

## **EPISODE 2: TREATABLE BUT NOT CURABLE CANCER**

**Emma B:**

What's it like living with cancer that's treatable, but not curable? 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 Adam.

**Adam (clip):** 'We've identified there's something in your brain, but we don't know what it is. So, we're going to have to operate on you tonight, and then do a biopsy on you.' I just looked at her, and she was solemn, looking upset, and I was like 'we're talking potential brain tumour, aren't we?' and she said 'yeah, potentially'.

**Emma:** At 31, Adam Carroll was enjoying life and enjoying a job that allowed him to work in New York. Then on one of those work trips, he had a seizure and collapsed.

**Adam (clip):** Because I work in a quite a 'laddy' environment, they all just thought I fell over. So, I was on my way down and I could hear everyone laughing and cheering, and then someone went 'hold on, that's not normal'.

**Emma:** Adam was diagnosed with a grade three brain tumour. While doctors can manage it and treat it, it's something that Adam has to live with forever.

**Adam (clip):** But if you concentrate on the treatable part of it, treatable is obviously maintaining your life, and I always knew it is something that has to be managed for the rest of my life. And even if there is nothing that can come to just come alongside and zap it away or whatever, I'll manage it for the rest of my life. I'm fine with that. It doesn't matter how long it is.

**Emma:** You may have seen Adam on the TV show First Dates, or from the press coverage which followed. I think you'll really take a lot from his story. And later the kettle is on for Macmillan professional Dany, who will be here to talk about the 130,000 people in the UK with treatable but not curable cancer.

**Dany (clip):** The biggest impact is living with uncertainty and not knowing what's around the corner. Even if you're responding to treatment, you don't know how long that's going to be for and for some people, they find it quite difficult to get their head around that.

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

**[Music]**

**Emma:** Hello, welcome Adam. It's lovely to have you with us. We are going to talk a lot about your cancer during our conversation. But let's start with life before cancer. What were you like back then? What was your life like?

**Adam:** To be honest, exactly the same as it is now, but minus the cancer.

**Emma:** What kind of a person would you say you are?

**Adam:** A bit of a Jack the lad.

**Emma:** Really? [Laughter]

**Adam:** Yeah, I don't know if you can guess.

**Emma:** So, how old are you?

**Adam:** 35.

**Emma:** What do you do for a living?

**Adam:** I work for a stock brokerage, but the geeky side of it, in IT. Not the money-making side.

**Emma:** Yeah, there you go. Should have worked harder in school, I say to myself every day! And in New York were you staying at a hotel? Were you staying with friends? I mean, life must have felt pretty bright...

**Adam:** I was in a hotel, but a really swanky hotel. I was working out there. And I was like, 'yeah, this is absolutely brilliant'. And then messed it up.

**Emma:** You didn't mess it up. Don't be silly. Was your life going to plan then? What were your hopes and dreams at that stage?

**Adam:** To be honest, I don't think I really had a plan. It just was just day to day. It always was and I think more so than ever, it always will be.

**Emma:** Have you got a family, any brothers and sisters?

**Adam:** Yes, older brother, older sister. Mum and dad, they live down in Kent.

**Emma:** And were mum and dad quite pleased with the way Adam, their gorgeous son's life was working out?

**Adam:** You'd have to ask him that. To an extent I reckon.

**Emma:** Was it more like, 'oh, what's he done this time?'

**Adam:** I think when they got that phone call, they thought, 'oh God, he's been sacked' or something like that.

**Emma:** Let's talk about the day when you collapsed then, because this is where everything changed. Was there anything that you had noticed about how you felt that could have predicted this?

**Adam:** Absolutely nothing. That was the weirdest thing, because I didn't even have a headache or anything like that. I didn't feel ill whatsoever. I just stood up in the office to go to someone else's desk and try and say something to them, and then I can actually remember not being able to speak and slipping over my words and then I can actually remember collapsing. And because I work in quite a 'laddy' environment, they all just thought I fell over. So, I was on my way down and I could hear everyone laughing and sort of cheering. Then someone went, 'hold on, that's not normal', because I'm on the floor convulsing apparently.

**Emma:** And from that, the memory's a little bit cloudy about what happened next.

**Adam:** Yeah, then it's a complete blackout. And the next clear memory is I'm waking up surrounded by New York paramedics, which sounds all dramatic like in a film but –

**Emma:** Well, to be fair, it is quite dramatic. It's probably not nearly as glamorous but that is quite dramatic. And you know, for you to be so ill, so far away from home. So, had anybody come with you from the office?

**Adam:** No, I was sent out there to work on my own, and it was only once everything had happened, and I'd gone to hospital and been diagnosed with what it was that my company took steps to get my father out to be with me.

**Emma:** So, you're being dealt with by the paramedics in New York. What are you hearing about what they think it might be?

**Adam:** To be honest, the bit with the paramedics, when they've got air on me and stuff like that, and the bit being blue-lighted to hospital, it's all a blur really. I don't remember. I remember trying to speak. So, when my colleagues from the New York office came to the hospital with me, and I kind of remember trying to talk to him, as if to say, 'you're making a bit of a fuss out of all this, aren't you? Can't I just go back to work?'. And he was just like, 'no, we have to do this'. And then I remember getting to hospital, and there was a nurse that I spoke to originally. And she was like, 'well, obviously something has happened, so we're going to have to do a scan on you'. And at that point –

**Emma:** And you're conscious by then and –

**Adam:** Yeah, I'm fully aware of the conversation at this point. And at that point, I was quite jokey and almost quite flirty with this nurse, she was quite pretty. And she was laughing back and she was really cool. And then I had my scan, and I came back up, it must have been an hour, an hour and a half later, whatever -

**Emma:** So, this must have been happening quite quickly?

**Adam:** Yeah, it was like that (clicks), it's all just a blur. And then the same nurse, she says, 'we've got your results'. And her whole demeanour had changed to the point where I was like –

**Emma:** You knew.

**Adam:** Yeah. She was like, 'we've identified there's something in your brain, but we don't know what it is. So, we are going to have to operate on you tonight, and then do a biopsy on you.'

**Emma:** Woah!

**Adam:** I was like, yeah, exactly that. I was just looking at her and she was really solemn, looked upset. And I was like, 'we're talking potential brain tumour, aren't we?' and she just went, 'yeah, potentially.'

**Emma:** How did you – why did you jump to that conclusion?

**Adam:** At that point when everything had gone so crazy, I just thought it's got to be something really, really bad. I wouldn't just collapse with a headache. So, my mind instantly went to the worst-case scenario.

**Emma:** Were you in pain at this point?

**Adam:** No. Zero pain.

**Emma:** And at that point it doesn't affect your movement, or –

**Adam:** No, that's what I think they were worried about. If you have a seizure, then obviously... your speech... So, where my brain tumour is, it's an area of the brain where it affects all of your cognitive functions. So, that would be like things like balance, walking and talking, and stuff like that. All that was fine, believe it or not hearing my voice now. All that was fine but a very surreal few hours.

**Emma:** How long are we talking then, between you hitting the deck at work and going in to have your brain scanned?

**Adam:** I probably collapsed at about one o'clock in the afternoon. I was being operated on by 8pm that night. And then I came out of – because obviously they put me under to do the brain surgery – so then I came out of that the following morning. And by that point, they'd already got my dad out to New York.

**Emma:** Had you had a chance to speak to your mum or dad before you went into surgery?

**Adam:** No. Because it was all hands on deck because of obviously what I've got going on, I had no chance to talk to anyone. No family or anything.

**Emma:** You must have been terrified!

**Adam:** Yeah, I was. It's the most scared I'd ever been in my entire life, by a mile.

**Emma:** Absolutely. I can't believe you didn't have time to speak to anybody

**Adam:** I know. But I think when you're in that situation they're just like, 'oh we need to do this, we need to do that', you're just like, 'do it then. Because I don't want to die, just do it.'

**Emma:** Was that on the cards at that point? Had somebody mentioned that we need to do this because you are critical?

**Adam:** No. Whether it was the case or not, I don't know, but they never said anything like that to me. They just said that time is of the essence.

**Emma:** And how does American emergency surgery situations compare?

**Adam:** I've never had emergency surgery in the UK!

**Emma:** Were you well looked after?

**Adam:** Extremely well looked after. Luckily enough, we get private care through work. So I was looked after really, really well out there.

**Emma:** At this point, were they using lots of long words that you didn't know? Were they explaining things, or were they just in 'let's do this' mode?

**Adam:** A lot of it was in very simplistic layman's terms. It's just like, 'this is this', 'this is that'. So, after the biopsy - so to guide them, I had a biopsy... This is another mad caveat to why I'm convinced that it was all meant to be, it was all supposed to happen in New York. If you Google his name, he's literally the most famous brain surgeon on the planet. Dr. Theodore Schwartz, I owe him my life.

**Emma:** He sounds important.

**Adam:** Very important. I was like, 'who is this guy that's chopping my head open?'. Googled it in hospital, and he's on Sky News, CNN, all the talk shows in America. He was like the oracle of brain surgery. So, I was like, 'yeah, he can cut my head open again, it's fine(!)'.

**Emma:** If you're not called Schwartz, you're not getting in [laughs]! So, you have your scan. They then do a biopsy, that you are awake for? Or not?

**Adam:** Yeah, so not fully under, because obviously they have to monitor your levels and stuff. But yes, as close to being under as you possibly can, without actually being under. But not to the point where I actually remember him doing any surgery or felt anything, or anything like that, because they did pump me full of some ridiculously strong drugs. They said when I woke up after the biopsy, I was trying to take all my vital cables out and stuff like that and saying, 'I want to go to the pub' and they weren't letting me!

**Emma:** This is a reaction from the medication surely! You were taking all your lines out –

**Adam:** Yeah, I'm not that desperate for a Guinness!

**Emma:** To be honest with you, after the experience thus far, I think most of us would be reaching for a strong gin and tonic. So, you've got the biopsy, you've got the incredible doctor, but this whirlwind has all got to come to a point which is your diagnosis. At what point are you told that this is what you have and what did they say?

**Adam:** I was told after the biopsy that it was a grade three blastoma brain tumour. Dr. Theodore Schwartz again said, 'but I can cut more out. So, we're going to put you back in for more surgery'. And at that point, I was actually more scared about that one than the first one, because I couldn't really remember the first one. For the second one, I had about three days to think of it. Because they said, 'yeah, we're going to get you back in in a few days' time and operate again'. He said, 'I can take more of the tumour out and then let you be on your merry way'. And then I just remember, for three days, I was sitting in the hotel with my dad and I was absolutely shitting myself.

**Emma:** Everybody that we speak to, the wait is the worst. And now you have your dad there as well. So, the world is a very different place all of a sudden.

**Adam:** Yeah, well, he made it like a holiday. We were at Central Park, he started picking up pictures that he wanted to buy it from all the street sellers and stuff like that. I was like, 'Dad, you do realise why we're here, don't you?'

**Emma:** Did you talk about the important stuff with him on those three days?

**Adam:** I think we were both aware of it and it kind of got a brief mention, but we're both not very good with emotions and stuff like that. So, we were like, 'let's just get drunk and then worry about it on the day'.

**Emma:** 'We're in New York!'

**Adam:** Exactly. So, he wanted to go and see the hotel from Home Alone and stuff like that.

**Emma:** He wanted to what? Go and see the hotel from Home Alone?

**Adam:** Yeah, he's sad like that.

**Emma:** My husband Damian would do exactly the same thing, hilariously. Christmas is not Christmas without Home Alone, so they'd get on well.

**Adam:** He was trying to find the bridge in Central Park where the pigeon woman was!  
[Laughter]

**Emma:** My goodness me! Sit there and hopefully she might come out and save everybody! Yeah, who needs Dr. Schwartz when you got the woman with the pigeons? So, what do you at this point now that you've been told you've got this grade three brain tumour, you're going to have some more operations, what do you at this point know about what that means to you?

**Adam:** So obviously I made the cardinal sin of Googling an illness –

**Emma:** Hey, everyone does.

**Adam:** - and scaring myself more. And then realising that you can treat it, but it will never fully go. At that point I was like, 'yeah, this is pretty rubbish'. After he'd done more surgery, he came back and said he was delighted with how it went, and that there are only residual cells left that are cancerous. He says, but with radiotherapy and chemotherapy, that should be under control and you'll be absolutely fine. He says, I'm happy to send you back to London. And I was like, 'amazing'. So, I started doing radiotherapy. Do you know what, I was pretty naïve because I started doing radiotherapy and chemotherapy thinking this will get rid of it, and then obviously it doesn't. It just manages it.

**Emma:** And is the reason why you thought that because this phrase, which is treatable but not curable, had that been fully explained to you at that point? And actually, when somebody says that phrase you for the first time, it's actually not a specific as you might imagine...

**Adam:** I think the person who made the most sense to me was my oncologist at Macmillan, Dr. Mulholland. Because he said 'obviously, we're going to manage this, we will treat this, we're going to manage it, but it's one of those ones, you would never ever get a full all clear'. I suppose by that point, I was just accepting, I was at the point where I was like, 'well, every day is a bonus. So just keep treating me.'

**Emma:** Did that make you more determined to live your life well on a daily basis?

**Adam:** Yeah, I know people say you could get hit by a bus tomorrow – it's that kind of mentality. It's not like I could just go out partying and, you know, live a playboy lifestyle because I'm having treatment, so I'm feeling pretty ropey through all of it, but I did just get to the point where it's like, whatever happens, I'm just pretty blessed to still be here.

**Emma:** Let's talk about the treatment, the managing of that. Did you come up with a plan, did they give you a plan so that you knew what you were going to expect?

**Adam:** Dr. Schwartz in New York said the best course of action would be to do radiotherapy and chemotherapy. And then Dr. Mulholland came up with a time plan for that. So, I did that and it took, I think, nine months to a year.

**Emma:** Did you do that at the same time? Because what we're learning as well is that everybody's treatment is very specific to your type of cancer.

**Adam:** Yeah, mine was 31 days in a row of radiotherapy. But going into UCLH, every day, for 31 days, getting zapped and then going home. And then I think I had maybe a month break after that. I then started doing my chemotherapy, which was oral chemotherapy, so I was taking tablets at home. I did that for 12 months, maybe just over 12 months... no, I think 12

months exactly. And then, after that, Dr. Mulholland suggested something called immunotherapy, which is... I should know more because I've been doing it...! It's a targeted combination of drugs, which as far as I know is rarely used for brain tumours. But Dr. Mulholland said, because I reacted so well to radiotherapy and chemotherapy, he felt confident enough that I'd be strong enough to take it.

**Emma:** Are you working through this time?

**Adam:** For the first nine months, for the radiotherapy and chemotherapy, no, work gave me that time off.

**Emma:** And how was that, how were the lads at work? Were they good?

**Adam:** They were incredible, yeah. Obviously when I got back to London, I got ribbed a little bit, they were like 'anything for a day off!'. [Laughter] Same old stuff. But yeah, work have been amazing. When I had my immunotherapy, the first four months of that are more intense than the rest of it, kind of thing. So, work gave me that four months off.

**Emma:** What do you mean by that, what do you mean by really intense?

**Adam:** The regularity of going into hospital or Macmillan and getting your treatment. So, it's spread out over the course of a year, with two different drugs, but the first four months, you get them like every two weeks or three weeks. They cram it all in at start and then spread it out to make it more bearable for the rest of it.

**Emma:** And how is it, how does it affect you? Like, physically?

**Adam:** That was one that gave me a bit of a kicking to be honest. Yeah, it wasn't nice. I was aching, tired and a little bit sick because it's over the course of 12 months and you get scanned quite regularly. But the proof was that this brain tumour, it wasn't doing anything. It was just stable, so I felt like I'd take any kind of sickness or aching.

**Emma:** And those little wins must have kept you positive...

**Adam:** There's points where I'd be throwing up or feeling horrible, and feel like, 'what's the point?'. Then you get a scan result and you're like, 'that's the point. That's why I'm still here.'

**Emma:** Yeah, exactly. Emotionally, I know that you know, your dad and you are –

**Adam:** Geezers!

**Emma:** Yeah, and that's probably the way most people are and how you get through it. What about your wider family, what was that like breaking the news to them?

**Adam:** When my mum found out about me in New York, she took it quite badly. But she was at the retirement age and she just said, 'guys, I'm taking retirement'. She told work, she goes, 'I'm not coming in', she goes, 'I can't handle this. There's no point in me being here because I can't concentrate because Adam is where he is.' So, she retired. So, she owes me one for that [laughter]. My brother and sister, my sister said she was in absolute... in pieces when she found out what happened in New York, which I wasn't surprised about. But my brother said the same thing which I was surprised about, because again, he's like me and my dad, kind of thing. But he said it hit him really hard. I think once I got through that initial bit, I don't think they were as scared about me doing the treatment. They were like, 'well, if you've had your head chopped open twice, you can take a few tablets'. So, after that, they've all been fine. I

think it's got to the point where they forget how ill I actually was, because for them, it's just like hanging out with a normal person. I was like, 'I am normal!'

**Emma:** Yeah, of course! Well...

**Adam:** Normal-ish. Normal for a Carroll!

**Emma:** [Laughter] And, apologies for the phrase, but your brain does tend to forget bits trauma on purpose.

**Adam:** Yeah. Well, mine does. Mine forgets everything now.

**Emma:** And this is how this is affecting you on a day to day basis. You must miss work, I'm sure, in that environment with everybody.

**Adam:** Yeah, I did. That's what I found hardest actually. Just being off work and not being around people. I get really bad cabin fever. And I like being around people. I like chatting. I like being gobby and stuff like that. So, sat indoors on my own, just contemplating my life of living with cancer – it's not ideal for me.

**Emma:** It's not. What did you do to try and relieve that?

**Adam:** I started running. Tried to get fit and healthy. So yeah, couldn't even run for a bus, decided to start running around a park every day.

**Emma:** Is there a goal? Or how –

**Adam:** Yeah. The London Marathon this year.

**Emma:** Oh, you're running the marathon this year? Oh my gosh.

**Adam:** I'm going to run and then walk.

**Emma:** Yes, cool! The best of luck with that. What an achievement! So how far can you run at the moment then?

**Adam:** I regularly run, sort of, 10k. I've done half marathons before, so I know I could do a half marathon. I've just got to do one of those twice.

**Emma:** What's your best 10k time?

**Adam:** 50 minutes maybe? But that was a while ago. I haven't done a 10k run for a little while.

**Emma:** Are you the type of person that needs a goal?

**Adam:** Yeah. Because otherwise I just wouldn't bother.

**Emma:** Yeah, my other half is exactly the same. And so, the running is keeping you busy, which is good. And keeping you out of trouble.

**Adam:** Ish.

**Emma:** [Laughter] And you're also needing to be careful about what you eat. So, the pork scratchings and the pints may have gone.



**Adam:** [Laughter] So I actually did six months of no drinking quite recently. But I went full on, eating salads and stuff like that. I know, I thought I was kind of like, some kind of reincarnation of God. And then it got to Christmas, I just started drinking again, so it's all gone out the window.

**Emma:** When you're in treatment as well, I'm sure you have to be careful about what you eat.

**Adam:** Yeah. You can't just have takeaways every day. So, you do monitor what you're eating a lot more. Before everything that happened, I was just a standard, working in city and getting takeout every lunch.

**Emma:** Coffee, coffee, coffee, coffee, coffee!

**Adam:** Yeah. Then once everything happened, I was like, 'okay, there's probably more I can do to help my body.'

**Emma:** Do you think what's happened to you has affected your group of mates as well? Like giving them an opportunity to reassess their lives, do you think?

**Adam:** I think so. I think in a handful of cases there are people on the verge of that mindset anyway, and then this happens, and they see how I've reacted and what I've been doing, and I think that's given them a little nudge to pursue what they were thinking of. My pals, who would normally be like, 'pub, pub, pub, football', and that kind of stuff, I think the ones who wanted to get away from that, had seen what I went through and were like, 'actually, yeah'.

**Emma:** It was a bit of a wake-up call.

**Adam:** Yeah, a bit of a nudge in the ribs - get fit!

**Emma:** Get fit, look after yourself. Talk to me about First Dates. [Laughter]. We couldn't do this without talking about First Dates!

**Adam:** I think I need to re-apply and go on 'Second Dates', because I'm still lacking on that front. But First Dates, obviously there was a selfish reason behind it, because I was looking for love. But also, because of everything that had happened, and other charities had got wind of my story and knew I was applying for it, they got involved. They asked if they could use me as a focus study, I was like, 'yeah, of course, bring wider attention to brain tumours'. I was kind of like, only wanting to go on the show for a laugh, and thought that it's a pretty big platform, it's a very popular show and a lot of people will see it. So, it was an ideal chance to get my story out there. And even if one person saw me doing what I was doing and felt like, 'you know what, there is hope', kind of thing, then it's worth doing. I didn't find love though.

**Emma:** Right, well, we need to sort this out. Is there anybody out there? [Laughter]. What sort of reaction did you get? You're a poster boy for brain tumours.

**Adam:** Absolutely overwhelming. The reaction of people on social media was just like nothing I ever expected whatsoever. It was good though. Oh, it felt amazing.

**Emma:** Macmillan are doing a lot of work to raise awareness of treatable but not curable cancer like yours, Adam. Is it a useful term when you're telling people about what you have?

**Adam:** Yes, it is, because you get people that see me and think I don't look ill, I must be better. So treatable not curable, at least that kind of insinuates that there is no end, all clear, kind of thing, but it's just manageable. But to come this far, three years basically since my diagnosis, and I still feel... well, I feel better than ever. I thought if I was to benchmark to get

somewhere, then in your head you'd be like 'maybe by this time in six months or twelve months there will be new treatments and stuff like that', and I think that is happening more and more. Now I'm not saying something is going to come out, and it'll just be like right, brain tumour is done, but I think there's always hope, kind of thing.

**Emma:** Well, you know, the immunotherapy, that's quite new – trying that on a brain tumour...

**Adam:** Exactly, that's quite pioneering. It wasn't a trial or anything like that, I don't think...(!). But no, yeah, it's quite pioneering.

**Emma:** That's really interesting as well, because I guess the 'treatable but not curable' tag could quite happily sit really heavy with you and make it very difficult to look forwards –

**Adam:** Yeah, but if you concentrate on the treatable part of it, treatable is obviously maintaining your life and I always knew it would be something that has to be managed for the rest of my life. And even if there is nothing that can come along and just zap it away, or whatever, to manage it for the rest of my life – it's like, I'm fine with that. It doesn't matter how long it is.

**Emma:** You're a very proactive person, aren't you? You're like, 'we'll just do it, it's fine, we'll just get on with it'. Have you met other people with the same condition as you, and has that been helpful?

**Adam:** Yeah, a good friend of mine, she does a lot of work for the cancer community – Lauren Mahon. She regularly does get-togethers and she does ranges of t-shirts and stuff like that. So, I've met hundreds of people in the cancer community. We're obviously all in the same boat, and it's not a boat anyone wants to be in, but you just kind of deal with it don't you? Get along. But yeah, you do meet some amazing people. You can meet people, you think you're doing really well, or no, sorry – you have a down day, and then you meet another person and you're like, 'I've actually got nothing to moan about'.

**Emma:** Wow, you know, that's the strength that you get from talking to people that have similar conditions, is that everybody has these good days and bad days. When you are given that diagnosis that it's treatable, not curable, I know that some people in the past have had a very, sort of, physical relationship with the tumour, with the cells that are still there. Do you feel like you need to get rid of it the whole time? Or are you at one?

**Adam:** I think I'm at the point now where it's just like, every time I have a scan and it's not doing anything, I'm like, 'fine, you just keep on not doing anything. I'll carry on. I'll do me, you do you! See you in three months' time'.

**Emma:** Absolutely. I suppose with the big questions in life, Adam...

**Adam:** Tottenham.

**Emma:** No, I'm not talking about Tottenham! I'm an Aston Villa fan! I know, I have to carry that cross, okay! [Laughter] Can you pinpoint how this has really changed your life, apart from the, obviously, massive physical aspects of it and how that has changed you, but has it changed you as a person?

**Adam:** I would say not loads, but other people would say it has.

**Emma:** What would they say?

**Adam:** I think they'd say I'm a bit more caring, a bit more worried about other people. I seem to have a bit more of a purpose in life, which is why I'm doing stuff like this.

**Emma:** And the future looks...

**Adam:** I was horrible before this(!).

**Emma:** Were you? Were you horrible before this?

**Adam:** No. Absolutely not. [Laughter]

**Emma:** Maybe at a Friday night at about ten o'clock, you were a handful, were you?  
[Laughter]

**Adam:** Pretty horrible then, yeah.

**Emma:** You are daring to look forward to the marathon and things like that. What's on the horizon of things you want to do and are you going back to New York anytime soon?

**Adam:** No, work won't let me, just in case I collapse again! With future goals, the marathon is the most upcoming one, and then beyond that, just live a life as normal as possible. Maybe go on First Dates again...

**Emma:** Just for the record, Adam is still young, free and single. First Dates here we come.

**Adam:** Free and single, yeah.

**Emma:** It's ace to talk to you. It's been really, really, really, really fun, and we wish you all the best.

**Adam:** It's been amazing, I've loved it. Thank you very much.

**[MUSIC]**

**Emma:** Dany, our Macmillan professional is back with me. Hello, lovely. What do you make of Adam's story?

**Dany:** Oh, really interesting and slightly different in terms of being diagnosed in a different country, but amazing that it all came together for him. And also, that he got such fabulous support from his employers.

**Emma:** Very bizarre how it all unfolded, but in the right place at the right time, thank goodness. When we were talking with Adam, we talked a lot about the phrase 'treatable but not curable' cancer. What does that mean?

**Dany:** So essentially, years ago, those types of cancers often meant quite a poor outlook, and people may only have survived a year or two. But with new treatments, what we're seeing is that people have options for different types of treatment, the cancer will never be completely eradicated. So, the term treatable but not curable kind of identifies you know, that they can have treatment to keep the cancer at bay or control it or treat symptoms, but it won't ever eradicate the cancer.

**Emma:** At the point of diagnosis, would your doctor tell you that the cancer you had was treatable, not curable?

**Dany:** They might not use that terminology, in essence, but there are some cancers where it's fairly obvious that they're not curable, and also the stage of the cancer can indicate. So, it's a dialogue that might need to be ongoing. So, it might be the first conversation is around that staging. And that the hope is what the treatment aims are. But sometimes if the person is asking all the right questions, then absolutely the clinician will be as open as the person wants them to be. So, it might be that it happens in two or three conversations rather than bam, right at the beginning. It really depends on the person, the type of cancer and what treatments are available, because they may not be 100% sure what type of response someone's going to get, but they would definitely be articulating that the aim of the treatment is to hold the cancer at bay and manage symptoms – even if they don't say the words 'treatable but not curable'.

**Emma:** It's important as well, to clarify that 'treatable not curable' is different to terminal.

**Dany:** Yes, I mean, when somebody is not going to benefit from any treatment, the term that's probably used is palliative and supportive treatments, so you might still have chemotherapy or radiotherapy to manage symptoms, but the aim of the treatment is supportive.

**Emma:** Give us a sense of what life looks like for someone whose cancer is treatable, but not curable. I mean, Adam, you know, he's a geezer from the city and he's got his life and he's got his world and he's got his football. He has made adjustments, but what adjustments would you expect somebody going through that to have to make?

**Dany:** I think the biggest impact is living with uncertainty and not knowing what's around the corner. Even if you're responding to treatment, you don't know how long that's going to be for, and what we often find is people find it difficult to plan, like we would plan something for next year. You know, for some people, they find it quite difficult to get their head around that. I mean, Adam's adjusted and worked his own way through that. And I guess the other thing is that they're often on constant treatment. So, some of the treatments available to people with incurable cancer, they have to have for a minimum of two years, like the new immunotherapies.

**Emma:** It's a long time. With my little understanding of immunotherapy, during that time, you have to really look after yourself, don't you?

**Dany:** Yes. Even with other types of treatment and with any type of cancer, we know that if people take care of their physical and emotional health and their general wellbeing they tend to do better, and there is research in some cancers that it does help hold back a risk of recurrence, etc. So, taking care of yourself, your physical health, is quite important.

**Emma:** What are the different treatments that people might have then, in Adam's case? Because there was a patchwork of different treatments that he's encountered.

**Dany:** So, a lot of chemotherapy regimes are a combination of drugs and they all have acronyms, because the names of the drugs are a mouthful, but it's not uncommon in some types of cancer to have what we call neoadjuvant treatments. So that's chemotherapy or radiotherapy, or both, before you go on and have surgery.

**Emma:** What's the purpose of that then before surgery? Because in my head I'd be like, 'surely you need to go in there and, and cut it out'...?

**Dany:** In areas where things are more difficult to do surgery, because you've got lots of important structures around, trying to shrink down the tumour, so it makes the surgery easier is why they do it.

**Emma:** In someone in Adams situation then what kind of support might someone need with this particular type of cancer? And where would you go to find it?

**Dany:** If he was looking for help with physical and emotional impact, his GP is a good place to start. There's lots of local support services that will help somebody. Equally, he did find his own way, and some people can do that. In terms of some of the cognitive impact of having a brain cancer, that can be more difficult. Again, he might want to have a conversation with his specialist team or his GP, because that will be more targeted support. He was really lucky in that he had really good support from his employer, and unfortunately that isn't the case for everyone. But his story does demonstrate that, actually, if you have a good employer with good support, it makes the world of difference.

**Emma:** Chloe and Adam have found a lot of support in other people in their situation. How do they find those networks?

**Dany:** There's lots of different ways people find those networks. Sometimes they find them online and using social media. Sometimes they connect with people, when they're going for their treatment, because they're all sat in the waiting room. And there are often local support groups. And again, it's about what's right for you as an individual, because people will want a different approach, but actually, that's not uncommon and lots of people really value peer support. And they also like to see and connect with people that are further down the line, so that they can see that people have come through it.

**Emma:** And as things stand with the current treatments available, there will come a day when someone with treatable but not curable cancer will eventually reach a terminal phase. How does the system deal with that?

**Dany:** The consultant or the clinician or the team supporting the treatment, recognising that the treatments not benefitting the person anymore, and I guess the person themselves will have a sense of that, actually, they're not getting the same impact from the treatment. And conversation has to be the key and talking openly about it and allowing the person to make their choices. There's lots of support out there for people to, kind of, live their life as fully as they can right up until the end. And it's just about having the conversation I think, with either the GP or the hospital support team that's been supporting them, to help them find the right support for you.

**Emma:** Dany, thank you ever so much. Such a stabilising voice in all this confusing terminology and these incredible stories. My thanks to Adam 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](https://macmillan.org.uk/talkingcancer). Next time, we're talking life after cancer with Errol.

**Errol:** My wife came in and she sat in the car with me. 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 I need to take it.'

**Emma:** I'm Emma B and Talking Cancer is a Macmillan Cancer Support podcast.