

Emma: Hello there. We're talking about end of life with the lovely Max on this episode. I would like to warn you that this podcast contains content which might be upsetting for some listeners. To be honest, I struggled to keep it together myself during the recording, and if you are affected by anything you hear our fantastic Macmillan support line staff can help. I'll give out the number at the end of the podcast, or you can find it on our website, macmillan.org.uk/talkingcancer. Okay, let's get started.

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Emma: Hello, I'm Emma B, and welcome to *Talking Cancer*, a podcast from Macmillan, where I'll be meeting real people to have honest conversations about living with cancer. In this episode, we're talking cancer with Max.

Max: We were sitting 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. Straight away, I think, as my dad had said, "No, it's going to be rubbish. It is. So, yes, we will have to cry together.

Emma: Just over a year ago, Max lost his mom, Nand, to breast and sarcoma cancer. She'd successfully overcome it two years before, and Max was initially optimistic.

Max: Well, there we go. We've done it once, we can do it again, but that didn't actually last too long because she was having some trouble breathing and the doctor basically told us it's too late on this time. Nothing's going to work.

Emma: Max talks about going through a period of pre grieving, mourning the loss of a loved one before they pass away, but it was a period where they could all talk and plan as a family.

Max: We were, I suppose, lucky in a way that we could plan mom's funeral with her. We'd only do 5 or 10 minutes at a time because it would get too much for all of us, but it was nice that we knew that the day when exactly how she wanted it to go.

Emma: If you're having to contemplate the end of someone's life, perhaps your own. Then, I think you'll find Max's story very inspiring, and later our lovely Macmillan professional, Danny, will be here to talk about how to deal with the end of someone's life.

Danny: You need just to be very aware of your feelings and know that it's okay to be sad, and if you're struggling to pick up the pieces, then there is lots of support out there.

Emma: We're Macmillan, and we're talking cancer. Max, welcome along. Thank you very much for coming. It's lovely to meet you. I think we should start by you telling us about your lovely mom, Nand. What was she like?



Danny: She was full of life. She had bright pink hair. Everyone says she was-her favorite phrase was pink and fluffy. That's what she says to everyone. Yes, so she loved drama. She ran a youth theater. She lived in Cyprus, and yes, she was over in England for a couple of months, I think Coventry. That's where we're from originally, and she was one of those live-action and like actors in Warwick castle, she did it for free just for a few months because she loved it so much.

Emma: No way. Wow. She was Mary, Queen of Scots, or someone like that if you were lucky with bright pink hair.

Max: Yes, pretty much.

Emma: I get the impression that you are quite a close family. How many brothers and sisters do you have? Were you around each other the whole time?

Max: We are really close still, and it was my dad and my mom and my sister, Ruby, and me, just us four. We all lived apart. My mom and dad lived in Cyprus. My sister lives in Coventry, and at the time, I lived down at Eastbourne. We lived all over the place, but we all met up at least once a month. It was really good.

Emma: Now, your mom got diagnosed not once, but twice. Tell us about the first time.

Max: Initially, it was just breast cancer and it was while I was still in the army, and I was just about to go over to the Falklands for six months. Yes, they came, visited me down to Southampton, that's where I was at the time. Yes, they broke the news to us then, and obviously, it was devastating, but it didn't really get us down the first time from the visit really faced anything like this before, and we're a really, really positive family. If I came back from work or school or something, it was negative or saying I didn't like it, my dad would be like, "No, enough of that. Come on, we're really positive and our family."

We were like that straight away with the first cancer. Although, it was sad, for honestly, about half an hour. We were like, "Right, we're going to beat this. We're going to really do it." It didn't really feel that real if you know what I mean.

Emma: For you at that point, did they come already armed with lots of information and answers to questions that you might have? What the treatment might be? And that helped you say, "No, no, no, it's okay. This is going to be okay."

Max: Yes, I think they did, but I think that blind positivity I didn't even ask about that, and I think it was a bit of a shock, obviously, at first. He didn't really go into too much of the detail, really. I was just like, "How are we going to beat it?"

Emma: She did get better?

Max: Yes. She made a full recovery. I think it was nine months to a year. She just went for a checkup and the doctors they couldn't believe it, that all the tumors had gone. It started with breast cancer, but then she also had osteosarcoma cancer as



well. I think she had 10 tumors at the time, and they'd all gone, which was crazy. We were so happy.

Emma: This leaves you as a family shaken, but resolute. I'm ready to carry on. How old is Nand? How old is your mom at this point?

Max: When she beat it the first time she would've been about 52.

Emma: Was she affected by the treatment? Did she seem to be herself or was she left with any lasting symptoms that made life different for her?

Max: During **[unintelligible 00:05:30]** she was totally not herself sleeping all the time, but afterwards, she was back to normal, which was great.

Emma: There was no reason for you to think that this was going to come back?

Max: No. We didn't think so.

Emma: Now, you and I do have something in common because my mom died at 62 with first-time breast cancer, and then the cancer came back. I know exactly where I was when we had the news that it had come back. How did the second bit of news come to you then?

Max: My mom she had some back pain. She was complaining of back pain. She left it for like a month. Like, "I'll be fine. I've had cancer. So, it doesn't matter, does it?" She was like, "No, I don't need to get that checked." Eventually, she was like, "It's hurting quite a lot. I need to take some painkillers." My dad, I think then took her into hospital, and then, yes, that's when they did some scans and they found out it had come back. Yes, sarcoma cancer second time.

Emma: That must've been so horrendously disappointing for your mom and for you and just had worked so hard. How was it for you all at that point being given that news that, yes, for a second time the cancer had come back?

Max: Initially, it was the same as the first time, we were like, "Well, there we go. We've done it once, we can do it again," but that didn't actually last too long because she was having some trouble breathing and she had to go into hospital. The doctor, basically, told us. "It's too late on this time and nothing is going to work." We then had to stop this positivity because as I said before, it worked once but it was blind positivity. We were like, "No, we can do it," but we actually couldn't this time.

Emma: Emotionally coming to that conclusion, especially, this is your mom, especially coming to that conclusion as a child, it must have been really hard.

Max: Yes. It was really tough. I remember it clear as day. We were sitting around her hospital bed in Coventry, and then I think me and my sister, even my dad, one of us started to cry, and immediately you do the same thing that loads of people do. I'm sorry. Straight away I think as my dad had said, "No." Then he started crying. He was like, "No, let's stop this now. It's not strong to hold your emotion, or



[unintelligible 00:07:36] anything like that. Let's just have a cry." Then he's like, "It's going to be rubbish. It is. There's no one saying it's going to be good. If you're going to cry let's cry. Let's not apologize for it. Let's just say it."

We all had a cry together for a bit. She was in for about a day then, and we were always just having these conversations and talking and coming to realization that we don't have very long left at all. It was weirdly nice. It was horrible, but then it was nice to be that vulnerable with each other.

Emma: Well talk about your blog because you've written a blog and it's amazing, and I'm sure has been a great help to many people who've read it. That bit that you are describing which enabled you to have those really great quality time with the remaining time that your mom had you describe as pre grieving. What do you mean by that?

Max: I don't know if I made it up. Maybe I did, but the pre grieving thing [crosstalk].

Emma: I'd take it. Own it. Own it, Max. Own it.

Max: Yes, it's a weird thing to own, isn't it? Yes, I thought it was really strange because we knew mom was going to die. We were given three to six months. We knew it was going to happen. You're already sad about that. You know you're going to grieve once she eventually goes, but then you're already sad about it. You're pre grieving at the same time. It's a really, really weird transition, and I'm sure you were the same when you were in that stage and many people listening or whatever. It's so, so strange because you want to be normal and have the best last few months, but at the same time, you are stupidly sad about it.

Emma: The thing is as well, is that it's such an unfathomable idea that somebody is going to die. Because until you're faced with it, you don't know what that means. You don't know what life is going to be like when they're not here. It's so difficult to pin that down and work that out. Isn't it? The pre grieving time, what did that enable you to do with your mom?

Max: It allowed us to have an actual great last few months, and we saw so much of our friends and family who came to visit because we were so open with what's going to happen. It was also really helpful for a lot of the actual grim stuff to organize, like the funeral and stuff like that.

Emma: You used some of that time to plan that, didn't you?

Max: Yes. I read somewhere online and to set a video camera up in the corner of the room.

Emily: Tell me about this. This is such a great idea.

Max: I was honestly so happy I read it, and I said to anyone who's going through anything like this, you just do it. I'm not saying sit there and act in front of the camera or something, you just leave it on while you're doing your normal daily life. It's really



good because you watch it back and you just see normal conversations and chats. I was really making an effort to get mom to talk about all the stuff for 20, 30 years ago that we didn't really know about. Even really boring stuff, like buying her first house and stuff, because my dad's memory is awful.

I want to get her talking and laughing and stuff like that. Then also, we had really hard conversations, we were, I suppose, lucky in a way that we could plan mom's funeral with her. It's so strange because it is a horrible conversation, we'd only do 5 or 10 minutes at a time because it would get too much for all of us, and especially my mom. It was nice that we knew that the day went exactly how she wanted to go, which is a weird, nice feeling.

Emily: During final months, if you have the capacity to talk about dying well, then, yes, you should. I think it's amazing that you managed to do that. All this time, I'm sure you really hunker down as a family and use each other as huge support. Did you get help and support from anywhere else? Because emotionally for you, even though you've got this framework now, which is super helpful, all this time, you're still going to work, still having to be Max, as day-to-day Max, and your responsibilities to other half and your friends. How did you manage to cope through this time?

Max: Initially, actually, I look back and think I was quite stupid at the start of it. We are a really close family, and I had the best network around me. Our wider family as well as all my aunties, uncles, cousins and everything, who will live really close to our house in Coventry anyway. I had my girlfriend now wife, I had loads of great friends and closest people, my dad and my sister. Even though we've been so open, most of the time, actually, feeling bad personally, three of us didn't talk.

Since then, we all spoke about it, we all thought we had to be the strong one, which is absolutely crazy because there's nothing strong about not talking about stuff. At the time, I wanted to talk, so I didn't know. I ended up texting to the mental health hub, I think it was mind. I didn't feel comfortable enough, or I didn't want to admit there was that much of a problem. I didn't want to actually pick up the phone and talk to someone or go and speak to someone like that, which now I think it's crazy. It's so important.

I started off with just a text, then I did quite a lot of online chatting with them, and it really, really helped me out. Sometimes, it's just having a bit of a moan, to be honest, and wanting to play the victim a little bit, I suppose, because it is a horrible situation and it really helped. Then, more recently, actually, a year on from that, last year, I thought I was fine, kept going, talking more openly about it, doing a blog and stuff like that really helped me. Since then, I' actually went to the GP, and you can register for talk therapy, which is really good.

I've only just made that step to go and do it, because I'm fine most of the time, but I sometimes want to have a chat about it. I've booked myself in, so we'll see how it goes. All I say to everyone is just talk to someone, find that someone whether it's that text, or a chat room online, or calling someone, you just need to talk,



Emily: It takes you very unaware by it, doesn't it? Because sometimes you have those days, yes, yes, yes, and there'll just be something that you go, "Oh, my God," and that huge hole is there again. That's time.

Max: Yes, you do. You just take some time for yourself as well. What happened with me, I was driving 180 miles home every week. I'd work an early shift at work, drive up that day, have two days off, then the day after BLH then drive back that day. I did that every week for two months or something. It got to the point where mom could feel me being stressed and the tension. Even though I was there, absolutely knackered, I wanted to be there, but she could then feel it, then she would be down as well.

At that point, I think my partner was like, "We just need to do something." On one of those two days, we actually drove over to Paris and we had a couple of days just for us. I did feel really guilty at the start of it, driving over there I was like, "I should be back home now," but you just need that time for yourself as well, and it rubs off on your loved one as well. It's so important.

Emily: Did you ever get to talk to your mom about how you felt?

Max: No, I didn't really.

Emily: I didn't either.

Max: No, you don't really want to get them down. Some days, she'd be really up and really happy in her normal self, trying to do normal stuff like going for coffees and stuff like that. Having a glass of red wine with her, but then sometimes she would just start crying and be quite worried. I didn't really want to add another burden onto it, sort of thing, even though she probably would have wanted to talk about it really, but you just feel like you don't want to burden them.

Emily: What kind of things was she worried about in that time?

Max: She was really worried about as well being happy. As I said before, a lot of it is a blur all around that time. The one thing that I really remember as I was sat there, I think it was just me or it might have been my sister as well, we were just watching telly or something. She turned randomly and was like, "Oh, Max, you're going to marry Nina, aren't you?" I was like, "I don't know mom, I haven't got a clue actually. She's only my girlfriend at the minute. I don't know. I'm not thinking about that. She was like, "But you're happy, though, aren't you?" I was like, "Yes, I'm really happy."

She was like, "Ruby's got Tom." Ruby's my sister, and Tom's, her boyfriend, and they've got two kids together. She's like, "Ruby's got Tom. She's happy, isn't she? That's going to be all right, isn't it?" I said, "Yes." She's like, "Okay, I'm happy now. I thought that was really cute.

Emily: She's just making sure her kids are okay and the family's going to be all right. How are the wider circle of friends reacting at this point? Do you make an effort to



get people to see each other as well? With the knowledge that your mom's, she is going to die at some point, and now is the time to come and see her.

Max: We actually just put something on Facebook. My dad's words were, "I'm sorry to have to post this to everyone, but cancer has reared its ugly head again, but this time, we haven't got long left at all. It sounds horrible, but if you want to come and say goodbye, basically, please do." It was amazing. My sister had to keep a diary about-

Emily: Like a secretary.

Max: Literally, she had to.

Emily: Personal assistant, I should say.

Max: Yes, exactly. People came from all over the place. Obviously, as we said, we grew up in Cyprus, so we had loads of people who still lived in Cyprus, but there's a lot of military there, so they then flew all across the world after that. People would come in from Cyprus, Australia, all around the country, and just to come and visit. It was nice but quite sad at the same time.

Emily: All this is leading up to the moment that your mom passed away. I'm sure for you, quite a weird, very strange moment. Where were you? Were you with her? Where were you when the news came that she died?

Max: I wasn't actually, I was at home on a day off. This is really strange as well. That day, I didn't have two days off in a row for whatever reason it was, so I couldn't drive up and Coventry, and my partner was going to go to work that day. I was like, "What should I do today?" I remember it was cold, it's February the 27th. I thought I'd be nice to mom, so I was like, "Let's do something that mom would do." I was still in bed when it happened but then I was about to go and get all my jumpers that I don't wear anymore my Christmas jumpers, and go and give them to homeless people.

I remember that because I remember thinking, "Let's do something that mom would do." My dad called me and said, "Would you take mom to hospital? We don't know what it is, but probably make your way up here now." I was like, "Okay." I left straight away, then got another call about halfway up when I was driving. It was when it was that awful snow as well in February in 2018. Then, obviously got the news while I was driving. I probably should have stopped, but I didn't want to, I just wanted to get there.

Emily: How did you digest that, Max?

Max: It was really, really tough. I should have stopped. I didn't and I just had on the hands-free the car and driving. It's not really much to say on the phone. I said I'll be there in an hour. I was bawling my eyes out, to be honest, driving, cry my eyes out. It must have looked so strange to someone who'd driving past thinking I was going through a breakup or something. I just felt really numb the whole day. I got to the



hospital, and all my extended family were all in the waiting room, then I just walked straight in, I saw my mom.

Before, I didn't think I'd want to go and see her, but it was the best thing I've ever done. Compared to what she'd been like last few weeks, she'd been struggling to breathe and stuff like that, where tumors were pushing on different areas of her body. I just saw her looking totally peaceful and just looking to sleep and not ill anymore. I'm really glad I went in there actually.

Emily: I'm glad you said that. I think it's really important. The concept of seeing a dead body is terrifying, let alone when it's somebody that you love so much. A very brave thing to do, but obviously, hugely important for you.

Max: I really did not think I'd want to go in but they just look so peaceful, don't they? I liked that one of my last like memories I can see through my own eyes of my mom is her looking healthy and peaceful, not in pain and swollen with tumors and things like that.

Emily: Emotionally, immediately afterwards, for lots of people, you go into automatic mode, there are things to do. Emotionally, immediately afterwards, how were you after that day, when you said goodbye to your mom?

Max: I felt really numb, I didn't really know what to do. I think I'd already done most of my crying on the drive up to, be honest, but then, yes, we went home after an hour at the hospital, and then we just sat around and we were like, "I don't really know what to do now." We went to the pub and had a pint just us three, and then my uncle and cousin joined, and then straight away we started planning. We were like, "We'd already planned the funeral." We'd know which funeral director we'd go with. Mom had chosen a pink casket, obviously, because it's pink.

Emily: Had she really?

Max: Yes.

Emily: Awesome.

Max: Yes, so we knew we had a list of stuff we were going to do, so then we'd just booked if all. You're right, you do go into automatic, just let's do this, just try to distract yourself.

Emily: Some people talk about a sense of relief almost, and then feel guilty about that because the suffering anyway has stopped, but there's a little bit of, "Oh, should I feel relieved?"

Max: Yes, you do that didn't come for a few days to me, as I said, I literally just filled the few days organized as much as we could, and it didn't sink in at all, I'd say for a few days. Once it did, you're right, you do feel a bit relieved because you know they're not struggling anymore.



Emily: I've heard about this funeral and that you organized it pretty much all yourselves. Military precision. It sounds like it couldn't have been a better funeral for her.

Max: It was unbelievable. I still tear up things about how nice it was. The crematorium, was placed just outside Coventry and the capacity was about 100 people, and there was easily over 200 people who turned up. Initially, so we obviously, got there with the casket a bit when everyone had already arrived. All the seats inside had filled up and there was a huge queue people outside, so we carried in mom, all the family did, and we put her on the plinth or whatever it's called.

Then my dad was like, "All right, we're not starting yet, come on, everyone get in," and so everyone was really squeezed in, there was no one left outside, but people were all around us. At the front, where the stage is, basically, they were all around those people around the casket, people were all up the aisles, it was really close, it was really nice. We live-streamed it as well, and it was watched by my dad knows the final figure. It was over 2,000 people in site for us, where we're from two pubs showed it on the live screen that was packed full of people. My dad counted the countries and it was something like 21 to 25 countries tuned in or something. It was crazy.

Emily: You spoke at the funeral, didn't you?

Max: Yes, so I did the eulogy. My sister did a poem that she wrote herself and my dad just like hosted and did spoke about mom a little bit.

Emily: That must have been super difficult for you to stand up and do the eulogy about your lovely mom.

Max: Yes. It was quite difficult and I held it together but I didn't care if I didn't hold it together like we said, if I'd started crying, I would not mind it at all. I would've brought that into the eulogy saying, "Let's do it guys. You need to be honest and tear up if you need to." It was quite hard, but I've happy we did that together. Initially, so the person who holds it is, I can't remember what they're called.

Emily: Oh, I know what [crosstalk] celebrant. That's it.

Max: Initially, my mom was going to do record that. That was our plan first which would've been so strange but it would've been, so my mom so she would've been like, "Hello, welcome to my funeral and stuff like that." We're doing really strange, but she got a little bit quicker than we thought, so we couldn't do it in the end.

Emily: In retrospect, you think she would've been really happy with her day?

Max: I think so because there was no one else talking. It was just us three who talked. We're not religious, nothing wrong with being religious, but we are just not, so it wouldn't have been us if it was a religious service or anything like that. Then, if someone we didn't know was speaking about mom, it wouldn't have been the same. It couldn't have gone any better, really.



Emily: What tends to happen then that is for all dies down. Everybody goes back to their normal lives, which has changed significantly for you. How was that when all the buzz had died down?

Max: Yes, that was really strained, so I had about a week, no, about two weeks off, from mom dying to going back to work, I could have had a lot more work, really good about it, but after the first week I was like, it's not really, what am I doing? I'm just sitting around basically, being sad and which is fine, but then, life does move on and it has to move on. I wanted to go back to work. I went back to work within two weeks, and it's so strange because no one can win random as your employee your staff at work.

No one can win because if they don't mention it in your head, you think, "Oh, come on. My mom's just **[unintelligible 00:24:57]**, what are you asking about me?" If they do ask about it, you shout down, "Yes, I'm fine. Don't worry about it. Thank you." They literally can't win it so strange, and I went working in retail. It was an awful time to go back to work. It was Mother's Day.

Emily: Oh, good grief, Max, no.

Max: I just wanted to get back, but that wasn't the best time to go back, looking back at it.

Emily: I think those are the things actually, isn't it? Because for that first year as well, you count that's the first Mother's Day. That's the first Christmas. That's the first my birthday, and all those firsts are really painful reminders. What words of advice do you have for people who are listening, who are going through this, or can expect this about moving on after the death of someone that you love?

Max: I would say, always take time to remember them. Don't try and force it down. If you are feeling sad one night, ride it out. Sometimes, I actually make myself, sometimes I'm there **[unintelligible 00:25:53]** I see a picture of mom when she was ill that day and I go, "I want to remember mom when she was normal." I'll just watching old videos or something like that, but it's really important too. You probably are going to want to be talking, you're going to be sad for probably the rest of your life. I tried to describe someone the other day, which I think was a weird analogy. At the very start, you're on an emotional rollercoaster. There's so many ups, so many downs.

If you were going to a theme park, it'd be the best ride there because there was so many ups and downs, but eventually, you're still going to have those ups and downs, but it's going to be a really boring rollercoaster. There's going to be loads of flat. Those are good times, and eventually, there'll be a few downs, but you'll get through it. I just say, talk to everyone.

Emily: How is this affected you as a family?

Max: I think weirdly, it's brought us a lot closer together. We were close before but now we are more, we actually asked twice. Now there's just a WhatsApp group, so File name: macmillan series 1 episode 4.mp3



we've got a big one with all our family. We've got one just my dad, my sister and I, and in that, if one of us feeling sad sometimes, you can normally tell because it would be text **[unintelligible 00:26:59]** I'd be like, "How are you doing guys?" They'd be like, "Yes, good. How are you actually doing?" "Yes, I'm feeling a bit sad today or whatever." We talk a lot more openly about probably mental health and stuff, which I think is really good.

Emily: Absolutely. Do you talk about your mom to each other?

Max: Yes, definitely. We do stuff at [unintelligible 00:27:16] all the time, so mom used to see trends that people do, like kids do these days or whatever. She would do them wrong, so there was a stage a few years ago when kids or teenagers would say like, "Oh, that smells," and you'd be like, "Your mom smells." My mom used to do that to me and my sister. It'd be like, "Mom stop being silly. Your mom's silly." I'm like, "Mom, that's you, that's it for you," so my dad still does that. You say something, I don't know, I'm a bit tired, today, your mom's tired. It's still like she's living on.

Emily: Absolutely. Yes. We have cook a dinner. I'm going to cook a dinner, like this and I'll start skipping and, yes, that she's back in the room immediately, which is really funny. The future for you, you're blogging, you're podcasting, why do you feel like you want to talk about this so much because it's unbelievably helpful. Why is it important to you to do this?

Max: I just think that I could have done with something like this when I was going through it, but honestly, maybe selfish. It's like my own therapy. I said on my first ever podcast I recorded last week. I said, "Guys, if you want me to do this again, let me know your honest feedback, if it was good, if it's a one off great, it felt quite good doing it. If you want to hear more, let me know. You're actually probably listening to my own personal therapy right now." My thing is if I can just have one person, it makes me feel better about it, so when I did the blog, seeing a few comments on it, and it made a difference to someone that's, honestly, all I care about. For me, I suppose, yes, kind of therapy, the thought of helping someone who went through something that I did feels really nice.

Emily: Here's to your mom, Nand. Cheers to Nand.

Max: Cheers.

Emily: There you go. That's tea, not vodka guys, Max.

Max: She would love that cup as well.

Emily: Would she? Oh yes, she would. On Wednesdays, we wear pink Mondays, Tuesdays, Thursdays, Fridays, and the weekend as well. Max, is lovely to speak to you. Thank you very much for being so honest with us, it's hugely appreciated.

Max: Thank you for having me.



Emily: Danny, our fabulous Macmillan professional, is back with me. First of all, Danny, Max, what a story? What do you make of how him and his family have dealt with it?

Danny: Oh, I mean, so many practical tips in there from things that they've done that feel like they're original, that you could put a different slot on but absolutely amazing. How they dealt with it as a family. Again, that experience is very different for different individuals and for different families.

Emily: What are the most common questions that you get about end-of-life.

Danny: I think a common question people often ask themselves and family members often debate is how long. How long have I got left to live when they know their time is limited, and that's very difficult because some people ask the question and perhaps they don't really want to know the answer. I think it's always very difficult to give a very specific time. I worked with a personal care consultant who was very good at doing this.

She always used to double-check that they actually wanted the answer, but then she would say whether she thought they had weeks or months. She didn't say you have two weeks or, she just would say, "I think it's going to be very few weeks," and I think that gives a good indication without it being specific so people are ticking the days off on the calendar and getting very upset and anxious.

Emma: In those days as well, Max described very eloquently this pre grieving process that I completely related to. Give us some explanation of what that is. What he meant by that.

Danny: He really articulated it really well. Well, you know you're going to lose someone, but you don't know when, and so you start the grieving process, in essence. That's different for everyone in terms of shock, fear, anger, acceptance. There's very good literature around the grieving process and some people experience all of that. Some people only one of those things. In essence, it's about you coming to terms with the fact that you're going to lose your loved one.

Emma: On a practical level, I think because, like we've mentioned, when you are in this huge emotional turmoil, structure is helpful. What if somebody's just received an end-of-life diagnosis? What kicks in? What steps should people expect, and what would happen generally to help them through that?

Danny: I think the most important thing, and that's why Max's story is just so important, is being able to talk. I know they were a close family, and some people don't feel that they can talk to friends or family about it. Understanding what you want, if you are in the situation where you are facing end-of-life, when do you want to consider having no treatment, if you're still having treatment? Where do you want to be? Who do you want to support you? What support is out there? You can have those conversations with your GP or even your clinical team.

Emma: Then you can have them.



Danny: You can have them, and you can actually undertake something called an advanced care plan, where you can document those things. So that all those people caring for you, like the GP, will understand what your wishes are, and you can share that with family members. Obviously, including family members in those conversations is really helpful too.

Emma: Talking about including people in the conversations, Max's story about how his family filmed conversations with his mom, and they just put the camera on. They've got a lot of normal that they've recorded as well, stuff that they didn't even realize they were recording. It was quite a unique approach, but served as a great example about how you might approach those final weeks or months.

Danny: I just thought that was such an amazing-

Emma: Wasn't it?

Emma: -idea. I think one of the things when you are going to lose someone, that feels really important to most people, is making memories. Reflecting on past memories, and often you will talk about things that happened historically that you remember that were happy times. Also, creating memories that you can keep hold of once the person's no longer around. That was such a good idea, unfortunately, because often people don't talk about things openly and have those open discussions. They lose that opportunity to make those choices and make those memories, which does seem such a shame.

Emma: If you've never been in the situation, contemplating death is a huge psychological minefield. What is your advice if you are really genuinely worried about the physicalities of it, about the psychological effects about how you are dealing with it?

Danny: It links back to your first question about what people expect, and there's lots of things. One of the things they sometimes ask is, "What will it be like?" Or, "What can I expect?" In reality, some people are active in doing things right up until the last few days. Whereas other people are much weaker and perhaps, the last couple of weeks, are very tired and in bed. I think they're very individual things.

They're also based on what's causing you to-- What type of cancer you have, what type of treatment you've had, and generally, how you've coped through that might be an indication. Actually, if people are worried about symptoms, you can just talk through some of the common symptoms that people can have when they're approaching end-of-life, and what you can do to actually alleviate those. People don't have to be in pain, they don't have to feel sick.

Sometimes people get very worried about people eating and drinking, and there's this need to try and feed their relative or their loved one and make sure they drink to keep them alive. In reality, it's a natural process and people won't suffer through that. If they're hungry and they want to enjoy something, let them have it. If they're not hungry, it doesn't matter. What is important is that, obviously, you keep their mouth comfortable and moist because, obviously, if they're not drinking their mouth will dry. File name: macmillan series 1 episode 4.mp3



Emma: In those final few days, Max, and his family planned his mom's funeral meticulously. It's quite an undertaking. It sounded like a really special day. How would you recommend people approach funeral planning? Because it's not easy.

Danny: It's not. Actually, doing after the event can be quite traumatic. I think that's a fabulous example where they had time, where they were able to talk and they were able to plan it. Actually, there are lots of schemes now where you can do that while you are well, and which feels much healthier. In a way, it takes the burden off of how many families, though, talk to each other about, "What would you like [crosstalk]?"

Emma: You don't.

Danny: It isn't, and that would be a really good thing to do. If you've got the opportunity as a family, and you've got an elderly relative, is to try and have those conversations, but people don't. I think they are a good example of how they approached it. You can still do it that way, even after somebody has died. Think about the person and the essence of the person and what they would've wanted, because in reality, you probably know anyway. I think there's lots of ways that you can approach it. There's lots of websites out there that give advice. We will have advice on our website, Marie Curie have advice on their website. There's lots of places. People can go to think about how you plan a funeral when you do it.

Emma: Words of advice for people who have lost a loved one, resuming their lives. It's a very strange period after somebody has passed away for friends and family. What is your advice in that period afterwards? How do you get back to any semblance of a normal life?

Danny: Yes, life does have to go on, but actually, the pain of losing someone can be quite physical as well as emotional, and talking is a really important thing. If you can't talk amongst people that you care about, talk to your GP about how you feel potentially. I loved Max's example about texting mind and looking online if you can't pick up the phone. All of that applies after the event. You need to just be very aware of your feelings and know that it's okay to be sad. If you are struggling to pick up the pieces and carry on with life without that person around, then there is lots of support out there.

Emma: I think I slept for a month. I was exhausted. I think there's that because you don't realize how much you are coping, and the emotional energy, the physical energy that takes up. I slept for a month. It was incredible.

Danny: It's okay to cry when a particular song comes on the radio, or you are in a place and you think, "Oh, they so would've loved to be here." It is okay to cry, it's a normal reaction.

Emma: I told you, I used to go into mommy to wear this perfume, and every time I'd go into like, "Debenhams" or somewhere like that, and I'd get a whiff of it for a long time. I'd just, "Ugh" and it does take you by surprise a bit, and it's good to know that that's okay.



Danny: I've still got the bottle of aftershave that my dad was using before he died. Now and again-

Emma: You have a quick [crosstalk] sniff.

Danny: -it just reminds me of him. It's just so nice.

Emma: Oh, Danny. I could talk to you all day. Thank you so very much again. Our thanks to Max for coming in to tell his story. If you've been affected by the very sensitive topics we've discussed in this episode, please contact our Macmillan support line on 08088080000, open seven days a week, 8:00 till 8:00. Next time, we are talking work and cancer with Helen.

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

Emma: I should think so. Subscribe if you'd like to hear that in every new episode, whenever it's ready. If you're enjoying the series, why not give it a rating or a review? It helps others find the podcast more easily. I'm Emma B, *Talking Cancer* is a Macmillan cancer support podcast. [music]