

Transcript

Blood Cancer Heart to Heart

Episode three: Facing blood cancer together

Voiceover: Welcome to Blood Cancer Heart to Heart. Scott and Tris have been together for over 20 years. The talk about how Scott's myeloma diagnosis has changed things for them as a couple, sometimes in a positive way.

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Scott: So, do you remember the day that I was diagnosed, and we went to a coffee shop before, and I was sitting there a little bit worried because the signs were coming in that something was wrong, and you were being really calm, by saying no, it's all going to be fine. And then I just had this feeling that something dark was going to happen. And then it just seemed to be a little bit of a blur. And I'm so grateful that you were there because I think I've said to lots of people, that when you're diagnosed with a cancer or any kind of traumatic health experience, or health problem, you need someone like yourself to be there to actually listen to the information.

Tris: Well, so first of all, it shows that I'm being my naive self, right? Because I – well not naive but maybe overly optimistic – because I did try to dial it down. We had some signs that it might be myeloma in advance, because we'd been on our way down to Cornwall, it had been our first holiday for a while. And there was a suggestion that you needed to come in for an MRI and a bone marrow biopsy. And one of our friends looked that up and said, oh, well, it might be to rule out myeloma. And then you said, oh god, it couldn't be myeloma, could it? And we sort of looked up, googled what myeloma was, didn't we? And we were on a beach in Cornwall doing that. And I said, ah well, I looked at it, and it can't possibly. You don't have a risk factors. I mean, yes, you're a white guy. And you're

not over this age, and so on. So don't worry, it won't be that. And then of course, maybe I was trying to be optimistic and keep you calm as well.

It also came at a really tough moment for us, just in life. And it sometimes feels like everything goes wrong at once. So again – I know you know, you were there! – but for the people who are listening to this, we had just had to close a business, which meant that we had had to, you know, make – well, there were 25 of us in the team – so make 23 other people redundant. Which was, you know, obviously, a traumatic experience. It was very stressful, we loved what we were doing. We were running this big, global LGBT news site, we were passionate about it. And therefore, it felt like all of the world was collapsing on us anyway. And one of the signs had been in the lead up to your diagnosis, before you even went to the hospital the first time, your energy was dropping, you found you couldn't walk so far. And you couldn't walk and have a conversation at the same time, so much, and your back was sore, and you had a back spasm. And we put a lot of that down to, well, we're not sleeping, we're having to close a business, we're really stressed out.

So I think that by the point that you got to the hospital, whether or not you were actually fearing the worst, and whether or not you really thought it was going to be myeloma (I don't think we were quite at that point), but it did feel like everything was going wrong. So it wasn't necessarily unimaginable that you thought, oh god, something else is going to go wrong.

Scott: Well, we already knew something was happening to my kidneys. And that seemed to, that conversation seemed to have dialed away a little bit. So this whole new problem kind of came out of nowhere. And I think that's probably why we weren't thinking cancer route. Because I was still, I was a month before turning 40. I wasn't the obvious, like groups of people that would normally have it. And you don't really expect anybody, you know, this young to have had it.

So I just, it was such a strange day, but having someone in the room that was calm, and I think we were both really calm, of course, you know, the mind was just, there was a load of fog. But I was hearing things in a different way than you did. And I think you always, if you don't have a partner, or if you don't have a family member with you or a friend that can go with you, you need to find that support because you need a person who is a bit more of a sensible head in the room to actually listen to the information. Because there was another doctor, when I was going through the stem cell transplants that said – I

heard, as it stands, you've got 10 years to live. And what you heard was, as it stands, if we do nothing, and you don't have a treatment, you have...

Tris: Well no, what I heard was (well, actually we can come back to that, maybe) but what I heard at that point – now we're just skipping forward, like 18 months, or six months – but what I heard at that point was different to you, because I recognised that the treatments were advancing all the time, that new options were coming, they were going to do a stem cell transplant and so on. And therefore I recognised it wasn't quite that, but nevertheless that was a bleak moment.

Scott: And do you remember that we went back, and we were given a load of booklets. And the CNS said, promise me one thing, don't google anything. All the information you need is here. And here's my number. And here's the number of this, this and this. And I was reassured by reading those documents by Blood Cancer UK and other charities and they were kind of like my go-to, but they were also your go-to. So do you think that...do you feel like you were supported enough through the literature that we were given? And through the CNSs? And through the doctors as well?

Tris: Yeah, absolutely. I think that having good quality information is what you need at that point. And, you know, I think that we are – I mean, we're both professional journalists, right – we're probably better placed than most to take in, absorb, and filter information, including, you know, the kind of slightly dodgy information you see on the internet. But nevertheless, I think that you need solid information you can rely on, and you need it to be up to date. And I can absolutely think that that was very useful for us and made me feel reassured I knew roughly what was happening. And I think that sometimes, quite honestly, I got a sense of what was going to happen better from the leaflets – the booklets – we received than I did, in fact, from the medical professionals, because I think that sometimes they were a bit hesitant to tell you too much from the outset.

But back to the other part of the question, I guess. I genuinely felt that from the outset, I was recognised as a partner, as a carer. And that there was an active attempt by pretty much everybody to engage and involve me in what was happening. And to know that I was your support network. And that's weird for...I mean, I think maybe we're at the tail end of a generation that might experience this, but as a couple of gay guys, the idea that you'll ever even be understood to be someone's partner was something which you

couldn't have taken for granted 10 years before. I mean, London, OK, perhaps. But even then people did have problems. And I didn't experience any of that.

And I remember, it was probably one of your low points, but we were having your first bone marrow biopsy, and the person doing it, who did struggle to get a sample from you, he had a rainbow lanyard. And you think about that, and you think, oh god, it's all just like, oh why do you bother? Is that really what's important? But it made me feel, and perhaps you feel, well, we're amongst people who understand who we are, and accept and reference us, and therefore the other colleagues probably do as well.

Title: An extra level of responsibility

Tris: I know we were going to talk about this idea of whether or not someone's a carer. You said, do I identify with it? I feel that there's an element of that, which is, my mind is in so many places on it.

So first of all, am I a carer insofar as literally, do I care about you? Yes, of course, quite a bit. And do I sometimes have to help take care of you? Yeah, of course I do. But then first of all, when you hear carer, you hear, and I imagined, stories about people who have much tougher times. You are obviously, particularly at the moment, in remission, and therefore are able to function in 99.9% of ways like a regular person. So it's not like I'm caring for an elderly mother or father with dementia. It's not like I'm a teenager who's looking after someone who's in a wheelchair who's their mum or their dad or whatever, and really struggling to balance that, because I don't have to do all of that stuff. And I see those people as carers. So I feel when you use that title for yourself, you feel like a bit of an imposter.

But on the other hand, and secondly, I feel that there's always times when you're sick. For example, when we both got covid, and we were going to be worried about you – we've only had it once – we were going to be worried about you, you bounced through it no problem because you just had the jab. I'd obviously been longer since my last booster. So it hit me really hard. And you were actually that time probably more caring for me than I was caring for you. So care is a two-way street, I guess.

So I feel that makes me feel less of a carer. But then I recognise that there are times when I have to almost be a second set of eyes sometimes, like when you were going to go for your transplants. And we were an ambulatory care. So we were in a shared room near the

hospital and you were going through the first bit of a treatment. And I was the one sort of just trying to monitor you and make sure you were OK during the nights and stuff. And there are times like that I suppose I'd be more of an active carer. And then when you first came out of your transplant, obviously, you had no energy to do anything. And I was cooking all of the meals and doing all of that stuff. But it's not a big deal, really. But then I suppose you are more of a carer.

And I think the other thing we joked about actually is, I probably benefited from getting more covid boosters than everybody else. I feel like this – I'm not going to get political because we probably can't – but I feel that we should all be getting more covid boosters for everybody, because you never know who's going to be exposed to a vulnerable person. And you could easily pick up covid from someone who's not your carer and therefore not registered to get a booster. But I've nevertheless benefited from it and probably ended up a bit healthier as a result.

I guess that a medical condition, whatever it is, comes with an extra level of responsibility for you and for everybody else around you, right? And to me, that's where we are. I'm a carer in that regard. But, you know, that whole idea of it being a massive pressure – I'm a bit of a pragmatist like this and I think I tend to look at these things as practical problems to be overcome.

Scott: But also, in context, your parents ran a nursing home and so you were around old, sick people. And your parents were really good at keeping older people into their – 100, what was it, 103? – and stuff. So even your...you've been around as a carer in some...because you didn't go and have a weekend job, you worked there cooking meals and looking after people. So I think it's come quite naturally to you.

Tris: Yeah, my mum's a brilliant nurse – well retired now obviously – but a brilliant nurse, and hospitals didn't scare me either. I don't think they scare you particularly, which is good. But the joke was when I was sort of six or seven, I knew the way from A&E to the X-ray department to whatever, and I'd be showing people around because my mum was always taking people over there, because of her job. So you know, I've never been scared by that kind of stuff. And that maybe helps as well. Other people are going to struggle, and it's not a competition to do it brilliantly, and we're probably going to screw it up at some point. Because it is difficult – a lot of it is difficult and complicated. And you are, I think you've responded really well to all of that. But it's not easy.

And the other thing, I mean, it actually came up last night because your temperature dropped. And you were like, oh, don't worry about it.

Scott: It's fine. My fingers are shriveling. It's fine.

Tris: And I was like, no, I'm not sure that is normal. And making sure you took your temperature. And then I, being really old-fashioned, I never believe the electric ones and we've got an old mercury thermometer – I'm not even sure you're supposed to have one anymore.

Scott: My wrists are so bad these days, when you flick them, I'm in fear of breaking a wrist like Patsy!

Tris: But anyway, your temperature dropped yesterday, I was like, no, we have to take your temperature, we have to be serious. And it's like, OK, it would be borderline if it was any lower than that, but I'm not worried about it. But you have to look out for things like sepsis, you have to be aware that...

There was a time when we were – it was almost a little bit, almost hairy – when we were in the south of France about 15, 16 months ago, eating a lot of cheese and drinking a lot of wine with our friends. And we'd all had a good night staying in this villa which some friends had rented. Your temperature started to rise, and it wasn't like it was at the danger level, but I was very aware we'd all had too much to drink. And I went down to Tom who is the one most sober person there and who I don't think had drunk or had only had a glass. And I was like, I'm just a bit worried you're going to have to go to hospital. And I'm even more worried I'm not going to be able to have the French ability to translate why this is important. And let's just see how it goes for the next half hour or whatever. So you have to take that level of responsibility, even when it's not immediately obvious. And there are some times when you would be worried as well.

The other time I particularly remember, your first birthday, which is very shortly after diagnosis – like a month after diagnosis – you probably only just started treatment that week, or like a couple of weeks before maybe, but around about then. And we were hoping actually to go away to Munich at that point, to get a proper break. We hadn't left the country for ages, we'd gone through this stressful time and of course, that was sort of off the cards, because you were only just starting treatment.

So we got a hotel thanks to a friend in London, and we just went to the zoo. And you were in that incredible monkey enclosure they have at London Zoo, where the monkeys sort of dance around amongst you, and you walk around them. And suddenly, you were slightly dropping. And I was like, oh, that's not normal. And I sort of grabbed you so didn't fall to your knees. And one of the keepers was very lovely and was like, do you need anything? And I was leading you out – of course, they don't have any benches in there. So I had to lead you out and sit you down for 10 minutes. We had a thermometer in your bag, took your temperature and then it's like, OK, just have some water, and you'll probably be OK. But those kinds of times can be a little bit scary, particularly until you're used to them.

Title: Fear of the unknown is the hardest thing

Tris: So, you know, I guess that was one of your worst moments as well, the actual diagnosis. But what was your worst moment?

Scott: Yeah, there's a couple of worst times, but I think it's not what's happened, it's what's going to happen. The worst point is I don't know when it's going to come back. That's the worst thing in my mind. Because even though today I had a call, my monthly call, everything's great, everything's normal, I'm healthy, it's still in remission. But I'm still on a maintenance drug, lenalidomide. So I'm still effectively on chemo. I just don't know when it's going to come back. And that's not just going to affect me, that's going to affect you, our families and our friends, and our careers and our futures. So it's not really what's happened, it's about when it's going to happen again,

Tris: I think the unknown is...so I thought about what the worst moments are, I think the fear that when you went into hospital and had to – were actually admitted during your transplants – one week in each time I was with you in ambulatory care and then one week into the stem cell transplant procedure, you have to go into the hospital. And both times that happened at midnight, basically, and both times it was like a bit of a – it's never in a perfect way. But I think for that sense that week, you were obviously on your own. And I was worried you were lonely. I was worried I wasn't there to look after you. And it was lonely for me as well, not because I can't function on my own – I just about function on my own – but because I wanted to be with you and I wanted to be looking after you. So I think that was...but I think we coped really well with all of that, and again, managed that really well.

I think that the low point was that – effectively a weekend – where we somehow got this message that you might only be around for 10 years. I think that's not the actual prognosis if you're really sensible about it. And it's not really what was being said to us for all sorts of reasons. And it's obviously more complicated and nuanced than that and we expect you now to go on for much longer than that. But we both went up to see, well, my cousin and his partner who are good friends of ours, and thanks to them, we went and spent a day walking along the beach up in Newcastle – really beautiful round there – and just trying to process it and talk to them about it. And just trying to talk about well, what do we do with the next 10 years? And then actually, we really broke it down and we're like, no, we're overthinking this. We're not looking at it the right way. It's not actually what's being said. And the clinical nurse was really good at clearing up what actually was meant by that because you wanted to ask some questions. So I think that like that was a bad moment, because that fear of the unknown is the hardest thing.

Title: What we've done is adapt our work life

Tris: But it's been a bit of an odd period for us, working life wise, because we've been in sort of consultancy roles and building up to doing something new, rather than a regular office job. But how do you feel like you've coped with that?

Scott: Well, we've known each other for coming up to 23 years, and we've worked with each other for 22 and a half. So for us, being confined in a flat in a working relationship, and a relationship, and going through cancer treatment, it just felt it couldn't have gone any better. And I don't think that it's changed our working life. I don't think I would have been able to cope whilst we were running our business, having, to get a diagnosis like multiple myeloma, I don't think I would have coped very well. It was too stressful. Everything was, you know, going wrong at that point. I think it would have been a lot worse for me mentally.

Tris: And as one of the bosses, it was largely dependent on you to generate income for the business. And you probably couldn't have coped with that, on top of...

Scott: I would have felt too guilty, and I would have taken it really personally. And I did. I took a lot, you know, lots of people would say, how do you feel? Did you reflect? And I thought, oh god, maybe I did do something wrong, maybe it's because of this or that. And then five minutes later, no, it's just luck. It's just your body. It's nothing that I did, or, or could have done. But I don't think I could have coped working in the same way.

And I think that what we've done in the last four years, and what we're going to be doing in the future, is adapting our work life. Because we've been speaking to quite a few myeloma people, friends now, that have actually changed their whole careers, and their whole life, around their diagnosis, and some of them are thriving. And that I find – I use inspirational, [laughter] because you go to an awards ceremonies, everything's inspirational. This wine is inspirational! But I do find that there are certain people that we've been chatting to over the last few years, the way they've handled their careers, their families and their own personal life through the diagnosis, they've just completely changed, and made it work for them. And I think that that's what we've done.

So we don't focus on it every day. We don't even talk about it every day. But we make sure that our future is going to work for us, even to the point where we're making sure that we get enough rest. And during the day, if I'm on my third week of lenalidomide, and I need a lie down for 20 minutes, I can do that, because we're working from home. I don't think you could do that in a corporate job.

Tris: Well, no, OK. Apart from I think there are some people are really lucky in their workplaces, and some people who aren't. And I don't think it's as simple as the type of job they are, or how senior they are. I think we are very lucky because we are, you know, effectively doing our own thing. And we were always the bosses and we are now going to be running something new in the future that gives us a high degree of flexibility. But to be to be fair to us, without tooting our horn too much, I think we had people who had various health conditions, when we were the bosses. And we were, I think, pretty good. I think maybe we would be even better now. I think we'd understand it even more. But I actually don't think we could have been better for the people we had around us than we were, really. I think we certainly gave them the support they needed. And the time they needed.

There are people who work in those sort of big corporate offices who have that and have supportive bosses, and we've heard some of that from people. But also you aware of people who don't have one of those great jobs and a great boss, and the kind of company who's interested in supporting you, and you're just another number. And I don't know how they cope with it. Because you know, you have to work to put food on the table. And some people will have families and they'll have a load more they have to support around them than we do. And I think for that can be really difficult. So I think we've been lucky but not everybody is, and you know we should count ourselves lucky as a result of that.

Title: You have to be gentle with other people

Scott: I think everyone really dealt with it so well. A lot of our friends have either had family members go through cancer or have known other people go through cancer. So our friends weren't coming into it...it wasn't so novel for them. And we made sure that we sensibly and sensitively told a couple of people, because of their family members, what we were going to go through, and I think they were the first...Antoine and Julio were the first two that we told, because we wanted them to be looking out for us and vice versa. But there were some things that some people have said in the past that were a little bit shocking. And they weren't, they're not family members, but there were some friends like, oh, you will lose so much weight now or, you can get your wedding suit fitted, or, you know, someone said, oh, I thought you would have lost a lot more weight. So there are some hurtful things. And I was joking within the first hour, to be honest, wasn't I? So I make a joke about everything and I've got a really dark sense of humour. But sometimes, when someone else makes a joke, I can handle it, but I feel that sometimes maybe you can't. So joking about, you know, my funeral or death, sometimes, it doesn't always land very well, for you.

Tris: There's been once or twice where I've just said, oh god, we don't need to talk about that, like out in public. And actually, I think that it's true that some people carry their own totally understandable baggage with this, because they've been through a traumatic experience. And I'm thinking about someone we know who – I've actually just read their biography. And in that they talk about a harrowing experience with a partner they lost through blood cancer, and that person was the most kind in saying that I need to look after myself too, and so on. But, you know, you have to remember, when you're dealing with other people, that they don't know how to cope. And therefore, I think you have to be quite gentle – gentle on yourself about not taking their reactions too seriously, but also gentle on them about understanding that nobody may have shared something like this with them before. And they maybe aren't the best able to make you feel better about it. And that they may say something inappropriate or silly, and I don't think you mind, you don't particularly mind silly questions, but I think you have to understand their emotions. They are just hearing this news, they haven't thought about how to react to it, they might screw up their reaction and then they might feel guilty or embarrassed about the fact that they said the wrong thing or asked the wrong thing.

So I think don't take what they say too seriously. Don't make them feel too guilty about what they say, even when they do say something stupid. Understand that that might happen some of the time. Those will be how I think you navigate that. Just be gentle with each other.

Scott: And there was lots of questions strangely from my nephews about, do you lose all of your hair? [Laughter] And I was quite graphic. No, you lose all of your...And that came, like, there was three of those different questions and I'm an open book on it. I went through everything. And I told them all the hair that I lost apart from eyebrows and eyelashes, and toe hair and I think maybe scared one of them, because I was a bit too graphic.

Tris: But, again, I think you're also dealing with people like you know, particularly when you're dealing with people who are kids, teenagers, whatever. They don't know, they haven't necessarily experienced something like this before. And they don't know what to ask or what, sort of social faux pas they might make. But that's OK, because I think you're really good again at coping with that.

Scott: Like on the train, Scott, do you still have cancer? [Laughter]

Tris: But it's OK to deal with that. And you, again, I think it's just about trying not to rise to it when it upsets you too much. And understand that it will upset you and it will be difficult sometimes. And if you need help to deal with that, or if they need help to deal with that, point yourself or point them in the right direction, right?

Title: It's a motivator to get on with your life

Tris: And then I guess the question is, how it's affected the two of us as well? And I think it's affected us in some good ways. I think we were always going to go through a strange point in our lives at this point, because we had stopped doing one thing, and we were going to be taking stock and working out what we're going to do in the future with our careers and what our life plans might be.

I think it's focused us more on making life plans. And one of the things which has changed is we went and had a civil partnership. And I guess it's worth telling that story in terms of the context. The two of us were at the first ever gay weddings in the world in 2001, in Amsterdam on April Fool's Day. And we reported from that as journalists, for Pink Paper, which you were chief photographer, I was – actually I wasn't quite the editor of it, I

was about to become the editor of it six months later. So we did that. And then we came back and we talked extensively about this. So we were in the media sort of landscape, you know, big advocates for marriage equality. And then when finally we won marriage equality, we were so busy running a business and we didn't have the money to have a big wedding and we kept going, oh we can put it off, we can put it off. And I think that after, not for any lack of intention to get married – we'd always intended, I mean, we intended to get married for 20 years – and we finally said, oh look, let's just get a civil partnership, get a sort of halfway house because it's full of the way legally. But you know, I think we will still change it to a formal marriage at some point. But that point where I felt that indicated to us we needed, and you felt it indicated to us that we needed, to get on with our lives. And that because it was covid, we could elope and do it in Cornwall with just couple of our friends and make it really low key, and then promise that when we turn it into a marriage, we can have all the big party with friends and family. So we could do it easily, we had an excuse but we also had a real motivator to get on with your life. And so in a sort of very formal legal way, it has changed the nature of our relationship. But I also think that it's shown us that we can rise to challenge. It's not like we haven't had any others in our lives. Because everybody does, right? But I think it's a particular kind of challenge. And we've shown we can cope really well. And that gives me absolutely every confidence will be able to cope with whatever comes along in the future.

Scott: Yeah, I agree. I don't think that...the civil partnership was a nice, lovely thing to come out of the whole cancer diagnosis. Because we could just go down to Cornwall, spend time with John and Steve, do the ceremony, be on the beach, our favourite beach, and then tell everybody, like show photos to family and friends. And luckily, we had the family and friends who didn't mind us doing that because of what it was and the situation and how it all arose. So I think we were very lucky in that timing.

Tris: Yeah, and it was one of those times where, you know, people were trying to hold weddings. And they were only being told they might have 15 guests or 30 guests. And then the rules kept on changing. We couldn't have done it any other way. We just couldn't have, even if we'd had the money and the time to plan, like it would have just been abandoned. So I think the way we chose to do it, civil partnership first and then changing to a marriage, hopefully in a few years.

Scott: And we were also at the first civil partnerships in the UK.

Tris: Oh, yeah, we were at all of it. We did it all!

Scott: And I was at the first civil partnerships in Brighton, had to get the train down. And then we were at the announcements of gay marriage 10 years ago as well.

Tris: So yeah, we've got a bit of a history there. But we finally turned out that history.

Scott: It was a bit of a running joke that we weren't actually...[laughter]

Tris: Well it was kind of ridiculous wasn't it. It was kind of ridiculous.

Scott: Even for us.

Tris: So yeah, I guess you've got to get on with stuff haven't you.

Scott: I think that's what it showed, and a few of my myeloma friends on social media, I just think that it's made them do a civil partnership and get married as well. So it's not out of the norm for people to actually think, oh, what do I need to do with my life? And how do I change things?

Title: Resources are out there and available

Tris: So I guess, like back to the other friends who've gone through it, does pull back to the question of what your advice might be to other people going through something like this, or to their carers, or to their friends and family or those around them? What, I mean, I think we probably pulled up some of those things. But what do you think?

Scott: I think you have to be as honest as you can be to the person you trust the most, and to your doctors and to your CNSs. You don't have to tell everyone what you're feeling and how you're feeling and the dark stuff. But there are key people that you have to be honest about. When you go to a CNS, and they're telling you they're asking you about your poo, the consistency of what it is, there's no more shame that you can have. Like what's the point of being ashamed or embarrassed by anything when you're discussing the how sloppy something is and they find that fascinating? Well, OK. I just think that mentally, it's having any kind of cancer, but having a long term health condition that's a cancer that you know that you're...well, with me it's not going to, I'm not going to die straight away, this is actually going to be, I'm going to be stable and the treatment is going to help me. So how do I keep myself healthy, happy and fit for the next time. I just think that mentally, you've got to be kind on yourself. And that helps other people around you. So be honest as you can be to the key people because they're there to help, and rely on those people.

Tris: Yeah, I think that's really, I mean, I think you've lived that. And I think you've really benefited from it. And I think it's one of the key things, which has meant you've been able to deal with your treatment and respond to treatment, and the problems that treatment causes as well, so effectively. So I think that's really good advice. I mean, if this is about advice to others, you have ended up chatting to several other people. And we've made friends with some people who are also going through this. And there is a wider network that people can draw on of people who actually have lived experience of it. And I think that you have put out a lot there and really tried to help other people. But I think you've gained from helping actually, and seeing their experience. So without it being you seeking help, particularly, you've actually received help, because you try to help other people.

Specifically for people who are maybe the main carer or another family member, or so on, I also think getting information, quality information, and knowing what you can rely on. Because I think it really empowered me, and it helped me to keep you calm, if I knew almost a little bit more about it than you did. And actually, you know what, even for – I think I said earlier that we're quite good at absorbing and reprocessing information because of our jobs – I think even for me, it's kind of baffling, there's quite a lot of technical terms, there's quite a lot of information to absorb lots of all of that, like what kind of version of this is it? And what kind of version is it that is it? And what drug combination is it? And so all of that, I think the more you can empower yourself with information, the more empowered you feel. And the better able you are to provide that information back to the person you're trying to look after.

So I would say that, and I haven't needed, I think, to call down on like a direct service. I know there's phone lines. I know there's people I could have spoken to. But I think to remember that that's there was backup as well. So, I mean, I feel that we've been fortunate in some ways in how we've been able to deal with this. But not everybody is in as lucky a position as we have been. And to remember that the resources are out there and available, and they should use them when they need them. Because I think I'm probably not brilliant at asking for help myself, sometimes. And that's why I would say don't do as I do, but do as I say on that one.

Scott: And on a scale of one to ten, how much of a treat was I during..?

Tris: [Laughter] Well, yes, well which bit? I don't know.

Scott: The whole thing!

Tris: Genuinely, you I think have been really, given what you've gone through, been really calm, really sensible, and quite determined to do what you can physically to get yourself fit. I mean, you go swimming, you go to the gym, we do a lot of walking.

Scott: You push me though.

Tris: We eat well and healthily. You've made sure that your mental health is as good as it can be. You have pushed forward with the treatment, even when it's been tough, but you've known what the limit is. And you've had great communication with the haematology teams and so on. I think you've done really well.

Scott: So you're saying ten?

Tris: Well, yeah, OK, yeah.

Scott: Not eleven?

Tris: [Laughter] No, genuinely, I think that you've done really well. I think we've both coped really well, actually.

Scott: I don't think I – it's so obvious – but I don't think I could have done any of this without the support network, the charities, the CNSs, the doctors that actually check up on me. But really, friends and family, but you – I don't think I could have done any of this without having you there every day. It would have been very different four years.

Voiceover: For support and information go to bloodcancer.org.uk/family or call us free on 0808 2080 888.