

Series 3, Episode 6: Cancer as a young person

Angie Graves: How do you come to terms with getting a cancer diagnosis in your thirties?

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Angie: Hello, I'm Angie Greaves, and welcome back to Talking Cancer, A Macmillan Cancer Support podcast, sponsored by Boots, where I meet real people and have conversations about living with cancer. I'll also be meeting some of the experts from Macmillan and Boots who can share their knowledge and guidance for anybody affected by cancer. In this episode, we're talking cancer with Nick.

Nick: My view was I want to get better and it's just the pain I need to go through then, let's do it. **Angie:** During the early days of the pandemic, Nick, a healthy 33 year old noticed blood in his stool. **Nick:** That was kind of the main catalyst of thinking I need to go and see the GP.

Angie: After his mom convinced him to get this checked with the GP, he was diagnosed with bowel cancer.

Nick: They said that we are not 95% sure that this is cancer, but this looks like it's quite a big tumor.

Angie: In this episode, I'll be talking to Nick about what it felt like being diagnosed with cancer in his early thirties.

Nick: At the age of 33, it is a weird feeling.

Angie: We'll also be hearing from Dany Bell, strategic advisor for treatment medicines and genomics at Macmillan Cancer Support will be providing expert advice about cancer in younger people and more information about living with a stoma bag. We're Macmillan and we're talking cancer. [music]

Angie: Nick, welcome. It's really lovely to have you here, but let me start by asking what was life like before your diagnosis as a young man in his early thirties?

Nick: Life was awesome if I'm honest. I'm quite a happy-go-lucky kind of guy. I'm from Kent originally, but I've been living in London for eight years. I have a great job which I thoroughly enjoy and I work hard and play hard really. That's kind of always been my attitude. I'm someone that realized late in life that fitness was really important to me for my mental health and I really got in involved in having a personal trainer and training at least three times a week and doing spin classes. That really helped me a lot. Really lucky and fortunate that I've got an amazing family, so I can't complain at all really.

Angie: Nick, as the world's getting to grips with COVID-19 lockdown, you are faced with a different kind of health crisis. I want to ask you, what were the first symptoms that made you think that something wasn't quite right?

Nick: Going back to that work hard play hard thing, I have felt really tired for a long time. I probably didn't really think anything of it. I probably thought it was just London

life, to be honest with you. What I started noticing is that my bowel habits were changing from diarrhoea to constipation. I actually got a puppy just before Christmas and I took her out for a quick walk and in the field and I thought, oh my God, I'm going to poo myself. I turned drop my trousers in the middle of a field. Again, I kind of thought weird, but probably being male I didn't moan about it, not doing and doing anything about it. Then I started noticing blood in my poo and that was kind of the main kind of catalyst of thinking I need to go and see the GP. She initially thought I may have a pile that was a bit further up than a finger could reach. As a passing comment, really, I just said, oh, my dad had bowel cancer 10 years ago and she said, "Okay, well, I don't think it is that, but let's just put you in for a colonoscopy." To be honest with you, I was really chilled out about it. I thought, well, I've probably got a pile let's go and do the colonoscopy and it'll all be fine. Hadn't really thought about the idea that there was going to be a massive screen, which I could also see as well, quite quickly into the, I guess the viewing I saw something which looked really weird. There was quite bloody and I said, "Oh my God, what is that?" The doctor said, "We'll chat later." I got taken back to my cubicle, a nurse rushed in said, "We need to take bloods from you." A different nurse rushed in said, "Who are you here with?" I said, "Well, no one because of, COVID, but my parents were going to pick me up and they're 10 minutes away." Another nurse came in and said, "Can you call somebody to come and wait in reception?" I thought what's going on? Then the doctor and one of the other nurses said, "Can you come in with me?" I went to like one the family waiting rooms and sat down. They said that, "We are 95% sure that this is cancer. We need to do more tests of biopsies, which they had taken and scans, but this looks like it's quite a big tumor." It was the weirdest feeling ever to be honest with you.

Angie: You noticed the symptoms. Now, I believe you confided in your mom didn't you?

Nick: Mom was like, "Look, just go and book an appointment, stop moaning about it. Stop talking about it. Just go and book the appointment."

Angie: Let's thank God that your mother is the woman that she is.

Nick: Mom is amazing. If it wasn't for her, I don't want to say nagging. She wasn't nagging me. She was just telling me you need to go and see the doctor.

Angie: She was encouraging you.

Nick: Yes. That's the right word. She was encouraging me to just go and get it sorted.

Angie: The words "We think it's cancer," took place at the colonoscopy, then you get the diagnosis and it's confirmed. Tell me about those feelings.

Nick: It was a couple of weeks of this balancing act of trying to play it cool and be okay and not worry and make sure your family's okay, but actually still not knowing. Then I received a call saying, you have cancer and it's a T4 tumour, which basically means the tumour has broken through all the bowel walls. It's the biggest size it could be and it's about to attach itself to my bladder, and we need to get cracking to try and sort this all out. Because of my age, they were viewing it as that we are going for a cure. The one thing actually, I think I'm very lucky about was because I was classed as a critical cancer patient. There's a hospital in London called St. Mark's Hospital, which is an NHS hospital,

which has a specialist bowel unit. They were also brought in to give their professional medical opinion as well as my local hospital in Kent. To me, and I think I'm very fortunate to have been in that situation because based there was two teams looking at all my stats and they both together agreed what my plan would be to go for cure. Which to be honest, mentally pleased me, but also filled me with dread because it being told what they wanted to do as the plan just sounded so intense.

Angie: Can you talk me through some of the treatment that you had, some of the treatment that followed?

Nick: Yes. I basically took the view of doctors and nurses they know what they're talking about you tell me what you want to do and I'll do it, because my tumour was really big. I could have had an operation straight away. The but is it was going to be very, very, very tricky, and it might impact my future living. The plan of attack was to try to reduce the size of the tumour to therefore make the operation "easier". The plan for that was radiotherapy every day, Monday to Friday for six weeks and on top of that, chemotherapy every day, Monday to Friday for six weeks. I was on something called capecitabine, which is a pill. I took 10 pills a day, on top of that go to hospital every day for radiotherapy. I was told that there's three outcomes from this. The tumours gets bigger, the tumours stays the same size or the tumour gets smaller, which is obviously what we want to happen. When I had my call with the oncologist to say, what the plan of attack was, you get given a huge list of what the side effects are, especially as you're doing chemo and radiotherapy together. It's almost like a dabble whammy, but I was just keen to start the process as soon as we could. There's a bit of back and forth thing of the hospitals. You have to have tattoos put on you, which is used for the radiotherapy to line you up so you are correctly in the position to be zapped by the radiotherapy. It was really difficult and the thing I found the hardest from that because it was all in my mid-region, I was told to have what's they call a comfortably full bladder and in my head, if my bladder is full, I need a way, there's nothing comfortable about it. Trying to have a comfortably full bladder I found really difficult. You get given a specific time that you need to go in to have your zapping, as I nicknamed it, but sometimes the hospitals' running behind schedule. What happens to that is you could get there with your "comfortably full bladder", but then we told that you wait 40 minutes for your zapping, which is fair enough. Then you go through this like, question mark of, well, what do I do? Do I have a we now and then try and nail a load of water in the hope that I end up having a comfortably full bladder? It is really difficult. I did wet myself one time when I was on the radiotherapy table because I just thought I could hold it and basically, I couldn't, and it was just a nightmare. The side effects from doing the radiotherapy and chemotherapy together where it weren't great. I felt absolutely exhausted, real fatigue, but I knew this is what it was going to be. You get told what the side effects were going to be and my view was I want to get better and if this is the pain I need to go through, then let's do it.

Angie: My understanding is that you moved back to your parents' house during diagnosis and treatment. Now for a young man in his thirties, that might have been quite a transition, but because of what you were going through, did you feel it was the best place to be?

Nick: Totally. I think, although I love London life and I love living in my flat. It doesn't matter how old you are, having a hug from your mom is amazing, and knowing that your mom is there to give you a hug when you are feeling terrible or emotional, and my dad

is just phenomenal as a person. As I said earlier, we are from a farming family originally and we don't have a family motto, but my granddad used to say, "We never give up," and that's something that's always stuck with me because my dad always had this attitude of never giving up. Being around them both was great because they kept me going and even when I was feeling terrible sitting in my bed, thinking what is my life, they were there. We had no control. Yes, I could have said, no, I don't want the treatment but in my eyes, that wasn't an option. We are allowing the doctors and nurses to do their best and I think for my parents, mom cooking me dinner, dad taking me to hospital, they could do something. They had something that they had control of that they could offer support and it was amazing. I'm back on chemotherapy now and I'm still living with them and I couldn't redo it without them, to be honest with you. It actually makes me feel a bit emotional because they know they've lived this whole journey with me and having them gone through it themselves it's like round two for them. Yes, I owe a lot to them actually.

Angie: Oh. Nick, you had a stoma bag after the surgery now for a young man in his thirties-- That must be a hard adjustment for anybody, but for a young man in his thirties, what was it like with your everyday life?

Nick: I knew I was going to have to have one, so it wasn't a surprise, but it's has taken me a long time to get used to it. Without being too graphic I have two red things that stick out of my tummy, where my poo comes from. Mentally that's just weird in my head and it was swollen. There was blood everywhere and it was quite just really sensitive. As I say, although you were told previously you're going to have one, until you have it, it just doesn't sink in. The stoma nurses were absolutely fantastic of teaching you how to do it. It's probably the one thing I hadn't really thought about is the care of what you have to do with the stoma bag. There's a hell of a lot, and I hadn't thought about it. I think in fairness to stoma nurses, they had told me prior to surgery, but your head's all over the shop, you're having an operation. At the age of 33, it is a weird feeling. The other thing to add onto that, I have an ileostomy which basically means food only goes into my small intestine and then it comes out and because of that, you have to specific diet, which is low fiber. I live my life on strawberries, berries in the morning salads in the afternoon tomatoes and peppers. That all has to go. You have to eat starchy foods, potatoes, and pasta. You can have carrots, but as long as they're cooked really well. Mentally I'm used to a certain diet that has to go out the window. I've never had a six-pack, but I was quite lean and toned. I was told I have to put weight on so I don't feel myself and I certainly don't look like myself. That's partly because of the stoma bag. The stoma bag is saving my life and there's no two ways about it. If didn't have, if this wasn't an option, I don't know what would happen, but I know the purpose of it, but it is something as a young man is quite challenging to get your head around, but I decided that we are in this together stoma bag. I decided that stoma bag was going to be called Zippy. Zippy comes to bed with me. Zippy is in the shower, we're in this together so let's try and be friends thing rather than viewing it in a negative way. It's really helped me.

Angie: Has life got-- I don't know if the right word is easier, but has life got easier with Zippy?

Nick: When I found out that I had to have six more months of chemotherapy, that really knocked me because I was told that I was going to have to have Zippy for the duration that I was on chemotherapy. Broadly speaking, if I didn't have to have more

chemotherapy, I wouldn't have the bag now. I would've had my reversal operation. Being told that I have cancer cells in my blood vessels, which means I have to have more chemotherapy that means you're going to have to have Zippy for six months, but it's actually longer than that. Because when you finish chemotherapy, you have to wait roughly six to eight weeks to allow the chemo to sink out of you and have scans and whatever before you have the thing. In my head, I was like, "Oh no. This is the rest of the year with Zippy." I initially found that a real challenge because I just thought, oh my I'm not sure I can do more chemo. I'm not sure actually I want to have Zippy for much longer. It has been difficult, but I've gotten to quite a good routine of it. I think that was probably what I just needed to learn. When is my bag or when is my stoma more active? It's probably like an obvious thing to say, but when you go to bed, you don't eat so there's no food in you. When you get out of bed in the morning, it's quite a good time to change your bag whereas if I was might be, I don't know, do it in the middle of the day. It's like, "Oh my God, what's going on?" I'm now trying to see some friends because I haven't really seen my friends in a while and now the pandemic eased a bit but you have to be careful what you eat. Everything goes back to Zippy and sometimes I've had a few nightmares in the middle of the night. It's in my words, blown up so your white bedsheets aren't white anymore, which is a bit frustrating, but I think I realized you just got to laugh about it and, and not stress and allow it to do its thing and remember that the stoma bag is there to help you get better.

Angie: You say you've got to watch what you eat, don't eat at night, but are there any other words of wisdom that you could share with somebody, especially a young person who around themselves with a stoma bag, maybe mental and emotional words of wisdom?

Nick: Well, two things for me, I changed my bag twice a day. My big issue was that I was getting very raw skin. It was bleeding and actually, I was only changing my bag in the morning. Changing it twice a day, I think helped because it gave the opportunity to wipe your skin but in terms of encouragement, there's actually a lot of people that have stoma bags that you don't know about. You're not the only one that's that that's got it but I think for me, it was really just remembering that this is saving my life. This is absolutely saving my life, allowing my body to heal where the operation was. I don't know actually what would happen if stoma bags didn't exist so although it is challenging, don't give up on it, make it your friend, give it a name. I think that's the important bit and as I say, it comes with you. Zippy sees me naked, Zippy sleeps with me, Zippy comes with me when I go for a wee, when I go for a coffee, and so it's part of me. I think if you view it as something that's saving your life and make it, your friend, you'll find it much easier to like deal with.

Angie: I love your outlook. I absolutely love your outlook. Now you have been posting about your journey and Zippy on Instagram, haven't you?

Nick: It's a weird one and I hadn't perhaps appreciated the feedback that I got from it. I put a post up halfway through when I was doing radiotherapy and I hadn't done any of this for self-indulgence. Give me a pat on the back, the likes or whatever. I just wanted to put a post up to say, "Go and see your doctor if something doesn't look or feel right, it doesn't matter what age you are, just go into your doctor." That was really the message that I wanted to say and the way that of the internet works and the social media works, loads of people started following me that were going through similar

challenges. One of my friends actually had a funny-looking mole on her back and a bit like me, she's my age, thought nothing of it, but looks a bit funny. She took my post as encouragement to see her GP and she was told it was cancerous and I thought, "Oh my gosh, like I've helped someone to give them encouragement to go and see the doctor." I felt really proud of that and I've helped her, so I decided that I wanted to make a phrase of "know your shit," because that was really what my view was, looking at my poo and thinking, do I know it? I don't know you. Who's this blood in there? I've started kind of doing a few posts really, about my journey and each stage that I'm at because I make sure it's like, "Oh, it'll be fine, I'll be better in a year, don't worry about it. In six months it will be fine." Actually, when I started radiotherapy, I thought, this is going to be the longest six weeks of my life. That was my first stage. I did a post about that. The second stage was kind of actually this sort of gap between finishing treatment and starting the operation and kind of getting ready for that. I did a post about that. There is actually the most amazing community out there on social media of people that are going through-- Doesn't necessarily has to be the same cancer as me, but just who have cancer, who are young, and are wanting to really promote that we need to support each other, and give encouragement and advice to people that are maybe too scared to go and see their GP or I can't get an appointment, so I won't worry about it. Well, no, the answer is keep trying, you know, keep trying, put yourself in. Now, it's helped me definitely talk about it. Let's just say if I can give a [unintelligible 00:21:17] encouragement, then I feel really pleased with that.

Angie: You sound very driven, Nick. It's really encouraging to hear the way that you talk. What does the future hold?

Nick: As I said, I'm on chemotherapy at the moment, so I had to do six months of chemotherapy, which is 14 days of chemotherapy, seven days off. Today, I am starting round six, and I have to do eight rounds. Hopefully, six to eight weeks after I finish chemo I can have my reversal operation. Then, I know this sounds really weird, but a lot of my friends are like, "You need to go on a holiday, you need to go and do stuff." I just want to go back to my flat in London, and see my friends and go for a coffee and go to the gym. My sister said to me, "What do you think your first meal will be?" I said it's really weird, "I can't wait to have a salad. I'm so excited about eating a tomato, and a pepper," which sounds ridiculous, but when you have your normal life taken away from you, you'd want to go back to like normal life. As I said, mum's 70. She'll hate me for saying her age. She's 70 in May. That's my goal. I want to get back to normal by then. Want to be fit and healthy and having some celebration, free drinks for them. Then I'll probably go on a few holidays but I just feel like that-- I don't mean this in a drastic way but I feel like you're in a sort of cancer prison when you go through this, especially with COVID as well. You can't really go anywhere because your immune system is low being on chemotherapy. I haven't had a normal life and I just want to go back to my normal life. I want to go to my local coffee shop and see them all there and say, "I'm back" and have a coffee and that sort of thing. Just normal life and my dog is now one. I'm pretty keen on maybe just going on taking care of her and going into the Lake District or something, going for some nice walks, that sort of stuff. Just normal life and perhaps not rushing straight back to work.

Angie: Any prospects of dating, have you thought about dating, given everything that you've been through?

Nick: Yes, it's a funny one because if I had the stoma bag, but didn't have to go through chemotherapy, I genuinely really would think about it. Now, I'm definitely somebody, I probably lean on having a bit of a needy personality. I like a cuddle. A lot of my friends are settling down and getting married and some children and I'm kind of not at that stage yet. I'd like definitely like to meet Mr. Right and, and do that but I think at the moment because the chemo that I'm on really knocks me out for two weeks, and then I have a week off. It's just not kind of really feasible.

Angie: At the moment?

Nick: Yes, at the moment. It's definitely something that I would like to happen. I think really at the moment for me it's just finishing chemotherapy, saying farewell to Zippy and then see what happens. I think before finding a boyfriend it will be salads and coffees and being in London, and then finding Mr. Right.

Angie: Nick, you've been really upbeat about your experience and really positive. My final question is if there's anything you could say to any young person facing cancer, what would it be?

Nick: Never give up. That's definitely, as I said earlier, must have our kind of family motto, but "never give up," is definitely what I would say. I've also learned it's okay to have a down day. I am a positive person, but there have been times that I felt very low, felt really upset. You know, and think kind of "Why me? Why does this happen to me?" It's okay to have those down days but just set yourself a goal for the day and try and achieve that. I think that's the important thing. Whether that's putting your clothes on and going downstairs and making coffee and just watching TV, because some days genuinely, I didn't want to get out of bed. Just being able to do something like that is really positive. If you have energy, go and see your friends, and go and see your family, do something nice and if you know that the next day you might feel quite tired and not great, that's okay, because you did something positive to help your mindset. Don't give up and give yourself little challenges to try and overcome each day. Never give up, set yourself challenges, try and keep as positive as you can, but remember, it's okay if you have a down day and keep in contact with your friends.

Angie: Nick, thank you so much for being so open, honest, vulnerable at times, but also for making me smile. Thank you so much for talking to me.

Nick: Thanks for the opportunity.

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Voiceover: Questions about cancer, Boots and Macmillan are by your side from the moment you're diagnosed through your treatments and beyond. Our Boots Macmillan information pharmacists are on hand with specialist support. From helping you make sense of your diagnosis to advice about living with cancer. You can now access this specialist cancer support at every Boots pharmacy in the UK. Visit boots.com/macmillan for more information. Subject to pharmacist availability. [music]

Angie: Dany, welcome, and thank you for joining us today. Now, I know you've been on the podcast in our previous series, but for any new listeners, can you tell us a little bit about your role?

Dany: Hello, yes, I'm Dany Bell, and I'm a strategic advisor at Macmillan Cancer Support and my thematic area is cancer treatment. Angie: Now we've just been talking with Nick about receiving a cancer diagnosis in your 30s and how much of a shock that can be at a young age. Can you explain the likelihood of getting cancer in your 30s? If there are more common types of cancers people can get in this age bracket.

Dany: Cancer is not common in young adults but there are some cancers that are more common in younger people. Sometimes, this is linked to hereditary genetic factors that increase familial risk of certain cancers and these are generally breast cancer, colorectal cancer, lymphoma, melanoma, sarcoma. There's a few more but there are there are some cancers that can present at a younger age.

Angie: What supports available for people who are in this age group and they're really finding it hard to come to terms with their diagnosis?

Dany: Most organizations that offer support will offer support across the adult age spectrum. However, people in their 30s are in a different place in their life than, say, somebody who is 60 or 70. There are some charitable organizations that specifically focus on people in their 20s, 30s and 40s. One of those is Shine Cancer Support and the other one is called Trekstock, but they offer very specific things in terms of networks, Facebook groups, talks and workshops whereas charities, I guess like Macmillan, and other cancer site-specific charities like Breast Cancer Now, they have a more broad spectrum of support. There is a lot of support out there for people and I guess it depends on what their particular need is in terms of support, whether that be practical, emotional, physical, or they just have information needs.

Angie: Earlier, we were chatting to Nick about his stoma bag. Now, why might someone need a stoma bag? Exactly what does the stoma bag do?

Dany: Essentially, if somebody is having a piece of their bowel removed, once that's been removed, they rejoin the bowel and sometimes in order to allow that join to heal properly, somebody needs a temporary stoma, but sometimes people have cancer and they need the whole of the large bowel removed. Therefore, they need a permanent stoma. There's a variety of reasons but generally, it's either because something's been removed and so the function is different, or because they need a join in the bowel to heal so they have something on a temporary basis.

Angie: Is there a specific length of time that someone may need to have a stoma bag?

Dany: If it's a temporary one, it's generally a few months, sometimes it can be up to a year but generally, you know, it's enough time to allow things to heal.

Angie: Nick's saying earlier that looking after a stoma bag, it can be quite difficult, so what are your top tips for caring for a stoma bag?

Dany: I think it's really important you've got to change in function of how-- You won't go to the toilet in the normal way. Diet is really important because there are absolutely some foods that can cause food blockages like nuts and sweet corn. There are also other foods that we know can cause an excessive wind, and that can be more difficult

to manage, like cabbage and sprouts and things like that. Actually, paying attention to diet, if those things trouble you, or you are going out and you don't want to be in a position where your stoma bag has become overactive, or you get a lot of wind in it, then just paying a bit of attention to what you eat and lifestyle really. There's no reason to change your lifestyle, you can still go on holidays, you can still swim, you can still do physical activity. Any of those things that you want to do, it just requires a bit of planning and some information really. Some swimwear for men and women that have a stoma. There's different types of stoma bags and caps that you can get, smaller bags and caps that you can get if you want to go swimming or be on a beach. It's just sort of finding out what works for you. Clothing as well, not wearing tight waistbands and just finding what works for you in terms of comfort because everybody's individual, all of our systems work differently and people just need to find the right way for them and what foods upset them. It's really all just about planning really and thinking ahead, whereas we take those things for granted when we don't have a stoma bag.

Angie: Nick's very young. Obviously, the last thing he was expecting was a cancer diagnosis. If someone is young and is struggling with a Stoma bag, what advice can you give them?

Dany: Everybody's an individual and they will cope with things in different ways. Some people find connecting with other people in the same circumstance, either digitally in terms of online forums or support groups, or just even talking to somebody else who's further down the line with a stoma sometimes meeting someone with a stoma before you have surgery can be helpful. It's really about the individual's preference and then there's support lines that can offer advice. Stoma nurses are amazing people and have lots of experience. If people are worried or struggling with particular problems, then talk to their stoma nurse and they would definitely know local support and equally be able to connect them with someone else if what you want to do is talk to someone. I guess my advice is don't bottle it up, talk about it, and ask someone for advice or search on trusted websites to get information.

Angie: How can family or loved ones support someone who has a stoma bag.

Dany: The key thing is they're still the same person. It is very hard. I know the person may be with the stoma may be very conscious about the smell and things like that and I think it's really important for family members to not necessarily really react in a way that upsets the person, but just treat them as they would normally. Nothing's really changed. I guess, understand the need for privacy for planning when going on holiday, all of those things, and be available to talk to them if they want to talk about it.

Angie: Dany, what happens when someone no longer needs a stoma bag, that must be a very liberating feeling, but can it be reversed?

Dany: Oh, yes. I mean, if the intention at the outset was that it was temporary, there will always be a plan, the person will know the timings for when that's going to be reversed and they would just go into hospital and it's a more simple procedure to have it reversed than when they have the surgery and it's formed because they've had the removal of cancer and yes, and you do see that liberated feeling from people when they've had their stoma reversed, but some people do have to live with a permanent stoma, even sometimes when it's planned as temporary at the beginning, when they do

the surgery, it's then not possible for that to happen. They have to obviously learn to live permanently with a stoma.

Angie: Dany, thank you so much for your guidance and advice.

Dany: You're welcome.

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Angie: Inspiring to hear Nick's attitude at being diagnosed at such a young age. Huge thanks to Nick for sharing his story and to Dany for their expert advice. For more information about what we've talked about in this episode, and for more information about how to donate, please visit our website, www.macmillan.org.uk/podcast. I'm Angie Greaves, Talking Cancer is the Macmillan Cancer Support podcast

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