



Emma: What happens with your work when you receive a cancer diagnosis?

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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.

In this episode, we're talking cancer with Helen.

Helen: I'd apply for a job, I was pretty good at getting through to second interviews, and as soon as you mention cancer, you suddenly found that it would stop.

Emma: Helen has a hereditary gene which makes her more susceptible to cancer. So much so, she's been diagnosed six times.

Helen: I've had bowel cancer, cancer of the wounds, cervical cancer, breast cancer, skin cancer.

Emma: Helen talks to me about how her numerous cancer diagnoses have affected her career and her finances.

Helen: The night before I went in to have surgery, my boss said to me, "I think we'll have to get somebody else in." I ended up, two days after my surgery, I was doing payroll from my hospital bed.

Emma: What has nearly three decades of cancer looming large taught her about the way employers handle the disease?

Helen: Years back, Big C was something you didn't speak about and you shove it down under the carpet, whereas, I think, now, people realize that it's not necessarily a death sentence.

Emma: Plus later on, Macmillan professionals, Dany and Liz, are popping in for a cover to talk about how to deal with work when you have cancer.

Dany: It's important that you're open with your employer and tell them about your cancer so that they are there to be able to support you.

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

[music]

Emma: Helen, welcome along. It's lovely to meet you.

Helen: Hi. Lovely to meet you, too.

Emma: Now, most people who we've had a chat with and who've joined us on the podcast have had a single diagnosis of cancer. Tell us how many times you've been diagnosed and what you've found out about it.

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Helen: I've been diagnosed with cancer six times. I'm at risk of getting several other types of cancer. I've had bowel cancer, cancer of the wounds, cervical cancer, breast cancer, skin cancer, and I've found out that I've actually got a genetic condition, which the easy word is Lynch syndrome. That gives you predisposition to actually get a lot more cancers, and it also is hereditary. My son has tested positive for it. It means that in the future, he's got an 80% chance of getting bowel cancer.

Emma: On a very basic level, it's really lovely that you are here. It's absolutely amazing. I had no idea that this was a condition, and we're going to talk about lots more.

I want to take you back, though, to life before cancer and before the diagnosis. What was Helen like before that initial diagnosis? What was life like for you?

Helen: I was bright, bubbly, and not long gotten married. I had a two-year-old son. I was working full-time. I enjoyed dancing, reading, walking. Just normal things, family things.

Emma: That initial bowel cancer diagnosis, then, what were the first indications, the first signs that you had that were worrying you?

Helen: First of all, I had a lot of stomachaches and a lot of bowel cramps. I was going to the toilet a lot more, and I lost a lot of weight. I went to my doctor and he told me it was IBS. Eventually, it took them 18 months to even refer me to a specialist, but only because I kept bugging them. When they eventually did the test-- I had the test on Monday, got the results back on Wednesday, I was in the hospital on the Sunday, had the operation on the Monday.

Emma: Tell us when this was as well, because we're going back a while, aren't we?

Helen: We are. 1991.

Emma: Okay. That's nearly 30 years ago.

Helen: Yes.

Emma: That process obviously sounds extremely frustrating. When you left the GP for the first time, how did you feel about almost being brushed off?

Helen: The GP that was telling me there was nothing wrong?

Emma: Yes.

Helen: I felt I was not being listened to. Basically, I was told that I couldn't have anything seriously wrong with me because I was too young, the wrong shape and the wrong sex to actually have anything serious like bowel cancer. It was actually hinted out that a lot of it was psychological.

Emma: Okay. Now, I know at this point, then you get your diagnosis and you're into a hospital. That must have been a really difficult time for you. I know that home life wasn't particularly happy at that point as well.

Helen: That's right. My husband couldn't cope with the idea that I had cancer. We were also not getting on that well. I had a two-year-old son, and at back the of my head, I was just thinking, "How am I going to cope? How is my little boy going to cope if I don't get through this?" I was scared, didn't know what the future was going on, and the doctors weren't telling me anything.

Emma: It's amazing how much has changed over the years, isn't it, on this?

Helen: I'm glad to say.

Emma: Now, this experience of the initial bowel cancer diagnosis, you get over that. At what point then are we into realizing that there's something else, there's an underlying hereditary issue that is prompting all these different cancer diagnoses?

Helen: I'd had my breast cancer, cervical cancer-

Emma: Oh, Helen, good grief.

Helen: -at that time. [laughs]

Emma: My gosh.

Helen: I had those, and I was saying to my doctors, "There must be something going on here," but they said, "No, no, there's nothing." Then just by chance, my sister started having some problems, and because I had had bowel cancer, she was worried. She wanted to get tested. Genetic testing was in its very, very early days at that time, and the only way that she could get tested was if I was tested. I had to prove that the cancer went back three generations. I had to come up with the death certificates and everything else to prove this-

Emma: Oh my goodness me.

Helen: -and to prove it was all on one side as well, because that was the way. I had a blood test done, and it took them six months to get the results back.

Emma: Waiting all that time must have been excruciating. Was this maybe an answer, an explanation to what was going on that was something that was quite welcomed, almost, that at least you could call it something?

Helen: Well, at least somebody was listening, and at least they were explaining to me some reasons why this might be happening. Also, if it was something hereditary, I wanted to make sure that my family and my sisters, and everybody else, because it doesn't just affect me, it would affect my sisters, their children, even my mom because it turned out that my mom had passed it to me.



Emma: No. I mean, yes, I guess, of course, of course. You get this diagnosis, which is called? One more time.

Helen: Lynch syndrome. If you want the real name for it-

Emma: Yes, please.

Helen: -it's hereditary non-- I've forgotten it. Sorry, it's gone.

[laughter]

Helen: HNPCC, Hereditary Non-Polyposis Colorectal Cancer.

Emma: Try saying that after a few Sherries on a Friday. [laughs] You've got this diagnosis. Does that then help you process what's happened to you and how you view and how you approach the future?

Helen: Knowing that I've got it, no, not really, [laughs] because it doesn't change anything, just makes me realize that I may have passed it on to somebody else. The good side of it is that everybody else in my family can get tested, and so they could get caught a lot quicker, and they wouldn't have to go through everything that I went through to actually get the diagnosis. My son now has annual colonoscopies and gastroscopies. It means that if he gets the teeniest, tiniest little polyp, they will take it away straightaway. The risk is high for him to get bowel cancer, but the chances are he will get caught a lot quicker.

Emma: Tell me about the current state of your cancer.

Helen: Current state of my cancer, I'm in remission, which is good. I still have chances of getting other types of cancer, but I have actually had all my colon taken away. I now have an ileostomy, so I walk around with a lovely little bag on my side who's lovingly called Donald. [laughs] I won't tell you the reasons why because it might look they don't do well. [laughs]

Emma: You should keep that to yourself.

Helen: Life's generally good. I get very tired. I do still have times when I wake up in the middle of the night, don't know why I'm feeling frightened or scared. If I do get something wrong with me, I do probably wonder more than other people might do, but generally, I'm fine.

Emma: I want to talk to you specifically about work, because I know it was important to you. What were you working at before your first cancer diagnosis?

Helen: Before my first cancer diagnosis, I was working for a design company, and I was doing finance. Perhaps most of my career has been in finance.

Emma: She's good with numbers. You worked full-time and were progressing, and enjoyed being a working woman.

Helen: I enjoyed working, and I loved being up in the city. I loved the buzz. I'm not really a stay-at-home person.

Emma: We're talking about the early '90s, which is way back now when you've got your first diagnosis. How supportive, initially, were your employers at that point?

Helen: Those employers, employers I was with at the time, they were fine. In the office, it was a bit strange because people didn't know what to say, what to do, so some people just ignored the fact that I'd been away and come back. Some people made jokes. Other people--

Emma: They made jokes.

Helen: Made jokes about me having new handbags and things like that. It was quite strange being back, but I loved being back.

Emma: How much time did you take off? You had some surgery, and then you had some treatment for the bowel cancer. How much time, door-to-door, did you have off work, really, at that point?

Helen: At that point, probably a couple of months.

Emma: At that point, did you negotiate the sick pay thing fairly easily through that company?

Helen: That company was fine. They gave me full pay, but unfortunately, I was made redundant from that company. After that, was when the nightmare started.

Emma: Tell me about how that did start.

Helen: I would apply for a job. Back at that time, there weren't a lot of rules in place to cover things like disabilities and sickness, so employees could more or less do what they wanted. I'd apply for a job. I would get through. I was always pretty good at getting through to second interviews. Then they would start talking about health. They would ask me about my health, they'd ask my sick days off. As soon as you mentioned you had cancer, you suddenly found that you didn't get any further. It would stop.

Emma: Really?

Helen: Yes.

Emma: Did that happen on several occasions, not getting through to the next stage?

Helen: On many, many, many occasions. I actually had one contract, I'd actually signed the contract. This was after I had my WHIM cancer. They sent me the contract. I was due to start. I filled in the medical form, sent it in, then all of a sudden, the job disappeared. Apparently, they'd restructured and they didn't need me anymore.

Emma: That must make you feel terribly sad and frustrated.

Helen: It made me feel very depressed. One of the big things about cancer is that you don't have a lot of control, and you feel a bit useless. Sometimes you feel that you're not the same person, you're not normal. To get back to work is one of the very important stages of getting back to as normal as you can be. To be told time and time again, that you can't have a job, makes you feel worthless.

Emma: You did get a job, eventually.

Helen: I got a job with a nice company, being Canary Wharf, nice people. That lasted a week.

Emma: I'm dumbfounded. What do you mean that lasted a week?

Helen: I started with them, started doing the job. After about four days, they called me in and they asked me if I had any problems. I said, "No, not really. I'm fit and well." They said, "We've noticed that you go to the toilet a lot, and we've been timing you and you spend about 10 minutes a time in there. We really can't be dealing with this. I'm sorry, you'll have to go."

Emma: Helen, at this point, man, how are you negotiating these tricky conversations with employers? At this point, are you more aware of your rights as an employee at all?

Helen: At that time, the rights weren't very much in place. It was quite difficult, but at the time, you've already been through a long struggle. I'm quite lucky because I'm quite open, I'm quite extrovert, and I will stand up for myself, but there are a lot of people out there who don't. I found the conversations very frustrating, but I was quite optimistic that I find something else.

Emma: Spool forward a decade, and where are you now? 10 years later, you are working and there are multiple diagnoses that you've experienced already. What was the situation at work at that point then?

Helen: I then eventually re-looked back about 10 years ago. I got a job in a company. I did very well in that company. I started off as the finance manager, ended up as the finance director. During that time, my bowel cancer came back. I had several bouts in hospital. The night before I went in to have surgery, my boss said to me, "I think we'll have to get somebody else in." I said, "Hang on a minute. I've been here for three or four years. You can't just do that." I ended up, so that he wouldn't get somebody in to replace me, I was working in hospital, two days after my surgery, I was doing payroll from my hospital bed.

Emma: What are the conversations that you have at that point? Was there verbal pressure at the time to come back to work?

Helen: Yes. Before I even got in, I was asked how long I'd be off. I said, "I don't know. Officially, probably about six weeks, maybe two months." He said that he was

going to be very supportive. Very supportive, but couldn't do without me all that time. Could I work at home?

Emma: You have your certificate saying you are unfit for work, but the expectations to work seem to have been quite high.

Helen: I came out of hospital, and I was working straight away from the moment I got out of hospital. In hospital, they actually confiscated my laptop.

Emma: I should think so. Goodness gracious me. It's interesting, though, because you're obviously a bright, hard-working woman, and I'm sure you had a great sense of duty to work, which a lot of people do. Is that being taken advantage of a little bit here in this situation? It feels like people know you enjoyed your work.

Helen: Yes. People can see that you are sick. I think at the back of their minds, they know that maybe you'll find it a bit hard to get another job. I think they do tend to play on it a bit because what they say is, "We pressurize her a little bit, she'll do some work because she'll be worried she's going to lose her job."

Emma: Obviously having time off work and then being out of work must have had a financial impact on your life. How have you managed?

Helen: With great difficulty. I got into arrears with my mortgage. I had to go on to benefits, which I hadn't done before. I had to take loans from friends and families. I have walked around a supermarket with a calculator to make sure that I didn't go overspending. I phoned my bank, they weren't very helpful. That's where people like Macmillan come in, because they do campaigns, and I got involved in a campaign to help try and get the banks to set up specialists people, because they have people on the phone, they don't know how to talk to people.

If your best friend got cancer, you'd find it difficult speaking to them about it. Somebody at the end of the phone doesn't know how to do that. Campaigns to help getting people to specialize operators to put you in touch with. I was top of my bank, and there was nothing they could do. The person at the end of the phone, I was saying to them, "I got cancer, I need help." They were saying, "Yes, but you'd have to go into mortgage arrears and then they'll do this and then they'll do that."

Emma: They were not listening.

Helen: I'm saying, "I can't do that. I've got a young son, I've got this." Nobody listened at the time. It has got better, I must say.

Emma: You mentioned Macmillan, obviously, were there other avenues that you pursued to find financial advice, or did you very much feel there wasn't a lot out there at the time.

Helen: There wasn't a lot out there. My main backup through the whole thing right from the start has been Macmillan, because they got websites and they have helplines. They give a lot of information about financial stuff and what to do. They



were the people that really helped me with the work issues. They put me in touch with, I have a contact there called Allison, who helps me in a lot of stuff. When I told her I was having all these problems at work, she said, "Give them this." She gave me a copy of the Disability Act. I popped it on my boss' desk.

After that, generally, he started to perk up a bit and started to take a bit more notice. I would say to anybody out there who's having problems, first and foremost, be honest with your bank, and be honest and open with your employer. Have conversations with them. If they don't listen, drop the Disability Act in front of them.

Emma: Phone Allison.

Helen: Phone Allison. Yes, she'll help you.

Emma: You have a new job, don't you?

Helen: I have a wonderful new job.

Emma: Tell us about the job.

Helen: My new job is, I've done finance all my years, and I decided that-- my last job, I was managed out because I had been off too much, so we came to a settlement. I left, I took three months off, and then a friend said there was a job going as a finance test analyst. I thought, no, I can't do IT, but then I thought, hang on a minute. There's lots of things that I've never done before that I can try and do, so I decided I give it a go.

Now I'm working in an office where they take sickness and disability very seriously. They have wonderful sick pay and everything. The most exciting thing for me when I started, and this is going to sound really, really stupid to anybody who doesn't have a stoma bag, is that they have a disabled toilet.

Emma: Doesn't sound stupid at all.

Helen: They do, they care. First time because [unintelligible 00:19:51] does have a habit of leaking sometimes, so the first time that happened, bear in mind I had only been there a month, six weeks, they sent me home. I said, "No, no, no. I can change it." "No, no, no, go home." Because it's obviously a bit traumatic. They sent me home. If I phone up and say, "I'm really tired," they say, "Okay, work at home." They are brilliant.

Emma: It can be done. I'm so pleased. It's overdue that you've been treated well at work. Now, I did want to talk to you as well, because when you met your second husband, look at the big smile on your face, you decided to convert to Islam. Has that helped you?

Helen: It has. It's given me a lot of strength and a lot of comfort, and I feel like I've found myself.

Emma: An interesting question I think is, how have you found cancer is discussed in the Muslim community?

Helen: Generally, it's not. Some of it is culture, which isn't necessarily to do with Islam, but there are a lot of myths and cultural issues with women going to see male doctors, with husbands. They don't want to tell their husbands because they're embarrassed. Some people think that they have got cancer because they're being punished. There's an awful lot of work to do.

Emma: It's tricky.

Helen: There's an awful, awful lot of work to do there. I had a friend at my local mosque who eventually spoke to me and told me that she was worried because she had a lump in her breast. It turned out that she had stage four breast cancer. She'd had that lump for over six months.

Emma: Goodness me.

Helen: She didn't go because the doctor was male. I did explain to her, "You can ask to see a female doctor. Ask them to send you to a female consultant if you're that worried." I did also explain to her that she could have somebody with her because it's all about showing yourself off to other people. There are still ways to get around that, but we do need to set up more support groups. We need there to be more help. I'm sure it's not just in the Muslim community. We're probably talking about in Hindu and Sikh, everywhere. Different cultures.

Emma: The ripple effect of your experience and your cancer story is going to have a far-reaching effect, I think, isn't it? It must be very nice for some of those women to have another woman to come and talk to who has had some experience as well. It must be really nice for that lady to have come to you and said, "I've got this and I'm worried about that." That must make you feel good.

Helen: It does make me feel good. I try to do as much as I can, even talking today, because I feel that a lot of people, they sit there in silence. They're worried about it. They don't want to talk to their family because they don't want to put their problems on the family because they know their family is going to be worried anyway. They feel embarrassed about talking about stuff to people that they don't know, or to family and friends.

I've had friends who have actually crossed the street so they don't have to talk to me, and it's not because they don't love me and they don't like me. It's just, they didn't know what to say. I think that we need to get more help from training GPs to be a bit more understanding. We need there to be better facilities at hospitals so people don't have to spend loads of money on parking, and we need to be able to diagnose more quick. There's so much more to do.

Emma: I wanted to ask you as well, that your cancer experience is so unique because it spans almost 30 years. You must have seen improvements in the workplace in that time that make you feel encouraged.

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Helen: I have. I've seen attitudes towards people with cancer changing, more facilities are available. I just said you getting more disabled toilets, you getting more ramps. You're getting people being more understanding. I think people are more open to talking about stuff now. Years back, the big C was something you didn't speak about. You shoved it under the carpet. Whereas I think now, people are realizing it's not necessarily a death sentence.

Managers are more able to talk to people. I think there's been more training going on in the background so people know how to deal with people more. I think generally, people are more aware, so even your colleagues now are more aware of what's going on. You still find that some of the cancers don't want to talk about. That's why I have Donald rather than calling it stone. That makes it easier to talk about. Generally, it's much easier to work now.

Emma: We've only known each other for a very short period of time, but used to write me as a generally chipper type of last. I know that you are encouraged by all the changes that you've experienced, but it has been a battle, clearly, for you. Does that leave you bitter and angry, or how have you coped with not just the cancer and not just the multiple diagnosis, but the trauma at work and what you've been through? How do you manage that emotionally?

Helen: I try to think about the good stuff I've got going on, and I try and be positive. Every day they are finding new cures, new ways of dealing, new treatments. When I look at how things were back in 1991, and I see how they are now, that gives me great hope for the future because things have changed so much in that 30 years. How much more can they change in the next 30 years?

Emma: We have, obviously, there are lots of people listening that may be in a similar situation at work and struggling with how to start these conversations and negotiate the landscape of employment. When you have a cancer diagnosis, what is your top tip? What's your advice to somebody who is going through something like that?

Helen: Find somebody to talk to. They will tell you what your rights are. Then be as open with your employer as you can be. Have an open and frank discussion with them so that they don't have any false expectations, so they know what they have to do. Speak to your colleagues to make sure that they understand as well.

Most of all, make sure you tell your employer that if you've been through cancer, you've been through chemotherapy, you've been through radiotherapy, if you get a cold, you're not likely to stay off, you're more likely to be at work. You're more likely to stay there, work hard. Not because you think you might get the sack, but because you need to, and because you want to, and that's the biggest thing.

Emma: Helen, thank you ever so much. It's just been a delight to speak to you. I can only imagine what you've been through, and to come out the other end with a smile on your face is quite something. Thank you so much for your time.

Macmillan professional, Dany Bell, is with me as usual.



Dany, hello, lovely to see you again. We are also joined, however, by Liz Egan, Macmillan's work and cancer expert. Liz, fantastic to have you with us. Welcome.

Liz: Great to be here. Thank you.

Emma: Now, you've both been listening to fantastic, fabulous Helen. Dany, what do you make of her story?

Dany: What an amazing lady, and actually we so need people to be open and frank about the challenges that they've had, particularly around work, but also all their other experiences so that we can help other people.

Emma: We talked to Helen primarily about work, Liz, and what was so amazing to hear from her as well, is that affirmation that going back to work and being employed is so important, not just to you financially, but also to you emotionally. It can really turn your whole work landscape upside down, can't it?

Liz: Absolutely. It can totally do that. I suppose what I'd like to emphasize is that it's not the same experience for everyone. It's very dependent on the type of cancer you have, the sort of job you have, and all also how supportive your employer is, and how supportive your line manager is going to be in terms of your experience. Some people have a very easy journey, and then some people have much more difficult experiences, and it's just going to be different for everyone. I think we have to realize that and understand that.

Emma: Dany, particularly when we've been speaking, and I didn't think I would be, but I've been very surprised about how different everybody's story is because not everybody has six months off for chemotherapy. It's just not that straightforward, is it?

Dany: No, absolutely not. As Liz says, there are lots of different types of cancer, and they're all very different. They all have a different impact on you, and that's the difference.

Emma: At the beginning, then, when you are going to start negotiating this tricky time with your employer, how should someone begin to approach their place of work?

Liz: Well, I think talking about your diagnosis is the first step to actually having a conversation with your employer about your cancer and how you're going to be managed in the workplace. Most people actually find that their employers are very, very supportive, particularly when they're going through treatment, but they worry a lot that if telling their employer, they might have a negative reaction. They're worried that maybe they would be made redundant, or that they might lose their job.

Actually, there are laws that they're in place to protect you if you have a cancer diagnosis, and actually, it's important that you're open with your employer and tell them about your cancer so that they're there to be able to support you.



Emma: When you say employer, is this walking into on a Monday morning and saying, "Can I speak to my line manager or the CEO," or is this an HR thing? Literally, from the moment, who is the first person, in your opinion, is the best place to go if you can?

Liz: Your line manager is the most important person to you, absolutely, or your supervisor. They're the person that you're going to have to talk to throughout your cancer journey, through your treatment, when you go back to work. They're the first point of contact for you. It's really good. If you have a good relationship with your line manager, it can make such a difference to your whole journey. Absolutely such a difference. I would say, talk to your line manager as your first port of call.

However, if you don't have a good relationship with your line manager, then try to speak to somebody else in the business. Maybe somebody in the HR department, if you have a HR department, and if you're worried about having that conversation, you can actually bring somebody in with you into that first conversation with your line manager so that you can get support, and it could be a colleague at work, for example, and that's really quite important.

Also if you belong to a union, sometimes it's good to bring a union rep in, but you don't necessarily want to do that unless you're feeling really uncomfortable in having that initial conversation. I think in terms of thinking about preparing for that conversation, the first thing I would do, if I was in that situation, is I'd try to find it out as much as possible in advance of the meeting about your diagnosis, thinking about what time off you might need from work, ask your oncologist, ask your clinical team, find that information out, and then what is a good tip is actually to actually write down exactly what you want to say to your employer before you go in, and then that will guide your conversation, and think about things like, do I want this information to be confidential? Do I want to tell my boss to tell my colleagues about my diagnosis? What time off would I like to request? What would help me maybe if I want to work through my treatment to stay in my job? Things like, if I'm good to be off work for treatment, how are we going to stay in touch? How often should we do it by phone, by email, face to face? If you're in the middle of treatment, you're feeling very sick, you might not want to appreciate a phone call from your line manager. Knowing all of that's really important.

Then also asking about things like, what are my sick pay entitlements? What are the policies? Are there any good schemes at work to support me? A lot of places of employment have employee assistance programs, which offer counseling. There might be some good services that your employer has that you might not know about. Do you ask as many questions as you can, get as much information as you can, but be prepared, and be prepared for that conversation, and take some notes if you want to. If your employer takes notes, you can ask for notes of that conversation. All these things, all this advice is available on our website. If you don't catch it all now, just Google Macmillan and work, and you'll get all this good, good information and advice there.

Emma: For anybody that is just getting a diagnosis, who's at work, however, the basic premises, you are entitled to some sick pay.

Liz: Well, sick pay depends very much on your contract of employment. I would say, ask your line manager about sick pay. That's really important, because there's two types of sick pay. There's statutory sick pay, which is a minimum amount that you can get for up to 28 weeks, and most people who have contracts of employment can get statutory sick pay, which will be paid by your employer. On top of that, you may have occupational or a company sick pay. Some of those policies can be very generous. Some employers can pay full pay for a period of time, and half pay for another period of time. If you work in the public sector, for example, it's very, very generous sick pay.

I would say, talk to your line manager, find out what your entitlements are. If you're any way worried and concerned with what they respond to you, just call the Macmillan support line as well. We've got some really good work support advisors and financial guides, welfare rights advisors who can give you some very good advice around issues like pay.

Emma: For someone like me, who's sitting here as a self-employed person, is there some advice that Macmillan have as well?

Liz: Well, if you're self-employed, or you run a small business, it's really difficult because what you're doing is you're juggling your own cancer diagnosis as an employee of that business, and you're also juggling the business itself, and that's a real struggle. However, we have some very good advice on our website, and also our helpline advisors will also give you some advice on finance and how to think about your finances as you move along through a diagnosis. I suggest check the website, call our advisors if you're self-employed or you run a small business.

Emma: Dany, one of the things that Liz has just mentioned, is going to that meeting armed with lots of information about your likely treatment program. Who dictates how much time you might have to ask for off work? Is that your oncologist? Is that how you feel personally? Is it what you're allowed to take for as an employer?

Dany: It's a combination, really, because there are some types of treatment and some chemotherapy regimes where you might be more at risk for a period of time if you are in an open office environment. It's important to understand if there are any risks, a period of time through your treatment. Some people don't know how they're going to feel when they have their treatment, and they're much more tired than they think, but actually if you have that open conversation with your employer, once you know what type of treatment you're having, and you've been able to ask the specialists what are the likely impacts of treatment, then you can absorb that and think, okay, actually if I just travel into work two days a week instead of five days a week, and I have the ability to work at home, I might be able to manage it, or maybe I can do some part-time hours. I think that's a very individual thing.



As Liz says, once you've got the information about the type of treatment, the potential impacts of that treatment, then you can make some choices and have some open conversations with your employer.

Emma: Yes, Liz, because it seems like the encouraging thing is that this is not one meeting where it's black and white and it's an on-going conversation.

Liz: Yes. Because I think the time off that you might need at the beginning when you're just diagnosed, and you're just going back through treatment, it's going to be very different from when you've finished your treatment and it's time to go back to work. Actually, I think probably earlier on it's clearer what time off you might need because hospital appointments dictate that, really. I think the trick bit is when your treatment finishes and you're in that recovery stage, and whilst, like Dany said, your oncologist, your clinical team can give you some indication of how you might feel over a period of time.

What's really, really hard is to know exactly what's going to happen, and actually how much time off you might need, and how you would phase your return to work, for example. One thing that you can do is make sure that you talk to your oncologist, try and get some sense of that, and then talk to your GP about issuing you with a footnote. Footnote is really quite important because on the footnote, your GP can actually say, suggest adjustments that you might have for a period of time, like a phase return to work.

Emma: That can start with your GP as a conversation there.

Liz: It can start with your GP. They are not experts on the workplace, obviously, but they can listen to you and try and understand your needs, and ask you what has your oncologist told you. Then when you go to talk to your line manager, you can have your footnote with you, and have that as the basis of your discussion with your line manager.

Now, some workplace, they will have an occupational health department, and your line manager may request that you have an occupational health assessment to understand your fitness to work. That is also a fitness statement that could also form part of your conversation with your line manager.

Emma: This is fantastic, when you have a good relationship with your line manager. In the unfortunate event that you might not and things aren't going to plan, and you are experiencing some resistance, where's the first place, and what are the first things you suggest you do?

Liz: Well, I think, first of all, as Helen mentioned earlier, you have rights at work when you have a cancer diagnosis, and there are two aspects. Across the UK, there is legislation in place, equality legislation in place that protects you from being treated less favorably because you have cancer from other people, let's say, in the workplace. It also puts a requirement on the employer and your line manager to make what we call reasonable adjustments, to support you, to say, stay in your job.



Now, I want to be clear. What's a reasonable adjustment? It can be anything, absolutely anything that supports you to stay in work. It can be support for a phase return to work, for example, over, let's say two, three months to help you get back, to build up your strength, to get back into work. It can mean enabling you if you can, to work at home for a period of time, avoiding rush hour traffic traveling and rush hour. It can mean working part-time, it can mean changing your job description, in fact, or changing your job on a temporary or a long term basis with your agreement, of course. It can mean things like, seating you next to toilet areas. For example, if it's easier for you to use bathroom, for example.

Adjustments can be absolutely anything that will support you to stay in your job, but there's always a technical issue there in that they have to be reasonable adjustments. Reasonable means essentially, is there a cost there? Is it possible for your employer do that? What might be reasonable in a massive multinational company might be very unreasonable in a tiny small business. I think you have to take that into account, and it's a judgment call, really, on your part and on the part of your employer.

Emma: Helen mentioned not having to tell her employee pre being employed about her diagnosis. Is it a requirement?

Liz: This is a technically trickier issue. In England, Scotland, and Wales, your employer shouldn't ask you about your health prior to offering you the job. However, there are some exceptions to that. What I would suggest is that people come to our website and have a look, or talk to one of our work support advisors if they want to actually talk about those exceptions.

In Northern Ireland, your employer can actually ask you about your health as you're interviewed, but what everybody needs to remember and to understand is actually, if you talk about your cancer, cancer is classified as a disability across all the four nations in the UK. That means you get the protection of the law, so, you shouldn't be discriminated against in your interview just because you have a cancer diagnosis. You need to understand that.

Another important point to remember, if you're applying for a job and you're asked, "Are you disabled?" You should actually tick the box yes, because actually you are legally disabled for the purposes of legislation. If you tick that box, then your protections kick in. That's an important point to remember.

Emma: You two are complete legends. I feel like the most prepared person in the world should I ever be unfortunate enough to find myself with a cancer diagnosis, but you're a wonderful mine of information.

Dany, where do we need to go to get more information about cancer diagnoses and our workplace rights?

Dany: As Liz said, I think we have a wealth of information on our Macmillan website, and there's actually a tool kit that has everything in there. Information for your



employer, information for you, which is an amazing resource. I would let people go to our website and look through the resources there and pick out what's best for them.

Liz: Can I also plug also our work support service. We have eight advisors on our helpline who specialize in working issues, and they have a wealth of experience. They can offer you information and guidance about any stage, whether you're having difficulties at work, if you're looking for a new job and you want advice on how to talk about your cancer diagnosis, and maybe talk about when you've been off sick from work.

Really important, they're a great team. Please, do call them. If you're in trouble and you're having problems at work, our advisors can also offer you one-off legal advice as well, so an important resource to be aware of.

Emma: Dany, Liz, thank you so very much as always, and thanks to Helen for sharing her story. To get more information about what we've talked about in this episode, then go to our website, macmillan.org.uk/talkingcancer. Next time, we're talking cancer treatment 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: Subscribe if you'd like to hear that and every new episode whenever it's ready, and 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.

[00:43:18] [END OF AUDIO]