery and a lot of people are kind of, yes, it's still, that's still scary treatments, but actually they understand them better. And so I'd just love for people to just talk about it more, tell your, you know, talk about it with your friends. I've had a lot of people, a of patients who've come through treatment who have said once they've got their diagnosis and started their treatment, they've said, actually, I spoke about it with all my friends on the golf course. And now they're all getting their prostates checked. know, actually, that's really powerful. Even if just even if none of them have prostate cancer, at least they're talking about it. it's, and it's

Carly (52:49)

Mmm.

Paul (52:50)

Yeah.

Carly (52:52)

Yeah.

Jane (52:57)

really raising awareness.

Paul (52:58)

Thank you, Jane. And Roy, what change would you like to see for people living with cancer after your own experiences?

Roy (53:08)

I think, it's maybe slightly before, I think personally I wish there was a screening program for prostate, okay, for prostate cancer. I really do, but I know there isn't. But my advice is really for men, especially men, are notoriously poor sometimes, is to go and get their blood tested, okay, especially I would say, I'm not going to put an age limit on it, the information is out there, but it's really if you think you've got a problem go and get tested and even if you haven't got a problem your certain age go and get tested because early diagnosis is key.

Paul (53:48)

Yeah, absolutely. you know, as I say, that's why we're talking, talking about some of these things today. And finally, I mean, you've both shared so much with us today. If there's one message you'd like our listeners to take away about radiotherapy from the episode, what would it be?

Jane (54:05)

I'd just like people just to know your patient. As Roy said, there's so many other factors around when you have treatment or, you know, other things going on. If you've had hormone treatment, surgery, chemo, all these things make a difference to how you as in that patient as an individual will be affected by the treatment that is then being delivered. So just to know your patients.

Paul (54:27)

Thank you and Roy, what message would you like our listeners to take away from the episode?

Roy (54:33)

Yeah, it's very simple, you said to keep it short. It works. The radiotherapy works and here I am and my PSA result is great today. So, you know, it works.

Paul (54:46)

Great, thank you very much, thank you.

Carly (54:47)

Yeah, thank you. Thank you. And that that theme really came through for me when talking to you both about how important that is to really reach out and to have those people around you during that time. And that really spoke to me so much through this conversation. But I would like to say thank you so, so much, Jane and Roy. It's been an absolute joy to have you both talking about this topic and thank you, Jane, for really sharing your expertise and talking about your experiences and really helping our listeners to understand more about radiotherapy. And then of course, Roy, thank you for sharing such personal experiences and thank you for everything that you shared. It's been an absolute pleasure for you to both be here. So thank you for being on the Cancer Professionals podcast.

Jane (55:40)

Thank you for having us.

Roy (55:40)

You're welcome. Thank you.

Outro music

Carly (55:43)

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Paul (56:02)

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by two guests. Claire Adshead, Project Manager for the Macmillan Deaf Cancer Support Project, which provides much needed emotional and practical support to deaf people living with cancer across the UK. And Gillian, who shares her experiences of being diagnosed with cancer as a deaf person.

Carly (56:27)

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Paul (56:38)

I'm Paul.

Carly (56:39)

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