## Transcript

## Immunotherapy and its late effects

Intro music

**Paul (00:10)**

What does a new normal really feel like for someone who remembers who they used to be before treatment?

**Charlotte (00:16)**

You go through a grieving process, I think, because before all of this, I was a really healthy 40-year-old who rarely went to the GP, didn't have any conditions. I had a lot of energy. I've never been a sporty type, but I've always been a very active person, and not any real conditions. And so I think I grieved for that person, and I still do sometimes.

**Emma (00:41)**

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

**Paul (00:45)**

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. This episode is in collaboration with UKONS, the UK Oncology Nursing Society.

**Emma (01:07)**

If you enjoy this episode, please subscribe, rate and share with your colleagues and friends. We'd also love to hear from you. Please get in touch to ask questions, give feedback or even to suggest topics you'd like us to cover by emailing professionalspodcast@macmillan.org.uk or by filling in our short survey linked in the episode description.

**Paul (01:27)**

Before we get into the conversation, just a quick note- If immunotherapy is new to you, you'd like a refresher on what it is and how it works, we released an episode back in 2024 that gives a really clear introduction titled 'Understanding immunotherapy: What it is and how it feels'. If you haven't listened to that one yet, you might want to head back and start there, then come back to this episode where we focus more on the late effects of immunotherapy.

**Emma (01:58)**

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

**Emma (02:07)**

Today we're going to be talking about immunotherapy and more specifically about the late effects that can shape life after treatment. We're joined by two amazing guests, Charlotte Killeya, who has experience of receiving immunotherapy and Dr. Jo Bird to unpack and explore what late effects are, when they can occur, how to recognize these and practical advice about how services can support people experiencing the late effects of immunotherapy. Jo and Charlotte, welcome to the Cancer Professionals podcast. Shall we start with some introductions?

**Charlotte (02:39)**

Hello, I'm Charlotte. I am, I always want to say my age because I think I get asked for it quite a lot at hospital. So I'm like, I'm 46. I've got a son, a teenage son. I enjoy lots of things. I love walking my dog when I'm able to. I love gardening. I love reading and writing. And I've also got stage four melanoma, which is why I received immunotherapy.

**Emma (03:03)**

Thank you Charlotte. And Jo.

**Jo (03:05)**

Hi, I'm Jo Bird. I work at Sheffield Teaching Hospitals as a consultant nurse in melanoma and immunotherapy late effects. I'm also a senior lecturer at the University of Sheffield.

**Emma (03:18)**

Thank you both. It's lovely to have you join us. So Jo, I wonder if we could come to you first to explore what do we mean by late effects in the context of immunotherapy and what can the experience of this mean for people who do receive immunotherapy?

**Jo (03:34)**

So late effects of cancer and cancer treatment more generally, the definitions can vary, but it mostly means any effect that doesn't go away after the end of cancer treatment or can occur after the end of cancer treatment. When we're talking more about chemotherapy and radiotherapy, that can include things like second cancers. And there are more broad definitions include things like the psychosocial effects of treatment, effects on people's working lives, social lives, and things like that as well. Because we know that cancer treatment doesn't just affect the individual, it's the whole family as well. So there's a wider effect. With immunotherapy specifically, it's slightly different to other types of cancer treatment. And that's because immunotherapy has an effect on the immune system, which then attacks cancer cells, rather than having a direct effect on the cancer as a lot of other treatments do. So because we're actually affecting the immune system or in effect taking the brakes off it, it means that those effects can go on even after the end of the treatment. And when we look at the literature, those effects can go on for, couple of years. I'd say I've recently seen someone who's potentially had a late effect nearly five years after the end of treatment. There's more and more reports of these things, but we're using the term late effects today, but there are other terms in the literature as well. Things like delayed toxicity, delayed side effects, late onset, late occurring effects. There's lots more wider terms that are used, but essentially mean the same thing. So we're talking about anything that's affecting someone after the end of cancer treatment.

**Emma (05:25)**

Charlotte, you mentioned earlier about your diagnosis, and I wonder whether you'd be able to share a little bit more about your diagnosis and treatment and your experience of living with the late effects of immunotherapy.

**Charlotte (05:36)**

Yeah, so I was diagnosed in 2020. So I had an existing mole which went very strange on my arm. It had all the symptoms to look out for for melanoma. And it was during COVID, but actually I got treated very quickly during COVID and had all the biopsies that you have with melanoma. gets cut out straight away. And then, because it was at a certain stage, it was stage two and quite a deep melanoma, I had a lymph node taken out from under my armpit and, melanoma, there were some small deposits in there. So I had a year of targeted treatment, so not immunotherapy. It was taking tablets every day and I

had that for 12 months. Came off that, I did have some side effects of that, but actually then I had 10 months of really feeling quite a bit better, working on my health and all those sorts of things. And then melanoma, came back into my, into both lungs, small little nodules in each lung. I was going to have surgery to cut one of them out, but whilst I was waiting for that surgery to happen, melanoma managed to get into one of the lymph nodes in my neck. So that's when I started immunotherapy and I started that in February, 2022. I've got all my dates here, cause you start losing the dates to be honest. I've had this for five years though, but I started in February 2022 and so I had two years of immunotherapy and I finished that this year. I had some side effects during treatment and then I've been left with some of them. There were quite a few. During treatment it was colitis which I think out of them all it was the most intense one and I'm not actually left with colitis. I'm a bit careful about what I eat but I think that was the most intense and probably the one that traumatised me the most. I had some arthritis. So at times when kind of wobbling into the see Jo, not really able to walk properly. So I'm on treatment for that now. I take a treatment for arthritis every week, and diabetes- my pancreas has stopped working. So I am now treated as a type one diabetic. That's been, I think, the hardest thing actually day to day to cope with, life changing really. And I think the longer that I have this the more I understand, you know, diabetes type one is a condition that takes a lot of management. And then I think like Jo mentioned, the late effects, mental health always impacts us and just encases everything, it goes through and weaves its way through everything.

And I think that's a really important one to recognise, not just to focus on the physical but actually how that interacts with the mental and physical, just go hand in hand together. So yeah, I'm left with that and then unfortunately my cancer has returned. So I have had a few months where I finished immunotherapy but my cancer has returned, multiple little lung mets. So I'll be going back on targeted therapy this week.

**Emma (08:49)**

Thank being so open, Charlotte, and sharing everything that you've been through. It's, like you said, it's not just the adjustment to the physical effects of a treatment, but that emotional and the psychological impact that going through a diagnosis and treatment can have. So thank you for being so honest. If I might ask Charlotte, in terms of your treatment and immunotherapy, those late effects that you've mentioned, so you talked about diabetes and having experienced colitis, are those side effects as you kind of had expected or has the reality of being through treatment and those late effects, has that been different to what you might have expected?

**Charlotte (09:28)**

I didn't expect to go through immunotherapy without any side effects at all. I thought there would be some. And when I had the list, you know, the list that you go through

when you start, they did say diarrhoea. And that was the one that really scared me out of them all. That was the thing. And I thought, I really hope I don't get that. And whoa, I really did. I really, really did get diarrhoea. So when I got that, I thought, yeah, that was kind of what I was really scared about and it happened. I didn't expect diabetes. I think because I'm in so many patient groups, I've kind of got a sense really that there might be some side effects on what they were and how common they were. So I know like colitis is quite a common one and I know joint pain, that's quite common. But diabetes, I don't really think I expected.

And I think initially we thought it might be because of the steroids. But no, that was the one I think that has shocked me to be honest. Yeah, you just, you don't have a choice. You just dive in and see what happens and hope for the best really, you know, that list of side effects. I think if you focus on it too much, it gets quite frightening. So I think you just dive in and think, and I really trust the team at the hospital I'm at. So I think, you know, if I let them know what's happening, then it'll get sorted, you know, so I think that's a lesson I've really learnt, tell them sooner rather than later.

**Emma (10:53)**

I think that's such valuable advice, Charlotte, to have that open and honest communication and dialogue with the hospital team. And Joe, in terms of the effects that people experience, what kind of context do you see in the clinics that you run where people are experiencing the impact of treatment?

**Jo (11:11)**

So the first time that I see someone in the late effects clinic, I'll normally do a summary of all the treatment they've had, look at the side effects that they've had so far, because quite often the side effects that they've had in the acute setting on treatment, they have the potential to come back in the future. So I want to be aware of that. And then we do a top to toe assessment, full systems review, start at the top and ask about their eyesight and have they been to the optician, all the, you know, and just work through everybody's system. So it takes about 40 minutes on average. Sometimes it takes longer. And that- just putting everything together and looking at the person as a whole can be really useful. But quite often, that consultation comes at the end of treatment. So usually when someone's sort of, they've had their cancer diagnosis or they've been diagnosed with a recurrence and then they've gone into treatment and it- once you're in treatment, it's very much one cycle and then the next and the next. And you go from one treatment to the next until eventually it comes to an end. And then it's sort of, okay, what now? And there's almost a sense of abandonment because everyone's used to such close monitoring and everyone being around, it's like, okay, you're finished now. Let us know if there's any problems, but we'll see you in say three months with your next

scan result. So it's just making sure that people have the opportunity to really take stock.

And that's quite often a therapeutic conversation to be able to go through those things, let people know that quite often what they're feeling is normal, that that's okay, and that there will be a recovery period and to allow some time. And I'd say in the, we've been running a late effects clinic in Sheffield for just under five years now. And I'd say it takes about two years to recover from immunotherapy. I mean, some people do it more quickly. Some people are absolutely fine after the end of immunotherapy, but I'd say for most people, even when they've got complex side effects, I allow about a two year period to find out what that kind of new normal is. lot of that, as I say, the psychosocial assessment, as well as all those physical effects, and then going through those common kind of, you know, looking at the most common side effects that people experience. It's quite often the things that have been rumbling along for a little while, things like skin reactions, they can just sort of flare every now and again. The side effects at the end of treatment don't always stay the same. And that's the thing to bear in mind. They can be controlled for a little while and then something may happen that just causes it to get worse for a little while that may or may not need treatment depending on how severe it is. But at least letting people know that they can expect these things can help them be prepared. And the fact that you can get completely new side effects after the end of treatment. So any new side effects where people just aren't feeling quite right, things aren't going away, you know, is it sort of new tiredness that's happened. Is it new headaches that aren't going away or any other new symptom that's not going away? We really need to know about it just in case. And if it is a brand new, quite severe side effect, we may treat that very similarly to how we treat an acute side effect.

And I guess some of the complexities come with people say in Charlotte's case, where they go on to treat- to another line of treatment. And that's not just with melanoma. We see it with lots of other cancers. Quite often it's the patients with kidney cancer that I'm seeing where we're treating the side effects of the immunotherapy that they had first. And then they're moving on to a more targeted therapy, but we're still looking after those immunotherapy side effects.

**Paul (14:58)**

Just expanding on Charlotte's experiences, and we've talked about some of the late effects. What late effects do you kind of see most commonly after some immunotherapy treatment?

**Jo (15:12)**

Okay, so I have actually got a top 10 that we gathered in our clinic. And that's been reflected in some other studies that have been done since. So the main side effects, the

physical side effects that we see are skin reactions, fatigue, arthralgia, and then breathlessness, diarrhoea, dry mouth and dry eyes. But then things that also feature quite highly on lists of concerns for patients are issues around sexual function, anxiety, low mood and financial concerns.

So if we're looking at the available information from, say, clinical studies, they most often focus on the side effect, the physical side effects of treatment. But there's also all of those other things that are important to patients as well. And it's very- we don't have very robust information on the most common side effects following immunotherapy treatment, just because the clinical trials aren't built to collect that information. Occasionally we do get long-term data follow-up and that's quite often voluntary, not always built into clinical trials because it's about getting the drugs to market, which we're all quite glad they are there because working and we need them. But they're not necessarily designed for that really long-term data capture. So we're more often seeing those things clinically than from clinical trials.

But so yeah, things like the diarrhoea skin reactions, they're quite often things that have happened acutely and then will flare. And over time, you find that they're not as severe each time they occur, and it's longer between each occurrence. So things do improve over time. It may be that we need to involve the specialities. So with, say, arthritis, we may involve rheumatology and get their opinion just to make sure there's nothing else that can be done. Often we use the terms arthralgia and arthritis interchangeably. It's around swelling of the joints caused by the immunotherapy treatment. So, you can get swelling of the joints without the definite diagnosis of arthritis.

**Jo (17:28)**

In late effects, we don't treat anything in isolation. We do it with specialists because we also have to bear in mind that it could be completely coincidental. We have to make sure that we're ruling out any other causes. So we work quite closely with lots of other specialities, whether it's cardiology, endocrinology, rheumatology, pretty much add an –ology onto the end of it and we'll work with them.

**Paul (17:55)**

Just expanding a little bit more on that. Why is early recognition really important?

**Jo (18:03)**

I guess the most important thing is that- because of the vague nature of immunotherapy late effects, they aren't necessarily presenting in a very obvious way. It can be tiredness or new headaches, just not quite feeling right sometimes. But that can mean people, say, going to their GPs repeatedly, feeling like they're not getting anywhere, or they

may mention it to other specialists. It could be confused with side effects of medication or sometimes for anyone who's had cancer treatment there may be this expectation that you should feel a bit tired or you should be feeling unwell but actually that can be an indication of something else that's wrong that maybe we can do something about. So it's just I think being aware that just because the treatment stopped doesn't mean that the effects have stopped.

And if other causes have been ruled out, then maybe it is the immunotherapy. It can be quite difficult to distinguish between the effects of immunotherapy and the effects of other conditions that someone may have, or if they're on other treatments, again, the effects of those other treatments. It's not always straightforward. But just having that in the back of your mind can sometimes help people think, is there another cause for this? Do we need to just have a chat to someone else to maybe get the best outcome?

**Paul (19:27)**

So I suppose just a flag really, you know, if a clinician hears from a patient, you know, those words, I completed immunotherapy six months ago, they need to maybe kind of listen to some of what you're saying.

**Jo (19:41)**

Yes, definitely a red flag. So on our alert cards now, we do say side effects of immunotherapy can happen six months or more after the end of treatment, just so that other clinicians are aware that it may be related to the immunotherapy. It's very hard to be specific, so we say six months or more and we do allow people to access our helplines still after the end of treatment, particularly for immunotherapy. And for people working in acute oncology, I think they're becoming more aware now that these immunotherapy effects can happen quite a while after the end of treatment. So its- the effects are slowly becoming recognised more widely, and certainly for anyone who's dealing more regularly with anyone who's had cancer treatment.

**Ad**

**Paul (20:33)**

Just to pause the conversation for a moment, if you're finding this discussion on the late effects of immunotherapy interesting, there's plenty more you can explore.

**Emma (20:43)**

Yeah, this has been a really thought-provoking topic. And if you want to go deeper, the Learning Hub has a range of resources on immunotherapy, as well as other cancer treatments.

**Paul (20:51)**

It's a great place to build on what we're talking about here or to refresh your knowledge alongside your practice. For example, we'd recommend the popular Introduction to Cancer and its Treatments eLearning as a great accessible resource.

**Emma (21:05)**

Head over to the Learning Hub after the episode. You'll find the links in the episode description. Everything's free and easy to access.

**Paul (21:13)**

Okay, let's get back to the discussion.

**Paul (21:16)**

And Charlotte, can I just, just coming back to you- when treatment ended for you, what did you expect kind of life to look like? Because you've obviously told us a little bit about what happened to you, but what was the expectation and what actually happened?

**Charlotte (21:33)**

So when I finished targeted treatment the year later, I kind of expected back then, so we're going back a few years, but I expected my recovery to be linear and going upwards like that. And I expected that. And I remember speaking to one of the oncologists who said, no, recovery from targeted treatment is not, it's up and it's down. And so I knew with immunotherapy that it was going to take a while to recover. And then I had, I think we had an extra long appointment with Jo. think I was there, I took my mum with me. I think we were in with Jo for longer than about an hour. And she was like- it's about getting back to the new normal. And you go through a grieving process, I think, because before all of this, I was a really healthy 40-year-old who rarely went to the GP, didn't have any conditions. I had a lot of energy. I've never been a sporty type, but I've always been a very active person, and not any real conditions apart from the odd thing I needed to go to the gym, but nothing. And so I think I grieved for that person and I still do sometimes.

I think if life hadn't been as it was, I compare myself to my friends who've not gone through cancer treatment, who are in their mid-forties, really healthy, you know, and all of this. then I'm, I've got chronic conditions now and also going back on cancer treatment. So I don't think I expected life to get back to any way that it was before. And that made me, know, it was, it is emotional. I do get angry about that. I do grieve for that person, you know, because I think what life would have been and I do want to be more active and, you know, but I think I never thought I'd be able to get, to go back to that. And you just got to learn to accept things and live with things. And that's really hard. And the interactions of things that are in play.

I never understood that about chronic conditions. I never understood what it meant to have diabetes, really. I never got that. You know, when I'd hear about people with type one and how when they got, you know, when they were ill, when they got cold, how it affected them, how a simple virus like cold can really affect your blood sugars when you're type one. I never understood that. I never understood drug interactions because I had no experience of them. I had no experience of anyone having cancer in my family and so yeah, I think it's just that complexity that you deal with, you know, but yeah, think Jo was really, it was really good to actually somebody to say- it's going to take time to recover because that's all right. Cause a lot of people who haven't got experience of cancer think that once treatment's finished, it's a time where it's like celebration and it sometimes feels that way.

But actually, just, that's the time of quite deep reflection, actually, and tiredness when you feel like you've finished a marathon. Because immunotherapy is a marathon. It's not a sprint, it's a marathon. And as I say, I think that people will be saying, well done and celebrate. And I didn't really, I'm not sure I really felt that way, to be honest. So it was good to talk to Jo about that.

**Paul (24:41)**

And you said, you said kind of you gained a lot of knowledge by the time kind of you had worked through some of the treatment. And just thinking back from that experience, were there any particular kind of pieces of advice or strategies that the healthcare professionals had given that kind of stuck in your mind?

**Charlotte (25:02)**

I think- Charlotte, just phone up early and tell us. I remember once I'd got some joint pain and I was like, everybody gets joint pain. You know, I'd been in my support groups, everybody got, you know, painful knees and I was like, that's just part and parcel of it, you know, and I'd got my immunotherapy treatment coming up. So obviously before immunotherapy, you have a clinical appointment and I was in the waiting room and one of the lovely nurses came through and said, right Charlotte, we're ready for you to have

your appointment now. And I couldn't get off the chair, and he basically had to like almost lift me off the chair. And I was like holding onto him, wobbling down the corridor. And he was like, Charlotte, I don't think you'll be having treatment today. Sit in this room for a minute, love. And I'm going to go and get Jo. I just remember Jo came in saying, Charlotte, you're not having treatment today. Those knees aren't good. You're going to need some steroids. And I think if I'd have just kind of maybe phoned up a bit earlier or understood that this wasn't normal and like the same with diarrhoea, I was popping loperamide like nobody's business thinking, oh, everybody on cancer treatments get diarrhoea. Well, not 15 times a day, actually, do you know? Not that extent. And I remember when the colitis got really bad and the, one of the junior doctors came in and said- Charlotte, it is not normal to crap in the car. That is not normal. That shouldn't be happening on cancer treatment. I thought that was because I'd been given loperamide. So I thought, well, you know, so it's understanding when to call in and earlier is the better. And now I'm starting new treatment this week. Yeah. Anything I'll phone up, but you don't always want to be, you don't always want to be a pain ringing up. I think you have to get past that point, you know, for thinking- it's okay just to phone up, that's fine and that's what's better to do. But I think sometimes as a patient you think, I'll just wait a bit. I don't want to be phoning up over it. I don't want to be one of those patients that's constantly phoning up. And I think you have to get over that. Just say. And the earlier that it's dealt with, the better. So by the time the second round of colitis came along, I was much quicker. I phoned up and I was on something called infliximab, which I was on it quicker and the colitis never returned. So I've learned, hopefully, my lessons on that to just go early.

**Emma (27:32)**

I think that's such an important point to make Charlotte that side effects can be expected, but it's knowing actually when it's reached that point that it's not the expected and actually there is support and that's when you need to be reaching out. And I wondered Charlotte, if I could go back slightly and you mentioned a new normal and I think that really shows how impactful treatment can be and how different life can be after treatment and after diagnosis because everything changes. And I wondered what support you found helpful during that time of adjustment?

**Charlotte (28:07)**

I'm really lucky, I am really lucky and I'm not just saying this because Jo is here but we are really lucky in Sheffield that we've got the support we've got, we've got a really fantastic team and it's when you meet other patients across the country I go wow in Sheffield I feel really well looked after and even times when I've not been on treatment I learnt that you do feel like you have that comfort blanket wrapped tightly around you but actually that comfort blanket never goes it just gets a little bit not as tight so you

can go and live your life off treatment and that's how I see it, that at times it's really closely wrapped by and then it's just let go a little bit but they're always there and your scans happen and all those things. But I've got a lot of support from my family and I think they've had to learn as well a lot about immunotherapy and what to look out for and they they they're on this they're on this kind of path with me but also other patients I get so much and not just not just patients on immunotherapy, but I think other patients help you understand, they're truly the ones who understand what life's like. And I get a huge amount of support from other patients and I hope I support them. And again, you don't give each other clinical advice, you know, but when somebody might say, oh, I'm just starting with diarrhoea, I'll be the one that goes- phone it in. You know, and I think now I feel like I'm one of the old school types. I'm like, just phone it in, you know, and don't be scared to. But I think people who have lived experience of cancer, there's always just a shortcut and you understand one another. And I don't think I'd have got this far without that community. Have counselling, I have a counsellor. And I also take antidepressants because that for me with that mental health, I felt like I'd got all this incredible support, but there was still something not there. There was still something that I needed and I'd had mental health, I'd had anxiety before and I just knew again, it was time to reach out and say, look, I need some extra support here. The GP, there are issues between primary and secondary care, but it was my GP that I went to about going on antidepressants and that did just, it just does help me because people sometimes say, how can I be so positive? But actually I say, I get an awful lot of help and I do have antidepressants which sometimes take the edge off because there are really dark times and I need support and I think it's fine to say that and I think that's why it's so important that the interactions of the physical and the mental are understood. If you can't walk properly, it's going to affect your mental health. Diabetes really has affected, do you know, really, really is having an impact at the minute. And they go together. They just go together. I don't think you can separate them out always. But yeah, I am lucky. I've got some incredible support.

**Paul (31:05)**

And it's brilliant, Charlotte, to hear you being so positive despite everything that you've kind of been through. And Jo, can I just maybe pick up on what Charlotte said about some of those challenges between primary and secondary care? Because immunotherapy is a fast-paced, advancing treatment, isn't it? So it's- there's always something new to learn.

**Jo (31:30)**

Yeah, it's, I mean, for other specialities or for primary care, immunotherapy is not a widely known area. And that's because it's still quite new. And for your average GP, they may only see two or three patients a year on immunotherapy, whereas for someone like

myself in a specialist cancer centre, it's every day. This is the bread and butter of what I do. So that differing experience, you know, we, in specialist centres, we're starting to see enough patients where even some of the stranger side effects, we're starting to see clusters and, you know, once something's happened to one person, we can recognise that when someone else tries to tell us a similar thing. Whereas if it's something very unusual that you've never come across before, or you just wouldn't necessarily know to associate it with cancer treatment, then it can be very difficult. And I think the expectations of patients around immunotherapy can be different. When we're counselling patients on starting treatment, I do let people know that it's not the same as traditional chemotherapy. It's not about your hair falling out or feeling sick and that you don't need to be living with side effects. We want you to report them. And hopefully, if we get better at reporting side effects early and managing them earlier, then maybe we can prevent some of the late effects because we've got things earlier. I don't think that's going to be the case for all. But hopefully as we evolve our management, we can improve things as well. But that management years after treatment does blur into primary care. And sometimes GPs do wonder what we're doing with patients and why we're asking for certain medications on repeat prescriptions and things, which can be difficult. Some of the things that can be more difficult for patients going forward are things like, as Charlotte said, managing diabetes then for the rest of your life. But there's also things like hypothyroidism. People may then need to take tablets every day for the rest of their life that they may not have had to have before. And then that's something that GPs manage from there on.

And adrenal insufficiency. People who then may need an adrenaline injection for emergencies if they can't manage to take their oral hydrocortisone tablets and then having to manage that and people tell me about having various members of their families trained up to be able to give the injection in an emergency and that's a change for the whole family, that sort of effect. And then patients, you know, concentrating so much on the cancer treatment that they don't necessarily recognise that some of these things will carry on. So people may say, do I still need to take these tablets? Well, yes, you do, because they're for your thyroid and that's not going to change now. That's an effect for life. Or I did have one patient tell me that she'd run out of those white tablets and did she need any more? And I said, yes, you do. And you need a prescription today because that's your hydrocortisone and it's really important. And getting people to understand the importance of some of those effects going forward. if you're unwell, you do have to then change your steroid doses. It can be really quite complex managing those things. Charlotte actually drew a fantastic diagram of all of the things that were affecting her at the end of treatment. And I use that image in teaching now just to show all of the differing moving parts that people are dealing with at the end of cancer treatment.

You know, whether it's- and it was a diagram of all of the different specialities that Charlotte was involved with at the time. So there was endocrinology, there was

rheumatology, there's the diabetic team. I think there may have been more. The GP as well.

**Charlotte (35:12)**

GP. I think I'd put like this big anxiety fatigue all around it didn't I Jo? Yeah. I use that diagram, I took it to the GP not long ago and had a conversation because like Jo said they don't always understand immunotherapy, you don't want to come across it you know I'm so clever patient I know this but but I need to explain and obviously going back on treatment like just I'm left with I'm going back onto cancer treatment while still dealing with the late effects of immunotherapy. And trying to explain that to other specialities. And so having the late effect clinic in Sheffield, it's that centre of gravity because you do get quite tired of repeating your story to different specialities, you know, to go through the whole story again. And it seems to get more complex each time. So I think a centre of gravity where people know you as a patient and know your story is incredibly important. Yeah, it's one of the most important things.

**Paul (36:07)**

And as we've heard, you know, it can be kind of incredibly complex managing all these different aspects of the treatments. And I wonder, Jo, just kind of thinking of all the things you talked about, what's kind of next on the horizon for immunotherapy? Is there anything, anything new coming or any, anything you want to kind of tell us about?

**Jo (36:29)**

There's quite a lot coming with regards to immunotherapy. So we have different targets with immunotherapy, different parts of the immune system that we're targeting. And there are many more drugs in development and combinations as well now. So we don't just give immunotherapy on its own. We're giving immunotherapy in combination with chemotherapy. We may give immunotherapy in combination with chemotherapy before surgery to shrink the primary tumour and make surgery easier and then give more after surgery just to prevent it coming back. And there may be radiotherapy in that mix as well. So we're giving it across more and more tumour types, although less so for the hormone dependent cancers. But certainly with the combinations of targeted therapies, immunotherapies, chemotherapies, the tricky bit can be pulling apart the side effects in the acute setting and again in the late effects setting because we still do get late effects from chemotherapies, targeted therapies and radiotherapies. So sometimes it's not easy to decide what's causing something. And it may be that we don't actually work out the cause and the late effect setting, but we treat the symptoms. And we'll just work out what's important to the patient.

**Paul (37:45)**

And anything else new on the horizon?

**Jo (37:52)**

So we're also going to start using vaccines in combination with immunotherapy to try and target it more. hopefully, because immunotherapy is quite a blunt instrument at the moment, we let the T cells proliferate and sort of multiply and go off and target whatever they want to. Whereas what we really need is more targets to the cancer without all of those off-target effects. So we also have bispecific drugs on the way where we've got immunotherapies and more targeted molecules fused together to hopefully deliver those drugs to the right place. So the science is fascinating. There's a lot coming. I've no idea where we'll be in another 10 years time.

**Paul (38:40)**

Well hopefully it'll be before we'll get back on the podcast series before 10 years so you can continue to keep telling us what's going on. And Charlotte, before we kind of move to our final questions section, is there anything else you'd like to kind of just share from your experience that you found help from healthcare professionals?

**Charlotte (39:02)**

I think the most important thing is for healthcare professionals to listen and I think that's the most important thing actually to actually listen to us and, because, when you're talking about your symptoms and actually taking them seriously. And I've always been lucky that that's been the case. I think there was just one situation when I said to a doctor, I feel really sick all the time. She said- no, that just doesn't happen with immunotherapy, you know, but it's to listen and to see you as a person. And that actually means that there has to be continuity of care. People listening to you, reading your notes, seeing you as a whole person is incredibly important.

But I think listening, and I think what's really immunotherapy, I know it's very new, but I think what I always think as a patient, me telling them about the side effects and the symptoms of all that. I'm helping other people in the long run. I'm helping myself because I'm letting you know, but I kind of sometimes feel like I'm part of the team and I'm saying this has happened and it might affect someone else. then, you know, learning together and sharing my experience, I think is just part of that. And that's why, that's why I do it really, because I think the more that we can share as patients, it's better for us, but it's better for treatment in the long run. And I think that's really important and

why I agreed to do the podcast, because it's all about learning about what immunotherapy is and how it affects people. And it's such an amazing treatment. yeah, listening is so important.

**Emma (40:34)**

So we're gonna come to our final questions in the podcast today. And Jo, I wonder if we could start with you. What would you like listeners to take away from this episode?

**Jo (40:45)**

Just two key things I think really, that all cancer treatments aren't the same and that recovery does extend beyond the end of cancer treatment. Being cancer free doesn't necessarily mean free of the disease and I'm sure I've coined that phrase from somewhere but I cannot remember where that quote comes from.

**Emma (41:06)**

Very powerful quote though and a very true quote, isn't it? It really reflects what people experience.

**Jo (41:12)**

Yeah.

**Emma (41:13)**

Charlotte?

**Charlotte (41:14)**

Again, I think it's repeating what I've said before really. I think health professions, the importance of listening to patients who've been on immunotherapy. If a patient comes to you and says, I've been on immunotherapy, almost have that sort of, ah, it could still be causing problems, late down the line. I think that's important. And I think for anybody who's going through cancer, it's like, know your body, you know your body and it's okay to advocate for yourself and it's okay to keep reporting these side effects. But you become acutely aware of your body when you're on treatment. And so it's for health professionals to understand and listen to that, but also patients to know that's all right. It's all right to just share that and it's okay to advocate for yourself as well.

**Paul (41:58)**

Thank you. I think that's a brilliant way to end the podcast. And if I may, Jo, Charlotte, thank you so much for sharing your time, experience and your honesty with us today. I think your insights into life after immunotherapy and the late effects people live with will be really helpful to the professionals listening. It's been a real privilege having you both on the Cancer Professionals Podcast. Thank you.

**Charlotte (42:27)**

Thank you.

**Jo (42:27)**

Thank you.

## Outro

**Paul (42:30)**

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**Emma (42:52)**

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by Sheetal Ladva, Macmillan's Chief Pharmaceutical Officer Clinical Fellow, and Lelly Oboh, Consultant Pharmacist to explore polypharmacy including how managing multiple medications influences and shapes the day-to-day reality of people with cancer and multiple long-term conditions.

**Paul (43:14)**

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

**Emma (43:28)**

I'm Emma

**Paul (43:29)**

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