The Cancer Professionals Podcast

Understanding immunotherapy: What it is and how it feels

(Intro music)

00:00:13 Lydia

Immunotherapy uses the immune system to find and attack cancer cells, making it a key treatment for various types of cancer. But how can you help someone navigate and adapt to the lasting effect?

00:00:26 Nellie

One of the things that that comes into my head. I know your melanoma is in remission at the moment, but do you regret to having the immunotherapy with all the side effects that you had?

00:00:35 Suzanne

No. Never, because I'd do it all again. That is your treatment. If I hadn't have had that treatment, would I have still been here today?

00:00:46 Lydia

Hello, I'm Lydia and I go by she/her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan.

In this series, we chat to a wide range of guests, including health and social care professionals, to lift the lid on current issues faced by the cancer workforce. In this episode, we're joined by Nellie Kumaralingam, former Melanoma nurse consultant and Suzanne who was diagnosed with Melanoma in 2022.

Nellie explains what immunotherapy is, how it is used and the effects that it can have on both the cancer and the individual long term. Suzanne shares with us her personal experience of receiving immunotherapy and how she's navigating the long term side effects.

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

00:01:35 Lydia

Hello Nellie and Suzanne, and welcome to the Cancer Professionals Podcast. It's really lovely to have you here today. To begin with, would you be able to introduce yourselves for us, please? So Nellie, if I start with you.

00:01:46 Nellie

Yes. So my name is Nellie Kumaralingam. I am currently working as a cancer CNS development lead for West London Cancer Alliance. But previously, I've worked as a Melanoma nurse consultant and the skin cancer clinical nurse specialist. And my area of interest is skin cancer and immunotherapies.

00:02:07 Lydia

Great. Thank you and Suzanne.

00:02:11 Suzanne

Hi, I'm Suzanne Walters. I was a patient of Nellie’s at Maidstone Hospital. I was diagnosed with metastatic Melanoma in my lung and trachea and a year today I rang the bell.

00:02:25 Lydia

Ohh, amazing! And to start with Nellie, I'm wondering if you'd be able to explain what immunotherapy is and how it works sort of in its simplest terms.

00:02:37 Nellie

Yes. So how I often explain immunotherapy to patients is that it's using your own immune system to fight diseases such as cancer and it's quite a sort of a simple way to explain it and it's kind of a no brainer. So for years we're using chemotherapies which were quite toxic and caused a lot of problems. But immunotherapies just sort of teach your immune system to find these cancer cells and then fight them and continue to fight them in the future, which is why there is thought to be a long-term sort of effect of the immunotherapies to keep the cancer at bay for a long time. So there's there's two ways that that the immunotherapies work so firstly, it's by stimulating the immune system’s natural defences to find and attack the cancer cells, as I said. And that's the main main area that we're going to be talking about today and that's the treatment which Suzanne had as well. But there's also a way of administering genetically engineered immune system components to improve the function of the immune system as well.

00:03:52 Nellie

Immunotherapies have been used or licensed in the UK since about 2012. They were first licensed in Melanoma, which is the cancer that I've worked in, cancer tumor site that I've worked in recently and that Suzanne had, but now it's used in multiple different cancers now, so it's used in renal cell cancer, bladder cancer, lung cancer. It’s started being used in breast cancer as well. So it's, as much as it started off with skin cancers and Melanoma in particular. It's now used in multiple cancer sites.

00:04:26 Lydia

And how do we use immunotherapy?

00:04:29 Nellie

So it's given in. It can be given. So in Melanoma it is usually given on its own, but sometimes in such as lung cancer, they're given in combination with other chemotherapy, which has been around for a long time. It's usually an intravenous infusion and that we give and the patients will go to a day unit which is traditionally called the chemo day unit, even though obviously they were giving him in the therapies and it can be given every two weeks, every three weeks, every four weeks, depending on the regime and the type of cancer that you've got. So it's it, it's, and also it can be given. So traditional chemo used to be sort of given for six cycles and or you know sort of six months or so but now immunotherapy is particularly for Melanoma we give it for 12 months if it's in the adjuvant. So after you've had surgery and you don't have cancer anymore, but we're reducing the risk of the cancer coming back, it's given for a year. But as with Suzanne's case, when you've got metastasis, you've got secondaries in another part of the body, we give it for two years and potentially longer if we're concerned about the Melanoma coming back.

00:05:37 Lydia

And Suzanne, I wondered if you'd be able to tell us a little bit about your experience with immunotherapy, perhaps you know, when you were first told that you'd be having immunotherapy, what was that like?

00:05:51 Suzanne

When I was told my diagnosis, I think the thing is you, you have to have this treatment to cure it, so that was very good, within a few weeks, I'd started my treatment and I had four cycles of the treatment. And last April, it affected my liver quite bad, which was one of the side effects.

00:06:22 Suzanne

And although last year I was told I was in remission, my liver levels just kept going up and down, up and down. So I was put on steroids, which I've been on and off for the last year, and I've only just been sent to Kings with new medication, so that's why I look a bit puffy. I need to be juiced. Like, what's her name off of Charlie and the Chocolate Factory?

00:06:53 Suzanne

But yeah, I mean obviously there are a lot of effects for years after with immunotherapy, but obviously you're told all that at the beginning.

00:07:04 Suzanne

That's what you sign up for, and that's what I did. But at the minute, I feel great in myself. Obviously I can't run the marathon cause I can just about walk. But yeah, things are going really, really well now. I've got a special medication from Kings which have started to settle my liver so I can start walking.

00:07:27 Nellie

Suzanne had four treatments, but the last treatment was beginning of 2023, but actually she's still in remission from her cancer. Unfortunately, she's got side effects of the treatment that we've given her, which we'll talk about. But her Melanoma is still in remission, so it responded very well, but unfortunately caused the side effects.

00:07:47 Lydia

It's really great to hear that you're in remission, but it's, you know, it's definitely tricky dealing with those long-term side effects. And I wondered, Nellie, would you be able to tell us more about what types of side effects people might get with immunotherapy sort of more in the general sense? And then I suppose it would be great to hear from you Suzanne and maybe you can chip in as well Nellie about what you experienced in particular.

00:08:11 Nellie

Yeah. So again, when I'm talking to non cancer specialists or patients and their relatives or carers about the immunotherapy side effects, so immunotherapies call can cause inflammation of any part of the body. So it you know, starting from the top. So inflammation of the brain, the eyes, the skin, the lungs, bowels, all those areas, the most common side effects that we get is inflammation of your bowels which causes colitis.

00:08:41 Nellie

And the symptoms of that can be sort of diarrhea and abdominal pain and things like that. So. And that's probably the most severe one, but the one that Suzanne had was hepatitis, which is inflammation of the liver.

00:08:53 Nellie

And unfortunately, people and Suzanne has had this, is that people can have sort of relapses of the hepatitis so as much as you have that initial time where when we usually find out on the blood test that that the liver's not working as well as it should, but it people have these relapses and Suzanne will talk about her, her, her experience. But we've had patients who've had two or three relapses of the hepatitis and even the colitis can return as well, so the common ones are colitis, the bowels, hepatitis, the liver, dermatitis, which is inflammation of the skin, which often presents as a rash or itching on the skin without a rash, which is quite difficult to control and then they also can get this inflammation of the joints as well, which is can be quite uncomfortable and quite difficult to get on top of. And I think one of the things that we've really learned with immunotherapy treatments is that we really need to work well with our non-cancer specialists, so the endocrinologist for things like problems with the thyroids and the endocrine system, the gastroenterologist for the bowels, the hepatologists for the liver, you know. So we really need to have those connections and those collaborations with our non-cancer colleagues to help us treat this.

00:10:11 Nellie

Because we're very cancer orientated, we know cancer really well and cancer treatments, but we don't know, you know, hepatology, which is the liver side of it and things. So that's one of the things that that I think we're learning even though it's been 14/15 years since we've had this sort of licensed treatment in the UK, we're still, we're still learning about the side effects and how we manage them and who we need involved with the management of these side effects.

00:10:42 Lydia

Yeah, I suppose it's all about effective use of the multidisciplinary team. Having all of those, all of those people involved, you know it's it's a huge effort, isn't it? But when we see such great effects from having it, you know, from having immunotherapy on the cancer, it's totally worth it so.

00:10:59 Nellie

It is and I think you know, from a service perspective for, for people who are sort of developing a new, or developing their immunotherapy services and then part of my role, when I was at working at Maidstone with Suzanne was actually was looking at service development and pathways for the side effects. So you know, we need to have this agreement with say, you know, one of the pathways that we had really well organised was with the endocrinologist for problems with the thyroid gland, pituitary gland, adrenal glands and you know he was very good, like he had a clinic set up which was specifically for patients who had this this side effect, we had a pathway, we had a policy, we had everything planned and he was also very easy to contact, but impacted on his other work. So from a service perspective, and I'm very much more like, if we're potentially adding to their workload, which we are, should we have some sort of service agreement where we say that we will, you know, cancer services will buy in these services from the endocrinology department, the gastroenterology department. So I definitely think from a service provision and service development perspective, we need to have more of those conversations because that impacts on the care that the patients get. So if we have a really good relationship, have a good pathway set up with these departments, then the patients get things in a timely way and, you know, Suzanne will talk about some of her experiences. But you know some departments are fantastic. And we've got these things in place. Others are really over overworked. We know about waiting lists in the NHS at the moment and, you know, our sort of referrals are then impacting on those waiting lists and those workloads for those individuals and those teams. So it is about looking at that sort of side of as well so as cancer professionals who were providing, seeing patients with these cancers, any type of cancer and providing these treatments, we also need to look at- one, how we prepare patients for those treatments, but also if they were to get a side effect, how do we help them with the right people advising us or seeing the patients, because we're not experts in those areas.

00:13:16 Lydia

So I wonder, Suzanne, when you first started your treatment, I suppose, how did you find the administration? And I suppose the initial side effects of the treatment, and I suppose compared to how things progressed and then maybe how you started to find out about the side effects and find out that there was a problem? Are you able to sort of talk us through that experience?

00:13:42 Suzanne

I finished my treatment, I did all four cycles that I was going to have of the immunotherapy.

00:13:50 Suzanne

And I was fine with that. I was very tired. I did lose quite a bit of weight, but it was a couple of months later where I started to have regular blood tests that it was showing up on my ALT that my liver levels were very high. They were that high at some point that I had to go into hospital and be put on IV steroids to get my levels down because they were really, really sky high. But I had to go through accident and emergency, so I spent six hours in accident and emergency knowing that I had to be treated sort of straight away.

00:14:30 Nellie

You felt quite well with it though, didn't you? So

00:14:32 Suzanne

Yes, although I was yellow.

00:14:35 Nellie

She was yellow, but felt, so that first time that we sort of got the blood results back and said it was and it was elevated. It was in the thousands. It wasn't even like it was just mildly elevated and, but you didn't feel particularly unwell, a little bit jaundice, a bit yellow, but other than that didn't have any symptoms as such.

00:14:55 Suzanne

No. So I spent 10 days in hospital to get my levels down, which was the safest place to be. But like we say, each department need to know about the help and what's available for the patient after immunotherapy. So I came out and I was getting better, but like Nellie said, I've had quite a few flare ups and I've been in and out of hospital a few times with my liver.

00:15:22 Suzanne

And obviously being on steroids for quite a long time, it gives you induced hyperglycemia. So I am treated for like a diabetic. So I have a freestyle libre in my arm, but I have an alarm on for low and high and I'm on a controlled diet and no sugar, just to help like the liver with the treatment that I'm on now.

00:15:46 Nellie

Yeah, I think it's, you know, with these side effects, it's, so- we give a treatment, it causes a side effect, we then treat this side effect with steroids or another, but mainly it's steroids that we use for immunotherapy side effects, which also has side effects which then we have to treat. So with Suzanne, it was the immunotherapy caused the hepatitis, the liver issues.

00:16:11 Nellie

We gave steroids, which dealt with the hepatitis but then caused the steroid induced diabetes, which then we have to do something about. So it's a knock on effect and I think for patients what I see is that it's just constant. So the Melanoma for Suzanne at the moment, it's fine. It's not causing any problems. Scans are all doing fantastically well. But this hepatitis is kept, you know, keeps flaring up, causing issues. She's having problems then with her blood sugars because of the steroids that she's been on, which then has caused, you know, issues with muscle weakness, the problems that she's had with the water retention, things like with appetite, you know, with those things and then obviously with the appetite, you've got the issues from the diabetes side which means that she has to be really careful about what she eats, so it feels like, as someone observing and caring for this individual, you're observing them, really struggling with this side, with this side effect, which has had all these knock on effects but in but you have to remember that the Melanoma which is what we were treating initially is is responding and responded and responding very well. But then you watch them go through all of these things, which impacts on your quality of life.

00:17:20 Suzanne

Yeah, yeah, yeah, it does impact on your quality of life because I thought after the cancer was in remission, I'd be going back to work, I'd be fit, I used to swim a mile a week and now I can just about walk up the road on my own. But like I said, I am getting better. I'm a tough old cookie as I've been told and I do my physio every morning, I do my walk every day and every day I'm getting better, and hopefully this time next year I'll be swimming again.

00:17:56 Lydia

Yeah, hopefully I think, I mean, it sounds a bit relentless. You know, as Nellie said, the knock on of all of those side effects of the different treatments that you have to have to then treat those side effects, yeah, it sounds, it sounds tough and I suppose, like, it's not surprising that it would have an impact on your life, but yeah, hopefully that you will get back to that, that swim and you know, going for those walks that would be really, really great. And I wonder, I imagine that probably when you first started having the immunotherapy, I suppose you get told about all of the side effects, but you don't necessarily expect that everything's gonna happen to you. And has your perspective changed about the cancer that you had and the treatment that you have had? Has your perspective changed throughout that?

00:18:42 Suzanne

Yes, definitely. Definitely. Now I get up and I factor 50 up no matter what the weather is because obviously I go for a walk every day, I cover up. I'm someone that liked holidays abroad. Obviously I've not been on holiday for a couple of years, but when I do, it's going to change the day.

00:19:02 Suzanne

I was a qualified scuba diver, but obviously I can't do that anymore because of my lungs and my breathing. But I will definitely get back to swimming because it's good exercise. You just have to change your life around a little bit to adapt.

00:19:17 Nellie

One of the things that that comes into my head, I know your melanoma is in remission at the moment, but do you regret to having the immunotherapy with all the side effects that you've had?

00:19:26 Suzanne

No. Never, because I'd do it all again. That is your treatment. If I hadn't have had that treatment, would I have still been here today? I can't ever. I don't think anyone can ask that ever answer that question. But you have to sign for your treatment. So what do you do when you're first diagnosed? Say no to the treatment and not be here now? Or still live a good quality of life when I'm better, although I've been really poorly, I've got good friends and family and I'm here to tell that tale. But yes, I definitely would do it again.

00:20:04 Lydia

That's good. And do you have any advice for anybody who is starting out having immunotherapy? Is there anything perhaps that you wish somebody had told you or done differently at the beginning?

00:20:18 Suzanne

Not differently, but you need to be a tough, strong cookie. Positive thoughts 24/7 and have a good family friend network because without my parents and my friends and family I would never have got through it. And no matter how strong you are.

00:20:35 Lydia

What support did you receive during your immunotherapy treatment? Our audience is primarily healthcare professionals, so I suppose any tips of things that you found particularly helpful or maybe things that weren't as helpful, that would be really great to hear.

00:20:50 Suzanne

Yeah- oncology, were fantastic, Nellie, my consultant, Dr. Parker and the nurses were absolutely brilliant. Everybody on, even though, like Nellie said, you're on a chemo ward, you still go there for your immunotherapy, all the doctors and nurses and everybody were fantastic. It's just that the other departments, when you're took into hospital for other stuff, just need to understand a little bit more about what you're going through. And I think this is the whole point of what they say- aftercare after immunotherapy. Yes, I go to coffee mornings, I talk to likeminded people about their different cancers. But we're not talking about that all the time. We're talking about other stuff- your life, your family, your friends, everything you do on a daily basis. Because everything I do I go- “Ooh, I got upstairs on my own today” or “I did this on my own today” and it's and it's good for me. It builds my confidence up knowing that I'm getting better.

00:21:57 Lydia

Yeah. And you mentioned there about how there's perhaps a lack of knowledge in certain departments. What do you think would be helpful for people to know or how would you like people to educate themselves in that field?

00:22:11 Suzanne

Like Nellie said before, everyone's busy in their own department, but it's nice to know that my diabetes levels are sky high and not because I'm not controlling it. It's just suddenly come on because I'm back on steroids again, it's not because I'm not looking after myself. It's because of the steroids. Because of the treatment, that just tracks back all the time.

00:22:35 Nellie

And I think what we did, Suzanne recently helped us with is, that we developed an immunotherapy study day, which was actually aimed at non cancer staff, so your GP's, your practice nurses, your A&E doctors, people you know, so your General Medical ward nurses and doctors and stuff.

00:22:54 Nellie

And actually, Suzanne spoke at that and it was probably the session that had the best feedback and you know, Suzanne had lots of questions because the patients voice is really powerful. So hearing Suzanne's experience rather than me going “well I had a patient who had hepatitis and this happened”, it's so much more powerful than someone who hasn't experienced it going talking about it. So I, sometimes I think it's worthwhile having events and like this, you know, professionals, podcasts that we're doing, the study days, taking the expert patient, as we call them, into these departments and things having that ability to do it, I think it'd be fantastic and Suzanne's obviously very, you know, very happy to talk about it.

00:23:36 Suzanne

Yeah, I don't mind talking, if people learn and get more information, then that's a good thing for the patients going forward because obviously there's a lot more people being diagnosed not just with melanoma cancer, but with all types of cancer. And obviously the flare ups can be for years, so you've got all them patients every year still being in aftercare for 2,3,4,5 years later that we're not just poorly people that have not controlled diabetes or, my liver levels aren't because I've been drinking because I haven't had a drop of alcohol for two years. Just to look after myself. So yeah, if people get to understand the side effects of immunotherapy and do some, not research, or they may have a staff training day for it once a month or anything like that, I mean that would be so helpful because I found in the hospital the struggle bit because they didn't understand.

00:24:38 Lydia

Yeah. And, you know, you mentioned a couple of times there about perhaps where people have had misconceptions. Do you sometimes go into other departments who perhaps don't understand immunotherapy and perhaps feel a little bit judged, you know, you mentioned about having the high sugar levels and how people think that they, that it's because you're not controlling them, where it's actually you're doing your best.

00:25:00 Lydia

But as you say, it's just cause you're back on those steroids.

00:25:03 Suzanne

Yeah, because one of my discharge papers actually did say poor control of diabetes, and I thought- that's not actually why I was put into hospital for. Well, it was. But it is like you say, because of the steroids, because of the immunotherapy.

00:25:18 Suzanne

And within two weeks, I'm now off insulin and my blood sugars are back to normal because I'm off the steroids again at the moment and on my new medication.

00:25:27 Nellie

And I think just with the hepatitis, I had, I had another lady who, it was a, it was a, it was a young patient who said- when I first used hepatitis with her, she got really upset because she thought about the infective hepatitis the, hepatitis C's and all those things which are which are different. So, there can be a bit of stigma around that sort of thing as well, and you know, Suzanne said, is that, you know, sometimes people have this sort of misconception of people who've got diabetes that they eat too much sugar or that, you know, that they don't exercise or something like that. But actually with Suzanne, it's a different situation. So.

00:26:03 Nellie

There can be that stigma around it, so you know the stigma around cancer, the stigma then around the side effects of the treatments that that someone like Suzanne's had, you know, the diabetes or the hepatitis. So there is that as well. And again we as professionals don't, I just, threw out the word hepatitis and she got, the patient got really upset and I was just like- oh, you know, and then when we talked about it, I knew why she was getting upset, which makes sense. And it was, like years ago when there was that, it was an awful article in one of the newspapers about cervical cancer, and it was a sexually transmitted disease and it, you know, it's like a full sort of centre double page thing in one of the papers and it caused so much stigmatism and so many problems because it was that the herpes like, you know, the virus and everything.

00:26:52 Nellie

So, I think we really need to be careful as professionals how we, the wording we use and how we explain things to patients and the public and also our colleagues, ‘cause otherwise we, you know, it can cause a lot of, you know, distress for patients but it could cause that stigma as well. So yeah.

00:27:12 Lydia

Yeah, I think that's something that's all registered for me. Even when you said about the fact that you’d had on your discharge summary ‘poorly controlled diabetics’ like the fact that just that wording can have such an effect on you. So I think it is so important about educating, you know, professionals about the use of words, and I suppose the power of language, both written and spoken, so you know, absolutely, I think that's a really great point.

00:27:42 Lydia

And Nellie, I wonder if you'd be able to tell us more about how you educate people about the side effects before they start the treatment. And I suppose, you know, we all know that there’d be a consent form which would have some certain information, but I wonder if there's anything sort of extra that you give to sort of reinforce the, you know, how crucial it is to get help, if there are any concerns.

00:28:06 Nellie

So when I would see patients such as Suzanne in clinic and talk about the fact that they needed something, that something showing up on their scans or they've been referred to as a new patient for this treatment, I would give them some information on, I would tell them what the drug drugs were, how they work. And then before I did the consent form which is quite daunting and a little bit scary because there's, you know, one of the things is that you, you know, death because of the some of the side effects can be quite severe.

00:28:36 Nellie

And they see that and you're just, you know, you have to explain that in the context of why you're, why it's there. I would go through the information leaflet, so we used the Macmillan information leaflets on the different treatments. So the main treatments that we give is pembrolizumab. And the one that Suzanne had was ipilimumab and Nivolumab.

00:28:58 Nellie

So I would go through the leaflets and those leaflets are really good because they are written for the patient to understand. They're not, they don't use medical terminologies too much. So you go through those and it's using words, and I had a consultant years ago within dermatology. So I worked with two consultants in dermatology and in dermatology we use a lot of medical terminology, so even a mole is a lesion, it's not a mole, you know, and things. And I had a clinic on Wednesday, one was in the morning was the afternoon and the one in the morning. He was a professor and he was lovely and I would see, I would go and see a patient and then I'd have to explain what I'd identified on the mole and I would use the medical terminology. And he was like, no, I don't understand why that is. Tell me what it is. You know, in in basic language, I don't want you to use medical terminology. And actually it made sense because the patient was sat there and I was talking about them, about this mole that I was concerned about. And so he was very much like- don't use medical terminology. But in the afternoon the consultants wanted me to use all the correct words and everything. So I think we have to be really careful when we're talking about, you know- hepatitis, what does that mean? And again it's that, you know, that sort of wording. Colitis- what does it mean colitis, you know, pneumonitis, which is inflammation of the lungs.

00:30:14 Nellie

What does that mean to a patient or a carer? And actually, even some of our colleagues who aren't working in these fields wouldn't necessarily know this. I know this because I've worked in this for a long time, so we do have to really be careful when we're talking to patients about these and you are giving them- It's a 20 minute appointment- you're giving them so much information and you're talking about the fact that they're scan has showed something which they need to then have a treatment for, which is, which by then a lot of people would have switched off, probably anyway. Then you go and say- we're gonna give you this treatment, which is really, you know, potentially it can cause lots of side effects and these side effects can lead to, you know, to potential deaths or, you know, severe issues.

00:30:55 Nellie

And that's a lot to take in, so. And that's how it works at where we're at, where I used to work. So what I would really like to do and doctor Catherine Oakley, who's a SACT so a systemic anti-cancer therapy nurse consultant at Guys and St Thomas's done has done a lot of research and has implemented at Guys is.

00:31:17 Nellie

Prehabilitation in immunotherapy. So it's preparing patients to have immunotherapy. So they would come to the clinic, they would be given all this information and probably take on, you know, a small percentage of what we're telling them. They then get invited to this immunotherapy prehab appointment, which can be done individually or it can be done as a group and you're with people who may not have the same cancer diagnosis as you but will be having the same treatments as you potentially. And you would then go through all of this again, you give them the chance of asking questions, whether it's, you know, whether and you can take a carer or someone significant, some significant other with you, but you can also talk about how to prepare at home, you know.

00:32:02 Nellie

Years ago I worked with men with prostate cancer and we used to do prehab for radiotherapy before they started this intense course of radiotherapy and we did this. And you know, we'd be like- drink lots of water, don't drink, you know, caffeinated drinks because actually, that dehydrates you. Think about when you have your last caffeinated drink, you know, don't have it after 2:00 PM because then you're gonna wake up in the middle of the night. But just how you eat and drink and, you know, and exercising and all those things are. It's not just about the treatment, but it's how the patient can help themselves at home because again, we take that control from the patient. We go right- You've got cancer. We're going to do this and we're going to do all this for you, so they lose that control. So actually saying at home- you can try and do a bit of exercise. Exercise isn't going to the gym or doing an exercise class. It's maybe walking up and down your garden, you know, or going up and down the stairs if you can, you know, make sure you eat to balanced diet, don't start any fad diets. I always say- don't start those fad diets it's, you know, it's about, so you do need a bit of fat in your diet as well as the proteins and everything else, and drink lots of water.

00:33:06 Nellie

Look at what you're drinking that's caffeinated or carbonated, because that affects you, how you're drinking, saying- you know for the water content as much as the, that it was anything else that you're drinking. Make sure that you're psychologically mentally prepared for this treatment, which is, you know, potentially is going to cause lots of side effects. And I think that's what Suzanne said earlier, it's having that support network and that ability to cope with these, everything that's thrown at you via the treatments, but also what can happen with it. So it's preparing patients, so that prehabilitation, preparing them for their treatment and then when they start their treatment, hopefully they'll won't have side effects, but they also they know what to look out for from side effects, who to contact, what they can do at home.

00:33:53 Nellie

And I think that really prepares them and I don't think we do that very well in a lot of organisations and I think, I don't know whether you would have found it helpful Suzanne, but I think that, for me, that's a really keen bit about getting people started on treatment.

00:34:08 Suzanne

Yes, I think being prepared a lot more would help because obviously you've got your husband, a lot of people have got family or children that live with them. I mean, I only had me and my husband, but obviously going through the treatment, you're poorly so your husband or your family, or whoever's living in your house tends to become your carer in a way because you're not 100%, you need looking after, you're weak, you've been sick, you need your food cooked or you need this so to be prepared not just for me, but for the people living with you. It would be great to have these things more put in place because, like Nellie said, when you're actually diagnosed like myself, I had stage four and with quite a few lumps in my lung and my trachea, where I couldn't breathe. But yeah, you're going to take the treatment because that's your only option. But to be prepared a little bit more would be so helpful.

00:35:19 Lydia

That the tips and hints that you that you can get from like a pre rehabilitation clinic as you say would be so helpful, and I imagine also having somebody who has been through that treatment as well, being able to give the tips and hints so that people can prepare themselves, their families, their loved ones, their carers to be able to go through that journey. Nellie, obviously, you've spoken about what you would like to happen for immunotherapy and how you could change those clinics.

00:35:48 Lydia

I suppose I wanted to know a bit more about how perhaps things have changed in the last, you know, more than a decade of immunotherapy. I imagine that clinics were perhaps very unprepared initially. So how have things changed since then?

00:36:06 Nellie

So when immunotherapies were first licensed, I was working at a big cancer center in London, and actually places like Maidstone where we've just come from weren't giving immunotherapy, so we would get all the patients who were eligible to have immunotherapy coming up to us because places like Sussex and Kent weren't actually giving their treatment because there was a fear about the side effect management, but there's also the capacity issue within the day units and also the staff training and all those things, and if you think about it, we're now you know, how many years down the line from when we first started using it and obviously the other cancer centres like Maidstone and places are giving it, but we're still having to do a lot of education and training to the cancer oncology departments but also to non-oncology departments as well. So things like that change, and I said, I said it's amazing how many different tumour sites are now using immunotherapy either on its own or as a combination, and I think you know there's trials going on either now using it in the neoadjuvant setting. So before you have surgery, you'd have so many doses of immunotherapy, then have surgery and then potentially have more immunotherapy and that was a traditional sort of chemo sort of thing. I remember we used to do it years ago for some of the Gynae cancers you'd have, you know, four lots of chemo, have surgery and then you'd have four more lots of chemo. So, we're setting it, you know, we're using it and I think there's a lot more sort of understanding with sort of the leadership team and the management teams around the supportive care needs.

00:37:49 Nellie

So, you know, NHS is brilliant at diagnosing and treating cancers, I think, in my view, but what we're not great and we probably need to improve on is that supportive care need. And I know Macmillan have, you know, provided a lot of information and advice. But Macmillan are a charity, and I think the NHS needs to get better at that. So I think you know it, it's there, we're working on it and and there's so many. So you know that there's things like the immunotherapy network now with clinical network which have been set up for professionals which anyone can access and it's free to join I believe.

00:38:25 Nellie

And they're doing a lot of work on pathways and information and all that kind of stuff. There's Immunobuddies, which is again for professionals giving immunotherapy. There’s like a podcast, there's, you know, there's an educational forum which is done by Doctor Ricky Fraser from Cardiff and that's every, you know, once a month on a Thursday. But you know there's lots of resources out there but people are doing often these things in addition to their clinical workloads, and I think that's the other thing as professionals that we need to think about. You know, there's always going to be the financial issues and the resource issues in the NHS, but for me, even though in my current role I've gone out of the clinical practice. But for me it's about patient care skills though, it's about what, everything that we do is about what, how the patients benefit from it. So I feel like there's more work we can do around the education, training, the pathways within cancer, but also outside of cancer, how we support GP's who are, you know, the general practitioners and their teams, so many sort of healthcare needs that they need to know about. Immunotherapy is going to be a tiny tiny aspect of it but- what support and training or what can we do for them to help them so there's so much work to do around it, but we are we are so much further than we were back in 2012. So that is the key as well because there is an understanding, there are pathways in place. but it's very much individual organisation rather than as the NHS for England or the UK, so more work can be done, but we have done a lot already and there's a lot of people, a lot of doctors and nurses who are working very hard in the background, in addition to everything else, to raise awareness of immunotherapy as a treatment and how we can support patients who are having those treatments.

00:40:25 Lydia

And Suzanne, is there anything that healthcare professionals could do more to help you as a patient?

00:40:30 Suzanne

Being aware that you've had immunotherapy that all these hundreds of things that could flare up could flare up because obviously it wasn't just my liver. I have got adrenal gland problems as well.

00:40:45 Suzanne

So I’m on hydrocortisone medication everyday.

00:40:51 Suzanne

But I've been told by my endocrinologist that I need to get my liver sorted first and then in three to six months time I sit some tests and hopefully my adrenal glands have kicked in and I can come off that medication. So it's not just one thing that flares up, it's two things.

00:41:12 Suzanne

And also having blood tests quite a few times a week they couldn't, they stopped getting blood out of me. I'm having to have them now, only every two weeks, so hopefully my veins will heal as well as my body.

00:41:31 Nellie

And I think, I just wanted to say with that we're talking about it in the car earlier and you know that discharge letter which said poorly controlled diabetes, that went to the GP practice, as it does, and what was written wasn't complete because the the, the GP surgery then saw it and phoned Suzanne said- Ohh we've booked you for a blood test and they were checking the liver function and the diabetes levels and Suzanne was like- well, I'm having them weekly or two weekly at the hospital so.

00:41:59 Nellie

If that had been written in the discharge summary, patients going to be having two weekly blood test, you know at Maidstone Hospital then then the GP said you would have done that. So it's it's that how we communicate to one another from the hospital to to the GP practices and other places is is really key and and I feel like there's some some work to be done about education of the doctors or the nurses who, whoever completes the discharge summary around, making sure that we use the correct language and also we give a very full sort of robust plan when we're sending patients out and you know with Suzanne, she has the diagnosis of the Melanoma, but she's got the hepatitis, the adrenal deficiency and then she's got the steroid induced diabetes but it's about making sure that all of that's clear it's written what the treatment for each of those complications is, and what the plan for dealing with each of those complications. And I think again, that there's there's work to be done around that. It's difficult because there's so much, so much pressure on staff. You know the the, the for, for, for the staff on the wards to do a proper full discharge summary is difficult. So it's not a, I guess it is a criticism, but it's also that sort of, it's that awareness when we're doing these things so that for the people that may be listening to this is, is ensuring that we we do make it easy enough for the patients that they don't get a phone call. And the thing is, because Suzanne knows she was able to say to GP surgery- I don't need to have a blood test with you guys as well because I'm having it at the hospital. But another patient would just go along and have another blood test. So for them its a blood test they don't need to have and, you know, it's a it's a needle for no reason but there's a cost implication then for the NHS. We're doing a blood test that doesn't need, is going to be repeated so, and those all of those things cost money so it's that sort of awareness as well. So, you know, it's it's hard, but we need to make sure that we are succinctly thinking about things for our patients and how we can just help them along the line.

00:43:54 Lydia

Yeah, yeah.

00:43:55 Lydia

I think, you know that's perhaps something I've not thought about before, even that even that GP calling up to say you need to have a blood test because of this, that is a that's a resource, that's time that someone has taken out that they could have been doing something else. I think that's a really, really great point just for everybody to be aware of that clear language.

00:44:16 Lydia

Before we go on to our regular feature, I'm really excited to announce that we'll be recording a further episode on immunotherapy in the near future. We'd love to hear from you- what aspects of immunotherapy intrigue you the most, perhaps something that's come up in the podcast today that you want to know more about. Share your suggestions by leaving a review or comment, or send us a message at professionalspodcast@macmillan.org.uk. We can't wait to hear from you.

00:44:43 Lydia

And so finally, I just wanted to move on to our regular feature where we ask three questions of all of our guests. So Nellie, if I could just start with you- if you could go back in time, what a piece of advice would you give yourself?

00:44:57 Nellie

I would say- understand the people you work with better, not necessarily patients, but the professionals, and where they are. So now I have an understanding as I said with the different departments that we work with, I understand that the pressures on them and why they may not be able to help us as much as we want them to help beforehand I'd just, you know, you'd just be thinking they're being a bit obstructive or not very helpful. So I think you know, just take that step back and try to understand where everyone is coming from.

00:45:31 Lydia

Great, thank you. And Suzanne, if you could go back in time prior to starting your treatment, what piece of advice would you give yourself?

00:45:40 Suzanne

The advice I would give would be- just stay strong, follow your doctors and nurses advice, stay healthy and be a tough cookie because that's what's going to get you through it.

00:45:51 Lydia

Great. Thank you. I like that tough cookie. And Nellie, what change would you like to see to improve the lives of people living with cancer?

00:46:00 Nellie

I think I'd like to say two things, if possible- more education and training for staff around communication, how we talk to one another, but also to patients and their carers as well. And secondly, I think having patients involved with everything we do is really helpful. So I think to Suzanne the reason I you know asked to be here is I think her voice is far more powerful than my voice and that's why I asked her to talk in our study day because her experience is more powerful than me talking about her experience. So I would say to professionals, whatever you're doing, whether it's writing a patient information leaflet or potentially developing a pathway for hepatitis, involve patients in it because they're the ones who are living through it.

00:46:48 Lydia

Thank you. And Suzanne, the same question to you. So what change would you like to see to improve the lives of people living with cancer?

00:46:56 Suzanne

More information, and staff being more aware of your condition’s after effects, being a bit more involved in the support, knowing when you've had weekly checks, but if you want the results to have the results when the doctors get them, I know sometimes there's not time for them people to make phone calls all the time, but it's just being aware of what's going on with your own body, what results and things are happening to you.

00:47:28 Lydia

Great. Thank you.

00:47:30 Lydia

And then, Nellie, what would you like listeners to take away from this episode?

00:47:34 Nellie

I'm hoping that they will really take on Suzanne's story and her experience of the immunotherapy, the side effects and the ongoing issues with the side effects. It's not a, you know, come in, have steroids, go home and it's all dealt with. It's ongoing effects.

00:47:54 Nellie

And it can be late effects, so Suzanne had got her side effects really fairly early, but potentially if someone finishes their treatment, they could get a late side effect two to three, maybe longer years after they've finished their treatment. So it's having that awareness.

00:48:11 Lydia

Thank you. And finally, Suzanne, what would you like listeners to take away from this episode?

00:48:16 Suzanne

I think just listening to the patient's point of view a bit more and obviously them being more involved and more staff training for people to be aware of aftereffects with immunotherapy because obviously mine's been 18 months ago and I've still got the effects now. So it just makes people a bit more aware that the cancer has gone, which is very good news. It's just the aftereffects with the treatment that are ongoing for one, two, three, maybe four years or more.

00:48:50 Lydia

Great. Thank you. So, yeah, finally, I just want to thank you both so much for coming to chat to us today. Nellie, it's been great to hear about your expertise in the field of immunotherapy. And Suzanne, thank you so much for being so honest with your own personal experience of immunotherapy. It's been a real pleasure having you both on the Cancer Professionals Podcast.

00:49:10 Nellie

Thank you very much.

00:49:11 Suzanne

Thank you.

(Outro music)

00:49:13 Lydia

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00:49:35 Lydia

If you enjoyed this episode, follow us so you don't miss our next conversation, where we'll be joined by Doctor Fiona McCarthy and Rosamund Dean to talk about skin care and cancer. 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 Wednesday of each month.

00:49:59 Lydia

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