

EPISODE 3: LIFE AFTER CANCER

Emma B: 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 Errol.

Errol (clip): Had it not been for my wife, I probably wouldn't be sitting here today having this conversation.

Emma: Ten years ago, Errol McKellar went to his GP to do something about his snoring. He picked up a leaflet about prostate cancer while he was waiting, and it was a decision that would change his life.

Errol (clip): They said to me, 'Mr. McKellar, I'm afraid to say that your prostate is covered in cancer'. I went and I sat in my car and I'm not ashamed to say that I just burst into tears.

Emma: Errol had his prostate removed and he's now been in remission for ten years. He's made it his life's work to educate men like him.

Errol (clip): 'Look, I'll give you 20% discount if you go get your prostate checked'. Two weeks later, when he came to pick up his car, he was waving this piece of paper... he had 25% cancer in his prostate.

Emma: Errol is very funny, he's driven, but he's also incredibly open about living with the side effects of having his prostate removed. Plus, later, Dany, our Macmillan Professional, is giving us some practical advice about life after cancer.

Dany (clip): The cancer nurse specialists would much prefer somebody just ringing and checking and, more often than not, they can relieve anxiety over the phone.

Emma: We're Macmillan, and we're Talking Cancer.

[Music]

Emma: Errol, welcome. It's lovely to have you here with us. We've spent maybe two minutes together, but I'm kind of getting the lay of the land with you. Big personality, extremely driven. Were you always like that before your diagnosis?

Errol: I've always been driven. I think since I've had this prostate issue, I'm actually in the fast lane now. So yes, I'm much more driven now.

Emma: What was life like for you before the diagnosis? What were you doing?

Errol: Well, I'm a qualified mechanic and MOT tester - so, I used to run a garage in the East End of London - and part-time football coach at Leyton Orient Football Club.

Emma: You just throw the football thing away, but we know there was more to it than that. For those people who don't know very much about you, you have coached some names we would know.

Errol: Yeah, I've been very privileged in my football life to have worked with the young David Beckham, Ashley Cole, Sol Campbell, Lee Bowyer, Jermain Defoe, but everyone that I've worked with is on an equal par for me when it comes to football. I mean, I was just very fortunate to work with some very, very good youngsters, who have grown up to be complimentary adults.

Emma: Thinking as well then, that in your line of work on both levels, so working in the garage doing MOTs – and you made this analogy perfectly yourself – and then working with young

talent... You've got quite good ears and eyes to pick things up. Did you pick up anything about your prostate situation before you went to the doctors?

Errol: You know, it's so interesting that you say that because had it not been for my wife, I probably wouldn't be sitting here today having this conversation, because I only found out about my issues because my wife was complaining about me snoring in my sleep.

Emma: And so she should(!).

Errol: Yeah, and this is a lesson to all men, right, when these ladies start nagging, please listen. Because it's painful if you don't.

Emma: To be very clear, snoring is not one of the symptoms of prostate cancer. So, you went to the doctor to talk about your snoring and nothing else?

Errol: No, exactly. I went to the doctor because of the nagging.

Emma: 'Can you do something about my wife?!' [Laughter]

Errol: Yeah, I didn't quite say that to the doctor. I just said, 'my wife has made this appointment so I'm here'. And you know, when you're sitting in the reception room waiting to see the doctor, that can be a long while, so you need to find something to occupy your time. And I picked up the leaflet purely by accident. To this day, I still don't know why I picked it up, but I picked it up, read the leaflet, and there were things in that leaflet that I thought, 'oh, this could be something to do with some things that's going on in my life'.

Emma: Like what?

Errol: Getting up three or four times a night to go to the toilet, having lower back pains, low abdominal pains. And I just thought that by the way that it's describing, it's a simple blood test. So, I thought, 'let me go make an appointment'. I wasn't planning on doing anything there and then. I thought if I spoke to the reception lady, and she was happy to give me a time to come back then I would come back. But the shock for me was when I approached her, she turned to me and said, 'Mr. McKellar, you don't need to make an appointment. This is a simple blood test that takes less than 10 minutes. We can do it now'. And I thought, 'okay, well, let's do it then'.

Emma: So, none of those situations you hear so much about, that if you want to go and see your doctor, you need to wait, it's impossible to get an appointment, you have to wait months... This is something that can be done by one of the practice nurses quickly.

Errol: Yeah, I have learned since my journey with prostate cancer that this can sometimes be a difficult appointment to get. But my message is, be persistent and get it done.

Emma: Can I ask you a question? How old are you now, Errol?

Errol: I'd like to say 21, but I'm not going to get away with that one, am I?

Emma: How old do you look? [Laughter] That's the answer –

Errol: Yeah. Unfortunately, I'm looking 62 and some days I feel 62. [Laughter]

Emma: Well, I'm just wondering as well because if you're an active person, and you know, the boys amongst us hate going to the doctors anyway, and we'll talk more about that. But some of those symptoms that you described, I just always put things down to 'oh, it's my knees, I'm getting older'. Was that part of your thinking?

Errol: You're spot on, because everybody that I've spoken to has a classic excuse for every symptom. In my job as a mechanic, I hear it, you know, 'oh yeah, the light came up on the dashboard of the car and I ignored it'. I thought, this is very similar to what we do as men, particularly as men.

Emma: What did you expect to hear back as well?

Errol: I didn't expect to hear anything else back, but what sort of started the alarm bells ringing is that a week after that first blood test, I got called back to do a second one. And I asked a question and the doctor said to me, 'no, this was just a routine check. We just want to follow up on what we've done'. But then the whole thing just started to sort of escalate very rapidly. After that second blood test, I got a phone call, 'can you come in to do a biopsy?'. I always remember the conversation. I said to the doctor, 'when do you want me to do that?' and he said, 'we've made the appointment for you this morning'. It was quite interesting because I put the phone down and I phoned my wife and said, 'look, I've just had a phone call from the doctor, they want me to come in and do a biopsy'. And she said to me, 'when do they want to do that?' and I said, 'they want to do that today, this morning'. She turned to me and she said, 'okay, don't worry, if you get a cab to the hospital, I'll meet you at the hospital'. And just before I put the phone down, I turned to her and I said, 'oh yeah, by the way, what's a biopsy?'.

Emma: Well, I was about to say, at what point did anybody start talking about PSAs, which you have to explain for us, and possible prostate cancer?

Errol: I didn't have a conversation about any of it until... apart from what I read. And, as the journey went on, I started to get more bits and pieces of the conversation. But I still didn't understand the graphics of what it meant and how serious a problem it was.

Emma: I suppose, to say that you must have all been shocked is a massive understatement.

Errol: Yeah, because I had the biopsy, and that wasn't very pleasant, but it's something that we have to do. And, almost immediately after the biopsy, then they call me to do a scan. And then things started to unfold. Because after the scan, they called me and my wife in, sat us both down and said to me, 'Mr. McKellar, I'm afraid to say that your prostate is covered in cancer'. Well, I got up and I walked out of the room because I didn't actually think he was talking to me, at the time. I came out of the building, I went, and I sat in my car. To this day, I don't know whether I was scared, frightened, or both really, and I'm not ashamed to say that I just burst into tears.

Emma: I don't know how else you deal with that kind of news because it wasn't a tiny little bit of cancer either, was it? It was quite serious.

Errol: Yeah. I sat in that car, crying my eyes out and this is why I always encourage men to listen to their partners and for men to listen to the women in their life. Because my wife came in and she sat in the car with me, and she looked at me and she said, 'look, all the years I've been with you, I've never seen you quit on anything that you've ever done'. And they're quite powerful words when you're sobbing your eyes out, because I stopped crying immediately. And I looked at her and I thought, 'is this her way of motivating me?', because if it is, then need to take it. And together, we got up and we went back in and spoke to the doctor. I said, 'right, doctor, what do I need to do to deal with this problem?'.

Emma: So, the treatment that you had, has been successful. What was that treatment and were there any side effects for you?

Errol: The situation for me was, when I spoke to the doctor, he said 'look, if we don't remove your prostate, you could be dead in six months'. So, I said, 'okay, let's do it'. And he said, 'well, you know, there will be some issues you have to deal with. There'll be some side effects that you have to come to terms with'. But I agreed to have the operation because there was no point in me trying to save the little piece that was left. But after the operation, there was still traces of cancer in and around that area. So, I had to have nearly three months of radiotherapy to burn away the rest of the cancer issues. And that was difficult. That was probably... that was the most difficult part.

Emma: Because it made you feel terrible?

Errol: Yeah. It drained me physically, and it drained me mentally. Which was a difficult part to deal with.

Emma: I'm sure. Especially when you go from being so active, so busy, to having to sit still and feel terrible.

Errol: Yeah. On top of that, I was out of work for six months, my body's not used to sitting still for one day, let alone nearly six months.

Emma: Talk to me about finding out you were in remission, the light at the end of the tunnel.

Errol: Well, I think the light at the end of the tunnel for me was when I went back to work, and a gentleman came into my garage and we got in a conversation. To this day, I still don't know why I asked him the question I asked him. I just looked at him and I said, 'when was the last time you had your prostate checked?'. And he looked at me, and he was quite shocked.

Emma: 'I came in to talk about the indicators!'

Errol: He turned to me and he said, 'what the bleep bleep bleep has that got to do with my gearbox not working on my car?!'

Emma: And, 'well, you say that, but exactly, is your gearbox working?!'

Errol: And then on top of that, I turned to him and I said, 'look, I'll tell you what, I'll give you 20% discount on the work I'm going to do on your car if you go and get your prostate checked'. Well, I clearly didn't think it through because two weeks later, when he came to pick up his car, he was waving this piece of paper and he turned to me and he said, 'look, I took your advice and I did that test.' And, to this day, he must have realised because I looked up in the sky, and I looked at him, and I thought, 'Christ, this has just cost me 200 quid!'. But he turned to me and he said, 'look, I don't want you to give me the money back. I want you to donate it to charity.' But he said, 'you need to read this letter'. And when I looked at the letter that he had, he had 25% cancer in his prostate.

Emma: Oh my, you are kidding me!

Errol: No, but he was the first of 48 guys, that walked into my garage, that was diagnosed with prostate cancer, of which two are no longer here. So, my journey for me and dealing with prostate cancer is by talking about it every day. I decided to set up the Errol McKellar foundation to get men talking. And the reason why I did that was, I spoke to 100 of my lady customers in my garage, and I said, 'girls, when's the last time you girls went to see your doctor in a year?', and 89 out of that hundred had been to see their doctors. I asked the same question to my male customers and one. One man. And what was frightening about him is that he only went because his wife was moaning at him, he said, and she decided she's not going to give him any more sex until he gets himself checked.

Emma: Errol, that's hilarious! [Laughing]

Errol: So, it's my journey now to raise this awareness and that's how I've had to deal with the bits and pieces that goes on with it.

Emma: I suppose lots of people talk about their new normal. Your journey and the projects that you have in the Foundation, the talking that you do, is that the new normal for you? Is this Errol now?

Errol: I think it's just amplifying the stuff that I've done before, but it has to be very direct because I'm not helping people to pursue a career, I'm hopefully helping to save lives.

Emma: Well, you are!

Errol: And I can't do that on my own. It's great people like yourselves, the fantastic support I get from my wife Sharon, and also family and friends, because I found out about prostate cancer by accident. What I say to people now is reading, lots and lots of reading to find out, because there's lots of different, conflicting things that people talk about. But the most important thing I've learned from the readings that I've done is the numbers are very, very high and they're getting higher. One in eight European men get prostate cancer, one in four Afro-Caribbean men get prostate cancer.

Emma: It's important to talk this through, it's important to talk it out loud. Also, can you explain what PSA stands for?

Errol: PSA stands for Prostate Specific Antigen. So that is what is produced inside the prostate to help with your reproduction and all the other exciting things that men have and dream about.

Emma: I know what you're referring to...(!) Okay, so, the PSA, we know, and that's the count and that's how they measure whether there is something going wrong?

Errol: Yeah, this is a simple blood test. And it's important that all men make a point of getting themselves tested. Whether the doctor is happy to do it or not, insist on getting it done. This is something if you treat it and catch it early, you're more likely to stay alive with it.

Emma: Do you think that the work that you're doing in and around prostate cancer and bringing the discussion to the table, getting people to talk more about it, has been helpful to you in dealing with the experience that you went through personally?

Errol: I think the help has been absolutely massive. I didn't realise how big an issue this was until I started to be involved in it. Why it's important to talk and what I've learned from talking is that if it's in your family, then it's very important that your generations know about the issues. Because my dad, when I had the conversation with my dad when I was diagnosed, he turned around to me and he said, 'yes son, I had that issue five years ago'.

Emma: [Gasps]. Oh my goodness me, oh my goodness me! Wow.

Errol: Yeah, that was my reaction. I was so angry and upset. I couldn't speak to him for nearly six months.

Emma: I'm sure! Why do you think that – or, have you come to any conclusions throughout this about why men aren't very good at seeking help, or being aware of their bodies?

Errol: Yeah, I have two issues with that. The problem I find with men, as opposed to women is that we suffer with two things, ignorance and silence. If we have this issue, we go into denial. We find every excuse to accept that it's not happening. And then on top of that, we completely

shut down, we just go into silence. Women are very, very good at, whether it's nagging or whatever title you want to give it, when they have something wrong... for me as a mechanic, if they've got a problem with their cars, they come in straight away. With men, we wait 'til the car breaks down.

Emma: But it is interesting isn't it? And I think with women as well, whether that's to do with puberty and starting periods, right through to pregnancy, I think we're much more used to our bodies changing. We talk about it a lot more and –

Errol: You're more proactive, you're more proactive.

Emma: I think so. But what you've been doing has made such a huge and significant difference. This has not gone unnoticed, has it?

Errol: I hope I can make a difference, but I always use the word 'we' because one person is not going to make this change.

Emma: I know you say 'we'... there was only one NHS Hero Award.

Errol: When they told me that they were going to give me this award, I said to them, 'I will only accept this award on behalf of all the people out there that are going through the battles with prostate cancer, all the people that we've lost through the issue'. And for me, really, I wouldn't have accepted it other than that, because I felt that I was taking it on behalf of all the people that are involved in this campaign as well. So, it's a people's award for me, more than it is personal.

Emma: I'm going to come back to you personally just for a second because there's this amazing work that you do, this fantastic Foundation and clearly this work is helping you Errol, looking forward into the future. When you were going through that, who did you look to for support? Was that family, friends? Was there any outside organisations? What else is out there for young men in your situation?

Errol: I've been very fortunate with people like Macmillan and Prostate Cancer UK. But it's forums, forums, more and more forums.

Emma: Online forums as well?

Errol: Yeah.

Emma: See, that's a common thread that we're taught, that there's a lot of very valuable support that you get from other people in the same situation.

Errol: Yeah, in house, my strength came from my wife and family. They realised a long time ago that they were happy to share me with everyone. So, I couldn't and wouldn't have got through what I've got to now without that help and that network.

Emma: With the treatment that you had, has there been any lasting impact on you and your health?

Errol: Yes, there has been lasting impact. My situation is that, you know, I have probably less than 20% feeling below my belly button. Erectile function is probably non-existent. But what I've learned through my journey with this is that some people will get a lot more than that. And it's how you manage what you have.

Emma: How do you manage that on a day to day basis. I mean, you know, that's you, you love your wife, but that's complicated and difficult, is it?

Errol: It's only difficult if you sit down and decide to do nothing about it. I may not be what we call Usain Bolt, but I can still be Mo Farah, if that makes sense. You have to improvise the best way possible, but you can't let it beat you. What you have to do is – and that comes back to why I set up the charity that I set up – by talking, you realise that you're not the only one going through this challenge. A lot of times people say things to me that are a massive help. So, I'm learning everyday how to deal with it.

Emma: I think particularly with prostate cancer and with men, and they're reticent to talk about things, there are I'm sure lots of myths and lots of concerns about what makes you a man, that maybe gets in the way of going to the doctor. Does that make sense?

Errol: No, it's a great question, and I'm glad that you've asked the question because a lot of men tell me they'd rather not go through this if it means they're going to lose their erection.

Emma: Or issues with incontinence... What would you say to those men? Because it is real, that's a real concern.

Errol: I have had the question and what I have said very frequently is, 'look, if you have a chance of being alive, and maybe helping somebody, it could be your children, your grandchildren... isn't that more important?'

Emma: Do you ever worry about it coming back?

Errol: I do worry about it coming back. I don't have a prostate now, so, if the cancer comes back, it would be probably more aggressive somewhere else. But my challenge is to save somebody from having to go through the battles that I've had to go through every day. That's my challenge. So no, I try to be positive and give the love to other people.

Emma: You're a magnificent human being! It's been an absolute pleasure to speak to you Errol, thank you so very much.

Errol: Thank you.

Emma: Dany Bell, Macmillan professional. Hello, lovely lady, it is great to have you back again. What an inspiration Errol is! What do you make of his story?

Dany Bell: Oh, absolutely. And an inspiration I think, for men.

Emma: They're not great at talking, are they?

Dany: No.

Emma: We talked a lot to him about life after cancer. Can you please explain remission versus cancer free?

Dany: They are very different things, but unfortunately sometimes professionals or public perception intertwine them. So when somebody is in remission, and you can be in partial remission or complete remission, remission is really that the cancer is not active. Partial remission is where you've still got some cancer cells, but they're not causing you any problems. Complete, obviously, is that the cancer is being held at bay. All clear tends to come when you've been in remission for a period of five years with no active cancer, and then your clinician may be confident enough to say that you are all clear at that point. So, it's really important to understand that.

Emma: During this remission, the period from the moment that your cancer treatment stops, through those partial remission, to all clear, what does recovery look like? You've had this

incredible trauma, the treatment, whatever that has looked like for you individually... What can that period then begin to look like?

Dany: It is very different for different people and we've talked about this before, different types of cancer and different treatments have different impacts. So, that makes it very individual. But there are common things that people struggle with. Energy and fatigue is a big one. And that can take a while to actually recede, but some people struggle with it long term anyway. Some people have problems with pain as a result of treatment. And, unfortunately, some people will have long term problems with pain, just because of the impact of the type of treatment they've had on their body, and pain and fatigue can be quite intertwined and then, unfortunately, have a knock-on effect on your emotional wellbeing.

Emma: Well, I was going to say, because Errol talked quite openly about the effects that his cancer had on his sex life. How do you maintain your emotional health as well through this? Are there places to go? Is it again, something that you should talk about when you go back to your GP or for your check-ups?

Dany: I think a GP is a really good starting point. Sometimes people aren't necessarily comfortable with talking openly about things that they find embarrassing and would prefer to talk to their GP about it. And GPs are used to talking to people and helping people that have, like Errol, had erectile dysfunction after treatment. So, certain types of cancer treatment have a physical impact on how your sexual activity happens. But, also, some people have a psychological impact on their body image and there are lots of different reasons why it might impact on your sexual health and your sex life, which actually has a massive emotional impact. And there's other people, so the GP can refer for counselling. You can join groups where people have experienced the same thing and learn how they've overcome it, and people find that very helpful too.

Emma: Whilst you're in remission, you aren't just sent out into the big world and let go. There will be check-ups. What do they look like? Is that a visit to the GP to say how you feeling? Or is that a return to the oncologist for something a little bit more invasive?

Dany: So that's a really good question, because historically, people always went back to the hospital for a clinic appointment, and then they would have their surveillance tests. But things have changed. And we recognise that for some cancers, and particularly cancers that are very low risk, GPs can manage and monitor them. You may just go and have a blood test regularly, and the GP can let you know the result of that. We even have electronic systems now where people can actually look up their own blood results, and there's lots of information that goes alongside that, so they know how to interpret them. So, PSA, which is what Errol talks about, is one of those, where in some areas they have a remote surveillance system that patients themselves have access to. For other people, it is going back to see the specialist, you'll find it'll be three- to six-monthly in the first year and then actually once you're two years with stable disease, you'll have an annual check. So, the longer you're in remission, the less frequently you go, but you will always have an annual surveillance test and that can be a scan, a blood test, or both.

Emma: Whatever is needed. Errol is just absolutely overflowing with positivity, such a great guy to be around. But he has worries that it might come back. So, there are emotional scars that it leaves as well...

Dany: What he highlighted is a very common problem. And you will often hear people that say once you've had cancer, you always have cancer, even when you don't have active disease because it's always in the back of your mind. And you know, when a scan or an appointment is coming up, people will get more anxious than normal. And that's understandable. In reality,

you know, that fear of the cancer coming back is very genuine and people need to find their own ways of dealing with that.

Emma: For some people, it might leave them hypersensitive to any ailment that might be around. When do you know whether it's something serious? That it's not just a cold, it's something you need to go and get checked out? That's a hard question.

Dany: No, but there are indications when you've had a particular cancer, what the likely recurrent symptoms will be, and people should be informed of those by their specialist team and the GP should be aware of those as well. So, you can be more vigilant about those, and of course if you have something that persists for three to six weeks, then you shouldn't hang around. It's always best to get it checked out, because most minor ailments will recede within that time. If you've had a backache because you've hurt your back, it shouldn't last for a protracted period, unless you've done some damage, but then you would need to seek help anyway. So, if you've had a backache, and you've had a cancer where secondary bone cancer is a risk, then you should know that if that back pain persists, you should go and seek help. So you should be given that information so that you can monitor, but equally people do get very anxious about every ache or pain and worry, and there are lots of telephone support services now so the specialist teams, the cancer nurse specialists, would much prefer somebody just ringing and checking and, more often than not, they can relieve that anxiety over the phone.

Emma: Finally, Dany. If you're a friend or a relative of someone who is recently in remission, they can still offer support. If there's somebody listening, what's your advice to friends and family?

Dany: I think the biggest advice is to carry on life with that person. You might need to make some adjustments if they're fatigued but don't make a big deal of it. Be understanding and still do the things that you enjoy doing together. But equally, some people with cancer say, 'no one will talk about it' and 'I'm struggling with all this, but I look okay'. It's okay to ask people, 'are you okay today, is everything all right?'. And most of that is normal behaviour. So, don't be afraid to have the normal conversations that you would have and do the normal things that you like doing with your friend or your family member.

Emma: Dany, thank you so very much, and my thanks to Errol for coming in to tell his story. To get more information about what we've talked about in this episode, then go to our website macmillan.org.uk/talkingcancer.

Emma: Next time, we're talking about dealing with the end of someone's life, with Max.

[CLIP] Max: We were sitting all around her hospital bed in Coventry and then one of us started to cry, and immediately you do the same thing that loads of people do – 'I'm sorry'. And straightaway, I think it was my dad who said, 'No! It's going to be rubbish, it is'. So, yeah, we all had a cry together.

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