Emma: What does treatment for cancer actually entail?

[music]

Emma: Hello, I'm Emma B, and welcome to Talking Cancer, a podcast from Macmillan where I'll be meeting real people, to have honest conversations about living with cancer. I'll also be meeting Macmillan professionals who'll be sharing advice and information to help anyone living with or affected by cancer to find their best way through. In this episode, we're talking cancer with Ben.

Ben: There was a nurse that came over to me, and she was explaining a lot of things, and I looked down at her name badge, and it said Macmillan on it, and I thought, "Oh my God, things have just got really, really real, really quickly."

Emma: Two days after his 40th birthday, Ben Green was told he had cancer of the esophagus, the tube that connects your mouth to your stomach, and for someone who loved his food, like Ben, it was a devastating blow.

Ben: We all eat together, and I was suddenly taken away from that. Everybody else would be finishing, and it would really highlight to me that I'm not well, and I'm not normal anymore, physically.

Emma: Ben, who is a nurse himself is now on chemo at the end of which he's going to have surgery to rebuild part of his esophagus.

Ben: You don't really realize how many chemotherapies there are out there. You just presume it's like a paracetamol.

Emma: We talked about the ins and outs of his treatment, the information he received beforehand, and we talked about living with cancer and all the things that keep him going like cooking and baking. Later Daney, one of our Macmillan professionals is joining me to talk about the treatments available when cancer is diagnosed.

Daney: It is mind-boggling, but there are fairly standard treatment regimes for different types of cancers.

Emma: We're Macmillan, and we are talking cancer.

[music]

Emma: Ben, welcome. It's lovely to have you here.

Ben: Hi, thank you.

Emma: You look very well.

Ben: Thank you.

Emma: Bright and sparkly. How are you today? How are you feeling?

Ben: I'm very good. I'm halfway through my chemo, and I'm about two weeks since I had my last chemo, so at the moment I'm pretty much side effect free, which is nice.

Emma: It is nice. Your eyes look sparkly, and you look really healthy, and it's great to meet you. Thank you for coming. We are going to talk a lot about your cancer treatment shortly because it's complex and super interesting and specific to you, and I want to know all about that. But first, it would be really lovely to try and get a picture of you before November last year. You've just reminded me, you're 40, and you were just turning 40, weren't you?

Ben: Yes, so when I got my first preliminary diagnosis, it was yes, two days after my 40th birthday, so it was the 21st of November, and then got my formal diagnosis Friday, the 13th of December.

Emma: You're kidding me, really?

Ben: No, that was the day. Yes.

Emma: Forever carved in stone, that damned day.

Ben: Yes, yes, so yes, I'd just turned 40. You expect your 40th to be a bit life-changing and you're going to do lots of positive things, so it was weird. It was a weird concept, just suddenly finding out you've got cancer two days after your 40th.

Emma: In the run-up to that, what was life like for you? What kind of a person were you?

Ben: I would consider myself quite a healthy person. I'm relatively active. I have a dog that I walk every day. I'm really involved in yoga. I used to do yoga retreats. Healthy diet, healthy weight, didn't smoke, didn't drink to excess. I basically didn't tick any of the boxes related to esophageal cancer, so I was really lucky when my GP said, "Let's send you for some tests. You probably won't have cancer, but it's a possibility."

Emma: Was there anybody in your family that had worried you? Had anything like this ever crossed your mind?

Ben: No. Nothing. There's no family history of cancer, no family history of esophageal cancer. I think one of the main causes of esophageal cancer is acid reflux, so I don't have any acid reflux either, but my brother does, and he's on medication for that, and I was always saying to my brother, "Make sure you take your meds, make sure you take your meds." because the acid can cause cancerous cells, ironically.

Emma: I need to know more about your cakes. Where did your love of baking come from?

Ben: I've always loved cooking.

Emma: Your gorgeous mom, Teresa, is here. Did you use to cook together?

Ben: Yes, so as a kid, I'd always be brought into the kitchen. They would let me help with the baking and the cooking, and I'm more of a savory cook, so I'd do lots of breads, main meals, and I thought, actually, I'm going to try and branch out a little bit and do something a bit sweeter, so it's not come naturally, but I really enjoy it. It's really good. I bought myself a stand mixer, so there's no turning back.

Emma: What color is it?

Ben: She's black, black, and sparkly. She's called Sinéad.

[laughter]

Emma: I'm really envious of your mixer called Sinéad. We must meet at some point. We've got a healthy, active, food-loving, fairly happy man.

Ben: Yes, yes, definitely. Yes.

Emma: Hurtling towards your 40th birthday, and you get a little rumbling that something's not right. At what point did you know that things weren't quite right?

Ben: I'd just moved house and we're sat in my surface, surrounded by boxes, hadn't set the dining room table up, and all of a sudden I'd just thought, "Do you know what? I'm finding food's quite difficult to swallow," but put it down to the fact that I was rushing my food down because I needed to empty boxes, tidy rooms, hoover, and I sitting myself in a position that is not conducive to healthy eating, I suppose. You're hunched over but it continued, and it got worse, and I thought, "Do you know what? I'm going to go to my doctors."

Emma: Was it painful?

Ben: Not at first, just difficult to swallow. The only way I could describe it was if you've got a really dry baguette, you take a massive bite out of it, and it gets stuck in your throat, and it's hard to swallow. It was like that but all the time, and I just thought, "Actually, this isn't right. I need to explore this with my GP a bit more." that's what I did. I made the appointment with my GP.

Emma: Was it a case of when you were there struggling to find the words to describe it, did he understand? Did he or she understand immediately what you were trying to tell them?

Ben: He was asking me different things. "Have you been through a lot of stress recently?" and I said, "Well, I've just split it with my partner. I've just moved house, and I've got a new job all within three weeks of each other."

Emma: Maybe a yes.

Ben: Pretty stressful, yes. He was like, "It'll probably be that, but I'm going to--" instead of sending me away and saying, "Come back in two weeks or come back in a month." He's like, "I'm going to send you for an endoscopy and just get that checked out because I'm not happy with it." and I'm so pleased, I'm so lucky that he did that straight away.

Emma: How long did you have to wait between him saying that and you going?

Ben: He said, "You'll probably get an appointment within two weeks." Within two weeks, I'd had my appointment, I'd had my endoscopy, I'd had biopsies taken, I'd had my preliminary diagnosis of, "We think you've got cancer, but we are not too sure until we get the biopsies back.' I'd been referred to Macmillan, I'd met my Macmillan nurse, and I'd been referred to my dietician all within two weeks. It was like a whirlwind. It was so quick.

Emma: In one sense, obviously, that's absolutely brilliant and the way it should be. In another sense, coping with that enormous amount of information in such a short space of time. You went to the GP on your own?

Ben: I didn't tell anybody I was going because I didn't think it would be anything, and I didn't want to worry people. Went to my endoscopy all by myself, and one of my really good friends actually works in a hospital, and she was like, "Actually, when you're finished your appointment, I'll have finished work, so I'll meet you." I just remember walking up to her, she was in the corridor, and she said, "How are things? Everything's okay, isn't it?" I said, "I think I've got cancer." She said, "What do you mean you think you've got cancer?" I said, "The doctors just said, 'I think you've got cancer.'"

Emma: You go to have your endoscopy, did somebody mention the cancer word immediately after that?

Ben: Immediately after that. I was still on the bed where I'd been laying, having my endoscopy.

Emma: Good grief.

Ben: I sat up, wiped my mouth because you obviously got a camera down your throat. There's dribble everywhere.

Emma: Super uncomfortable.

Ben: Yes, and the doctor went over to the computer, had a bit of a look at the images that he'd taken, came back, said, "These are your biopsies." I was really interested being a nurse. I wanted to have a look at the little bits of this growth they'd taken away, and then he said, "I believe you've got cancer," and those words will just ring in your head probably for the rest of my life, so yes, it was a shock.

Emma: Can you remember much after that word, of that day?

Ben: It was all a blur. After that, you get put into recovery for a couple of hours to make sure you're okay.

Emma: You are on your own at this point?

Ben: I'm by myself, yes, in this recovery bay, and I remember there was a nurse that came over to me, and she explained that she was the specialist upper GI nurse and sat down with me and spoke to me for ages, and then I remember she was explaining a lot of things, and I looked down at her name badge, and it said Macmillan on it, and I thought, "Oh, my God, things have just got really, really real, really quickly." Until I saw the words "Macmillan nurse" it was just a blur. It wasn't real, really, and that really hit home because obviously you know, "My gosh. I've got cancer."

Emma: Who'd you call? Who did you go in to-- but you bumped into your friend. At this point, have you spoken to anybody?

Ben: On the day I didn't-- In fact, I was actually out that evening with rugby. I met with another friend and said, "I've not told anybody, but I just need you to know, I think I've got cancer." and you make a list of people that you need to tell. I'm a list person. I like it written down.

Emma: Well, that's the next question is what do you do? How do you then handle this situation?

Ben: You would expect that you would write down everybody's name and you'd take people's names off as you get to them and you'd tell the important people first and you work your way down the list. It wasn't like that at all. You work out when you've seen people. Actually, I told some people before I would want to tell other people, but you wanted to tell the important people in your life face to face rather than a phone call.

Emma: Of course.

Ben: I told my parents the next day. I went to go visit them. Make out that it's "Just coming round to visit. Hi, are you okay?" Then, "Guys, I've got something I need to talk to you about." It all got very serious very quickly.

Emma: I bet that must have been super tough. Explain to me what you have then at that point, what you have been diagnosed with.

Ben: I was told that I had cancer in my esophagus. They thought I'd got two growths. They said, "We think you've got cancer in your esophagus and cancer in your stomach as well." Start with the initial information that I got, you're then sent for a couple of scans. Later on, I was sent for a TT scan and they said, "Actually, you haven't got two growth. You've actually got one growth." Which was a relief.

Emma: I'm sure.

Ben: It's in the base of my esophagus, which is where it started.

Emma: It's in that first dip underneath your ribs here.

Ben: Yes. Where your esophagus meets your stomach. It had grown into my stomach, which is why I thought they thought it got two. They thought I had one in my stomach, one in my esophagus. Actually, it just turned out to be one lump grown round. Then after another scan, which is called a PET scan, they could see that it was actually on my lymph nodes as well. I was told they didn't know whether I thought I'd be a stage 3 or a stage 4. Stage 3 means they can treat it with chemotherapy and then get rid of it with surgery.

Stage 4 is they can't get rid of it with surgery and they can with what they call palliative chemotherapy.

Whereas it aims to hold it in place and shrink it and hopefully, stop it from growing, but it's time-limited. The cancer that I've got is the people mainly diagnosed with it are men in the 60s, 70s, and 80s. There they don't have great outcomes because they've not got youth on their side and some of them don't have health on the side. The information that you're given is not based on my category. They're 20, 30 years older than myself. It's difficult to know the right information to believe. Well, not believe but information for me really.

Emma: It was a completely different context.

Ben: Completely. Yes.

Emma: When you end up having that conversation with mom and dad, which must have been really hard for them as well, obviously, and for you, how much about how they wanted to treat it were you able to tell them at that point?

Ben: All I could tell them was the doctor thinks I've got cancer. Then as soon as you say that, I then wanted to back it up with loads of positives to try and stop them from worrying so much. I was like, "I'm a good age. I'm healthy." I'm ticking all the boxes that you would want to tick if you had cancer, basically. Then my parents being the caring, loving people that they are, wanted to be involved as much as possible.

From then on my mom came with me to every single appointment. She's driven me to hospital, she's here with me today in London. She's got involved. She wanted me to move in with them. I've got a dog who sometimes I can't walk because of the chemotherapy that I'm on and the side effects that I've got they've looked after for the dog. They've got involved wholeheartedly really.

Emma: Did you feel as well, it's something that's coming through, it's quite common taking somebody with you as a different pair of ears really helps to properly understand what's being said.

Ben: Exactly. Yes. My mom turns up, she's got a little notepad that she writes in. She writes everything down in a notepad. With the appointments that I've had, you have the appointment with a doctor and there's also a Macmillan nurse in there as well. The doctor does his doctor talk which she understands, but not everything. Then you go to another room with your Macmillan nurse and your Macmillan nurse gives you in layman's terms, makes it a bit more digestible, all very bite-size. Then my mom gets out her notebook and says, "Can I ask you about this and can I ask you about this and what did this mean and la, la, la, la?" It's good to have somebody else there.

Emma: This is the thing though, isn't it? You're used to these environments, you are the new vocabulary that comes pouring out. When you had your first meeting with your oncologist that was to confirm your diagnosis and to start talking about how they wanted to treat it, what was said at that first meeting about how they hoped to treat it?

Ben: By that point, I'd had my former diagnosis so I knew that I definitely got cancer. The meeting with the oncologist, he basically just explained the type of chemo I'd be on and what that chemotherapy medication consisted of, and what side effects I'd probably encounter. It is just a barrage of information. It's funny until you either have cancer or somebody in your family has cancer, or you work in an environment or a company like Macmillan involved in cancer, you don't really realize how many chemotherapies there are out there. You just presume it's like a paracetamol, everybody has chemotherapy.

Emma: How did you find out that there were different forms of chemotherapy? Were you told, or was it something that you observed and found out?

Ben: I think, yes, just researching online really. Also when you go and have your chemotherapy, you're in a bay with a number of other people, and above them is a whiteboard with their name and what chemotherapy they're on. You look around and nobody is on the same thing. You're just like, "Oh my gosh. There is so many different types." Obviously, because it needs to be specific to the person and specific to the cancer, but you just don't realize it. It is so eye-opening.

Emma: I didn't know that either. I didn't.

Ben: You wouldn't.

Emma: No. You wouldn't.

Ben: You just wouldn't know that.

Emma: Yes, exactly.

Ben: It is so eye-opening

Emma: Is part of the consideration of the treatment the kind of person that you are obviously age, what you do, can you keep working, can you not keep working, are you moving around? Tell us then about the treatment that you eventually agreed on for you.

Ben: The chemotherapy that I am on is called FLOT, L-O-F-T.

Emma: There's no need for that type of language. It's just a question.

Ben: Sorry. Basically, it's an acronym. F-L-O-T is made up of four different medications. I get that every two weeks for two days and I have that four times. It's a period of eight weeks. Basically, I go into hospital on day one and have three medications. Then, because the chemotherapy that I'm on, I come home with a **[unintelligible 00:16:58]**, which is in a pump, which is weird. You expect it to be full of like cogs and battery-operated all plugged in, but it looks like a baby's bottle. There's a balloon inside of it full of your medication and basically, the balloons slowly deflates and pushes your medication out.

Emma: How is it administered to you?

Ben: I've got a PICC line in, which is basically a catheter straight into my vein which is there the whole time.

Emma: Where is that?

Ben: It's just above my elbow. A bit higher than where you would have blood taken from. You're basically carrying around this baby's bottle full of chemotherapy for 24 hours, and then a district nurse comes, detaches your pump, takes it off, and then you wait two weeks for your next FLOT. It's amazing being able to have your medication at home in your own environment, around loved ones, not in a clinical environment. It's amazing how far it's come on.

Emma: Now in the comfort of your own home with the support of your loved ones around you is priceless, is absolutely priceless. I'm sure. Also how quickly are you feeling the effects of those treatments? Are you able to bake at home? Are you able to do that for a short while, until it really kicks in?

Ben: Yes. Your side effects come in stages and they change each time you have your chemotherapy. The first time I had my chemotherapy, I was side effect free for two days, which I didn't expect. A little bit tired. I was told I would experience nausea, which I didn't have either time. Then the second time they came on a lot quicker, the side effects. I had lots of tingles in my extremities, which would be painful if it cold. I would have tingles in my mouth if I had a cold drink. No ice in my gin and tonic.

Emma: They're awful, awful.

Ben: Horrendous. You would have an upset stomach but in between each side effect, you'd have a couple of side-effect-free days. It's in stages. It doesn't all hit you at once. I know different people experience different things as well. This time round, I've had hair loss. My brother who is naturally bald and has all the equipment said, "Get around here. As soon as you start losing your hair, I'm going to buzz it off for you.

Emma: Because you're very proud of-- You have a quiff to grow back at some point.

Ben: Yes. I have really thick hair. I've always loved my hair and I've always been really proud of my quiff and it's almost become like a bit of a mascot. That's how I've been known, the guy with the quiff. Knowing that it was going to fall out and losing that control was difficult because you can walk around or I felt I could walk around and nobody would know I had cancer. Unless you see the pick line in my arm or I start talking about it. When you see somebody who has no hair and no eyebrows, they've lost the beard and you know that person's having chemotherapy. It meant that I was suddenly very visually a cancer patient and that's a hurdle, I think. It's difficult to get your head around. Thankfully, at the moment I still have my beard. It is coming out. I just thought I didn't need to accept this. I think I made a decision from a very early age not to let the cancer define me, and not be controlled by my cancer, and not be somebody suffering from cancer, but be somebody living with cancer.

I thought, "Right, I'm going to get this shaved off, I'm going to be bold, and it's going to be fine." I know that the chemotherapy is working. At the end of the day, I'm in it for the long run. I'm in it for the surgery at the end and to be cancer-free. If I lose my hair, if I lose my quiff, the mascot is not there for a while, it's fine.

Emma: That's a great thing about hair. It grows back.

Ben: Exactly.

Emma: It's really interesting. It's always really nice to speak to a man about it because I think people often assume that men would find it somehow easier to lose their hair. It's something that maybe only women will really struggle with, but not so and it's good to be reminded that it's still visually important as a means of identification **[unintelligible 00:21:16]** who you are. It's part of who you are.

Ben: I was speaking to a guy who, he doesn't shave his hair completely, but had it really short anyway and he was saying, people thought that it wouldn't affect me that much, because I have really, really short hair anyway. I have a bit of a crew cut but it was like it affects everybody. Not the same but your hairstyle defines the person that you are. It's almost like the crown on your head that matches the fashion that you waering. It defines who you are as a person definitely whether it's shot, whether it's long. It's difficult.

Emma: Did the schedule of treatment and the way that they spelled it out to you did that give you some comfort? Was that helpful?

Ben: Yes, definitely. At first, I was saying before that things just kind of went really, really quickly. I was saying to people, they'll probably have me in for surgery next week because everything's gone so quickly but then after that initial investigations that you have, there is a period of waiting, and you are just left in limbo, and you think, "When am I going to get my results, what my results going to be." As soon as those results have come in, and you're meeting with your doctors and your nurses and they give you that timetable of "This is when it's going to start, this is when it's going to happen, bum, bum, bum, bum," you can start putting things in your diary and you do feel a little bit more in control. That really, really helped knowing, saying to my friends, "I probably won't be okay on this day. I probably can't meet you. **[unintelligible 00:22:40]** the week afterwards, because I think I'll be a bit better then." It definitely helps just get a bit more control back really.

Emma: What goes through your mind in the waiting time?

Ben: I think everything. I think initially like I was saying, I wanted to have this positive outlook to support myself but also to support others as well but you do have your bad days and your mind does wander when you do think "What if the chemotherapy doesn't work, and I can't have surgery?" Then I've got a really limited life basically, in terms of time. "What if this doesn't work? What if it comes back again?" All these things go through your head. I think it's healthy to think about these things because you can get mentally prepared for it and you have to come to terms with maybe things won't work out as people are saying they might do or as well as the I hope they're going to do because there's always a what if. Your mind goes to dark places. I think that's healthy. I think you have to do that.

Emma: Once the treatment kicks in, you've got that framework to hang on to and you start doing the "Yes, I can do that on Saturday," how have you personally found the treatment? Apart from losing your beloved quiff, how have you found it dealing with it because you're on-- We're doing number three tomorrow?

Ben: Yes, tomorrow?

Emma: Oh, my Goodness me.

Ben: I know.

Emma: It's nearly done. I'm excited. I've only just met you and I'm really excited. That's got to feel good. Do you approach another chemo with a sense of dread or is it just something that you got to do?

Ben: People are saying, "How are you feeling about going for your chemo tomorrow or next week?" It's almost like you are stepping up the ladder to get to the endpoint. It's a mixture of feelings. I am excited to be going for my chemotherapy tomorrow because you know it's chemo three or four and it's a bit closer to the surgery that's going to be happening but you also know that it's going to come with a side effects and it's going to come with its downsides. There's a part of you that dreads it. For me, it has been about focusing on the positives and accepting that there are going to be bad days physically and mentally and that's what your friends and family are there for. That's who you pull on when you are having a bad day. It's a mixture of feeling excited, but dreading the fact that you might have to be rushing to the toilet or you going to have tingles and you can't go outside or you might be a bit tired. It's a strange concept.

Emma: How do you practically prepare because I know-- Who packs the chemo bag?

Ben: I'd actually not even thought about a chemo bag until somebody said on Twitter.

Emma: What is a chemo bag?

Ben: Chemo bag is basically just like a bag that you take to chemo that's basically full of anything and everything that you can do to pass the time. When you're in hospital getting the chemotherapy, you're there for about seven, seven, and a half hours.

Emma: Wow. Oh my gosh, that's a long time.

Ben: It is. My chemo takes about five hours to fully infuse. It's a bit like a long-haul flight bag. You'd have a pack of cards in there, you'd have Bananagrams or-

Emma: Bananagrams.

Ben: -Scrabble. Passes a lot of time this Bananagram.

Emma: You're 40, man.

Ben: I know, yes. It's a good game, I like it. I'd take a book, anything that you can find comfort in. You take the necessities. You might take a tablet that you might have downloaded a few programs on et cetera, a bit of music. Then you take things that are going to help in terms of making yourself feel better. I've got a little pencil case, it's got hand cream, it's got face wipes, it's got face moisturizer.

Emma: Have you got a spray mist?

Ben: I've got a spray mist.

Emma: Good man.

Ben: It's got things that are-- Essential oil roll-ons to help me relax, center yourself a little bit. It's just anything and everything. You don't use 50% of the stuff that you take with you.

Emma: Of course, you don't.

Ben: But it's there in case you need it.

Emma: Absolutely top. Did somebody suggest that to you on Twitter?

Ben: Yes. Somebody suggested it on Twitter and I'm really pleased they did because it means you can start getting a bit prepared and you can be like, "Oh, yes, I might just have a bit of a freshen up now and wipe my face, put a bit of hand cream on. [laughs]

Emma: Yes, you are absolutely right, though. All those little things matter. They matter-

Ben: Yes, those creature comforts.

Emma: -[crosstalk] matter. When you get home is there-- Because obviously, your cancer is in a really awkward place for you to eat and you love your food. I want to talk about your blog. How have you coped with that side of things?

Ben: One of the most difficult things that I found was not being able to eat food properly and finding it really difficult to swallow. When you're a big foodie, and you get a lot of comfort from food, I get a lot of comfort cooking for people cooking for myself. It's almost like a bit of a de-stress at the end of the day you come in from work, you get your saucepan out, you make something and you can kind of reflect on the day, and not having that was really difficult. Mealtimes we sit round a table, we all eat together. There'd be big pots of stuff in the middle of the table, you're leaning over, you're getting yourself some pasta, some wedges, and et cetera and I was suddenly taken away from that.

I would have a plate of food that would take a long time to eat, everybody else would be finishing and it would really highlight to me that I'm not well, and I'm not normal anymore physically. That was really difficult. At one point, I couldn't eat any solid foods at all and it would take me an hour and a half to eat a bowl of really smooth soup, a bit of tomato soup an hour and a half. It was really difficult. Thankfully, that's one of the things that I got back really quickly when I started chemotherapy. From day three of my first lot of chemotherapy, I just suddenly burped because I couldn't burp. That was one of the things that I thought, "Oh my god I just independently burped without having to try and make myself." I thought, "Oh, can I eat now." I started eating certain things like, "Oh, my God, the chemotherapy is working, I can now sit down with my family and have a small bowl of pasta with them and finish almost at the same time instead of feeling rushed or pressured." There was no pressure from anybody, but you put pressure on yourself.

Emma: Of course you do.

Ben: Because you want to be normal. That's all you want from this.

Emma: You've mentioned as we've been speaking, the four chemotherapy sessions finish, and then there's some surgery.

Ben: Yes.

Emma: Tell me about how that's scheduled and what you expect to happen.

Ben: After my last lot of chemotherapy, I'll have a four to six-week period where I'm going to recover from my chemotherapy, my immune system gets back up and running the way it should do. Then the beginning of April is the planned date for my surgery. Because of where my cancer is, basically, they're going to be taking the bottom of my esophagus off the top of my stomach off getting rid of that. Then they're going to join the rest of my stomach up to my esophagus. Create a hole in the esophagus and basically I have a smaller stomach. I'll have to eat smaller portions more often about five or six times through the day. When the surgeon was telling me this, explain that and he said, "Is that all right?" and I said, "Yes, that's fine. You do what you need to do. I'm just going with the flow so long as you can get at me, cancer-free, that's absolutely fine. You just do what you do."

Emma: I'm very excited for you. Does it feel like there's light at the end of the tunnel?

Ben: Definitely and in other people, they don't have that light. I have through my Twitter feed and through my blog have connected with people and I have met with people who unfortunately are at stage four and there's definitely light at the end of the tunnel for me. It's difficult because it's not there for everybody, but there is. When I meet with these people, they're saying things like, "I'm going to make the most of the time that I've got." There is glimmers of light for everybody. It's just different light for different people.

Emma: One of your lights has been your blog. Which is brilliant and funny and gorgeous and lovely and I'm sure has made a massive difference to how you've dealt with all this. Was it an immediate thought or did you think "I've got to write this down." Are you a writer?

Ben: Knowing this light? I had a Twitter feed. I dumped that quite quickly and then got a new Twitter feed that was specifically focused around me and cancer. One of the main things I wanted to do when I was diagnosed was to help others. Being a nurse, you want to be able to help others in terms of their healthcare. It also gave me a purpose as well. I worked full time and when I started my chemotherapy, I stopped and I thought, "What am I going to do?"

I started writing these tweets and I quickly got to realize I've got a lot more to talk about than this set number of characters that Twitter's given me on a tweet and people were saying, "Write a blog, write a blog." and I was saying, "I can't write a blog. I've never in a blog. I don't even read blogs. Do people read blogs anymore?" I didn't know. I very quickly just thought, "Actually you guys are right. I'm going to start writing a blog." I focus them around very specific areas around cancer and around esophageal cancer, recipes that are making it easy to swallow.

What my FLOTS been like, how my PICC line was done, to give people a timeframe of "All right, this guy waited four weeks for this to happen," or "This is what this person experienced." and it's quite therapeutic for me as well. I get to write down what's in my head so I get a bit of, "There's something positive for me as well."

Emma: Getting it out.

Ben: Exactly. People are coming back saying, "That was really helpful. My dad's got this," or "I'm experiencing this." It was really good to know what might happen to me as well. There's definitely positive feedback coming from it, which is all I want. I actually just thought, "No one's going to read this. My friends might join it." but there's so many people that are reading it.

Emma: The recipes, tell me about the recipes. I see a master chef challenge on the horizon here.

Ben: One of the things that I found quite difficult was knowing what would be easy to swallow and things that you wouldn't even think would be easy to swallow so people say, "Have toast." and you think "What? Toast is dry."

Emma: Yes. That's exactly.

Ben: Cheese and crackers were really easy to swallow.

Emma: That doesn't make any sense at all.

Ben: It makes no sense. One of the things I wanted to do was put some healthy recipes out there that would try and stay away from things like refined sugar, try to use more natural things like maple syrup or honey but also things that are going to be easy to swallow. Things like garlic prawns, seafood was with me for a long time. Fish and seafood, because it was easy to swallow. Garlic king prawns or garlic mushrooms, something that's got a bit of lubricant in it. I like buttered or **[unintelligible 00:33:56]** that's going to be easy to go down and something that's got taste as well. Thankfully my taste buds at the moment haven't been affected, but I know that they might do in the future, but people generally have a bit of metallic taste when things all throughout the day. I wanted something that's going to have a bit of spice or something that's got a bit of flavor to take that away-

Emma: It's really lovely to meet you and speak to you and share such a positive outlook. What does the future look like?

Ben: More immediate future, is get through treatment, get through surgery and come out on the other side, hopefully, and things to look quite positive. One of the things that has really hit home is I've really enjoyed making connections with people who are in this same situation as me, that I've been through something that somebody is going to be through and you do form those connections.

It has made me think to myself "Actually, is there a future in this for me, I've really enjoyed it?" and looking at things like Macmillan this is something I can do in the future to be working with Macmillan in the future. I'm definitely going to be raising money at some point. I've raised money in the past for Macmillan before I did the National Three Peaks 24-hour challenge back in 2009.

Emma: Yes, but you are from Yorkshire. You do this in your sleep **[unintelligible 00:35:16]** challenge, you guys. It's just like literally going for a walk for everybody else. I'm very impressed. Could there be a Macmillan nurse in you?

Ben: Possibly, who knows, watch this space. It's definitely something I've thought about for sure, definitely. Macmillan have been brilliant and they've really helped me. For me to continue my journey, hopefully being cancer-free with somebody like Macmillan, for me, would be amazing because I've just enjoyed it so much, so yes. It may be on the cards, who knows.

Emma: Listen, that you are literally the perfect combination of having experience, a natural instinct for caring as a nurse, and you can bake. Coffee morning.

Ben: Exactly. Grab your mug. We're off.

Emma: Grab your mug, we're off. On that note, Ben, thank you so much. We wish you the best of luck, with the rest of your treatment. We will speak to you again, I'm sure in the future about your fundraising activities and where your life has found itself.

Ben: Thank you very much, thank you.

[music]

Emma: Hello, Daney. Lovely to see you. Daney Bell is one of our magnificent Macmillan professionals. What were your thoughts on listening to Ben's story?

Daney: He describes really is what a lot of people experience when they get a diagnosis and go through treatment with cancer. I'm sure a lot of people identified with Ben.

Emma: He had an interesting combination of treatments as well. He had chemotherapy and then surgery. He had no idea that there were so many different types.

Daney: I know, it is mind-boggling, but there are fairly standard treatment regimes for different types of cancer. As I've said before, they're given acronyms to make it easier for the professionals to understand, but it's not an unusual process for some cancers to have what we call neoadjuvant and then surgery. Some people then have something after that as well. It depends on the type of cancer and your response as well to treatments.

Emma: Ben, we know took his fantastic mom with him who took a notebook and a pen to write things down. Dr. Google obviously answers some questions for some people. If you want to find out more about the treatment you've been prescribed, is there someone better to go to?

Daney: There are lots of information sources out there about the different treatments. Essentially the treatments center will have fact sheets or information about the types of treatment that you are having but what they need to understand is what type of side-effects that you're likely to get, just in case you need support out of ours equally going to Google and hopefully hitting on one of our webpages will give you understandable information and there's lots of downloadable information off the internet from our website that people can use.

Emma: Daney, are you entitled to a second opinion if you don't want a certain type of treatment?

Daney: Absolutely. You can ask your specialist if it's possible to be referred somewhere for a second opinion, and sometimes you can go to your GP for that as well. The specialist is likely to know. Some people will actually look it up and they will look up their clinician and they will compare to other hospitals. You do have to have a referral, unfortunately, you can't just rock up. My advice would be if anyone wants a second opinion and they just have to have an open and honest conversation with their consultant,

Emma: Ben gave us a really super tip about his cancer bag that he took. What are the things that you can tell us about preparing people for treatment?

Daney: One of the things that people often struggle with is the traveling to and from treatment that takes its toll, loss of appetite, feeling tired. Planning for that around your treatment regime can help and just making some adjustments to make it easier for yourself. If you are someone like me, I'm always rushing around and I have to do everything, but I probably wouldn't be able to do that and I'd have to make adjustments and I'd have to accept help.

For some people, they're not used to accepting help. I think it's having an understanding of what your treatment regime is, what the potential side effects might be. Then also after you've had the first treatment, you'll have a clear indication of how it might impact you so that you can plan.

Emma: Talking about side effects, Ben, bless him, did lose his beloved quiff, great thing about hair. It grows back. We will see the cliff again, taste buds are okay, but what are the common side effects of a generalized chemotherapy, radiotherapy plan?

Daney: Nausea and diarrhea are a common one. For some people, they get a very sore mouth and add it to losing your taste. That can be really, really challenging in terms of eating. Some people get issues with sensations in that-

Emma: He talked about the tingling, didn't he?

Daney: Yes. You can also get something, we call it hand and foot syndrome where you get painful sore palms and sometimes blisters. It depends on what type of drug regime you're having. I've heard people say in terms of all of the treatments that chemotherapy is what they found the hardest to cope with.

Emma: Tell us a little bit about losing your hair because it was really interesting talking to a man because I think everybody assumes that it's just women. We are the only people that would care about it, but it is a common side effect. Are there alternatives now available to reduce that or to help that?

Daney: There is a cold cap, but that in itself seems like an experience that you have to be resilient to coping with just to keep your hair, and when you think about how great some wigs are out there, made of natural hair. I've come across people and you wouldn't even know that they're wearing a wig. It's very individual. Really very individual. I think the thing to remember is it's not just the hair on the head that they lose. They'll lose their eyebrows and their eyelashes. It's that whole look really.

Emma: That's tough.

Daney: That's tough. Yes.

Emma: How do you know when your treatment's working? Do you feel better? How do they tell you, "Yes, this is going to plan?"

Daney: They do that by monitoring. They'll do that with blood tests, scans. Because you obviously have to have a blood test to make sure you're well enough each time to-- Your body is well enough to cope with the chemotherapy, so before each cycle, you will have a blood test. Usually about three months in if you're on a six-month regime, they'll do a stock take and see what the impact is.

Emma: Do you have regular meetings with your oncologist during that time or you're dealing with the treatment centers?

Daney: You will have monthly, depending again on the type of cancer, but generally, you will have a regular visit to a clinic just so they keep an eye on you. The GP will have been informed hopefully that you've started treatment. Although sometimes those communication processes aren't as efficient as they could be, but ideally, the GP will know.

Equally again, that's why we've put roles in like clinical nurse specialist because if you're struggling and you've got problems, you can phone them and they can even give you advice over the phone or just bring you in ad hoc just to support you with whatever you're managing or struggling with.

Emma: We met Ben when he was number three or four, so the light of treatment was definitely-- He was at the end of the tunnel which is amazing. What happens then when treatment stops? You finish your treatments or the planned treatment has ended, what happens then?

Daney: People often find that really, really difficult because they've had lots and lots of support through treatment. You often hear the term it's like falling off a cliff because they're suddenly have been given a three or a six-month appointment to come back for a check-up and then not having that regular interaction with the hospital [crosstalk]I--

Emma: What's your advice about that **[unintelligible 00:43:40]** that time?

Daney: I think if you plum yourself in to support right from the point of diagnosis, you will still have that when treatment finishes. Whatever works for you as an individual in terms of support, whether that's peer support or focusing on your health and wellbeing and doing that with peers or whatever, is just to keep doing that. If you start that before treatment and maintain it, then that's helpful.

There are always places to drop in like the information support centers or ringing a support worker or a nurse specialist, but it's not the same as peer support and having that support locally to you.

Emma: Daney, thank you again as always, and our thanks to Ben for sharing his story. To get more information about what we've talked about in this episode, then you can go to our website macmillan.org.uk/talkingcancer. If you're enjoying the series, why not give it a rating or a review? It helps others find the podcast more easily. I'm Emma B, Talking Cancer is a Macmillan Cancer Support podcast

[00:45:01] [END OF AUDIO]