

# Transcript

## Blood Cancer Heart to Heart podcast

### Episode one: From partner to carer overnight

**Kayleigh:** I thought this is it. I've driven here as your girlfriend, and I've left as a doctor, pharmacist, a nurse, a carer, like everything all rolled into one.

**Voiceover:** This is Blood Cancer Heart to Heart, the podcast for people who have a relative or friend with blood cancer. You've told us it helps to hear from others in a similar situation, so we've brought people together to share their experiences. In this episode, Gail and Kayleigh talk honestly about changing from partner to carer overnight. It's a frank conversation about some difficult thoughts and feelings. If you need to talk to someone about anything raised in this podcast, please call 0808 2080 888.

**Gail:** I'm Gail Lucas. I have two children to my husband, David Lucas. He was diagnosed back in 2021, in February – towards the end of February, beginning of March – with ALCL. That's known as anaplastic large cell [lymphoma](#), which is a T-cell blood cancer.

**Kayleigh:** I'm Kayleigh, I'm engaged to Mart. So we've been engaged two years now. We work together as well in the local shopping centre, that's how we met and got together. Mart was diagnosed with [myeloma](#) in October 2020. So just in the middle of a pandemic before second lockdown. He had a bad back for a couple of weeks – just woke up with a bad back, carried on as they do, not going to the doctors.

Eventually, he ended up with an emergency MRI on a Saturday, and they called and said a vertebra was missing, and that he needed to go in. From there, it escalated really quickly. So we had a semi-diagnosis on the Tuesday, that they thought it might be myeloma, but they needed to do a bone marrow biopsy just to check, which he had the next day. And then it was confirmed on the Friday. So that was pretty quick.

He had six months' induction treatment, and then had a stem cell transplant in November 21. So he's just like 13, 14 months post transplant. And he's had a complete response from that. So he's in remission from that. And he's now on maintenance. So I think we're coming up to...I think this is

the 10th cycle that he starts of maintenance tomorrow. So, touch wood, we're in a good, stable place at the moment.

**Gail:** Amazing news. Ours was pretty similar with how fast it came on. So our lives literally changed overnight, shall we say. He woke up one morning feeling a little bit unwell, had a very small pea-sized lymph node in the right side of his neck. Didn't think anything of it. He'd recently had tonsillitis. And over the coming week, he began with really high raises of temperature, only of an evening, and developed night sweats, which – I'm not talking about just a little bit of sweating, they were soaking, soaking the bed.

And then literally out of the blue one morning he woke up and the whole right side of his neck had ballooned, should we say, in effect. It was also right in the middle of covid. So he went to an immediate walk-in centre, where they put it down immediately to go out and get tested. You know, you could have covid. Very, very quickly, it was apparent by midnight when we got the results that it wasn't that, and he very, very quickly deteriorated within days. Many hospital in-and-out visits, until we had a biopsy. Very much desperately waiting for the biopsy results because hour by hour we could see he was deteriorating very, very quickly.

**Kayleigh:** It's crazy how quickly it goes because I remember like Mart had, looking back now, I know all the symptoms of myeloma. Mart didn't have any of them apart from the bone pain. When he was sent up for the MRI, from when they'd seen it on the Monday, a doctor came around and said they wanted to do full bloods because they could see something wasn't right on the MRI, but they weren't really too sure what it was. And that there was a vertebra missing but they didn't know why.

And from that moment, he was on complete bed rest. He couldn't move because where his vertebra was missing, the two discs either side had bulged. So it shut off his spinal cord. So that's why he lost feeling. And he ended up being on bedrest for three and a half weeks. He had to have a brace fitted. So he was in a back brace from hip to neck, front and back, like a little tortoise shell. And he had to go to a different hospital for that. Once he had that done, he was then allowed out, but when he was told in hospital [that he had myeloma], he had to tell me over the phone.

And all along I was like, oh, you've just slipped a disc. It's nothing this serious. And even when he got admitted on the Monday, I still went into work, went and seen his manager, oh Mart's in hospital. They've seen something on his MRI, but I'm sure it won't be too long. And he was like, well, I'll take him off the rota for a week, and then we'll sort it out. And that kind of never happened.

**Gail:** There's no way easy way of saying it literally changes your life overnight. And there's no going back to the way you felt beforehand. Because everything you perceive and everything you see, you see in a completely different light. And I remember walking away and coming home. And I mean, anyone else who's had to go through it and explain to your children. I think I'll forever hear the screams, you know, from that evening.

I mean, I've got an autistic son. So his take on it, he didn't really understand. However, what he did understand was the changes going forward. Him not being around. And week after week when he was admitted, because as you're aware, you're at high risk once you start treatments (he was put on a high treatment) and he was diagnosed on the Thursday and he started [treatment] on the Monday. But with every treatment, because it was an aggressive form of treatment, it gave him a lot of side effects and neutropenic sepsis. His own body started attacking itself. His organs were shutting down.

So time after time he was admitted, which was never good for the children to see, because it was always the negative side. So he'd come home, he'd look very poorly, he would have changed in appearance. Prior to being admitted he was a big strong man, you know, very, very dark, thick hair, thick beard. And week after week, he was coming home. And he'd lost all his weight, he was just bone. He couldn't walk, he went into a wheelchair, he lost all of his hair. And for us to see that, and for them to have that, never mind young children, is very, very difficult.

It's things like this, that you don't really take into consideration when anyone receives the cancer diagnosis. You know, you understand they've got that, you understand they're going through treatment, but it's all the other the other little bits. Sitting on the phone 24/7 Because I could not go in whatsoever. I was FaceTiming him and leaving him on FaceTime, and hearing the bleeps and the different checks that they were doing through the night. And having that 24/7 because you understand how busy they are in the hospitals and you can't get the phone calls, you can't get the full picture.

So I was feeling that by having him constantly on the phone and hearing what was going on and hearing what they were saying, I got some sort of element of control. Not that I wanted to control the situation. But otherwise, you feel out of control. And I felt when I was out of control, there's nothing you can do. You can't look after yourself. You can't eat, you're pacing.

**Kayleigh:** You can't do anything. Nothing at all. Mart's daughter is a lot older than your children. But I remember he wanted to tell her himself when he got out of hospital, but at the time, we didn't really know when that was going to be because of having to go to another [hospital] for the

brace and things like that. And she was going to her mum's for the weekend. So I said, I think we need to tell her now. Because otherwise if you wait, she's going to be at home on her own. I had that – I was at home on my own when I was told. And no one needs that.

So I spoke to her mum first and just put her in the picture. And I was like, I don't mind telling her, but I need you to be with her, to go through that. And her mum did tell her before, and then she spoke to me and then her heart broke. I knew it wasn't my fault. But I felt like I'd literally shattered her world, because she's his only daughter and they are close. And I felt like I'd ruined her life.

But it's just that, those words, isn't it. You want to be honest. But at the time, I didn't really know much myself anyway. I still had this negative thing in the back of my head. So I tried to be as honest as possible, which we were, and he then FaceTimed her.

But I think we were kind of lucky, because it was his back, we didn't tell – a handful of people knew for about eight, maybe seven, eight months, even his dad didn't know. Because he was in his back brace, we could get away with, he's hurt his back. And that's why he's not at work. Because physically and everything else, he still looked the same.

So we went with that for ages because I think even now if you say, oh, you know Mart's got cancer or he's had cancer and he's in remission, the first thing people say is, oh, I'm sorry, because they don't know what to say. And I didn't want that conversation over and over and over again. Being at work – we work in the same place – so people were asking questions. So for us it was easy for me to just go, oh he's hurt his back.

And it wasn't that I was ashamed of it. Because far from it. Now I'm so proud of where we both are, what we've done together what we've done separately, but at the time, you just don't want to keep having those conversations over and over again, do you? So that was kind of our way of keeping it in a bubble. And then when everybody did know, they were shocked. I announced it in a morning meeting at work. And people were like, you've worked all this time, and you've been going through all this? I was like, yeah, yep. Just because you have no choice.

**Gail:** I found that because of, obviously, the different situation – it's completely different paths according to what you're diagnosed with, how your body responds to treatment. With David, I ended up going off [from work] immediately and ended up being off for seven months. Because when he came home, I had to become his full-time carer. So then obviously, everybody needed to know. I couldn't have anyone round to the house due to the risks in the current situation we were in. I weren't going to work, he weren't going to work. And he literally ended up bed bound

and wheelchair bound, within weeks, within a few weeks of him coming home. And then I went from being wife to literally having to do everything.

I remember one thing that I really was grateful for was, people would always ask, well, what can I do? What can I do? And I was always like, oh, you can't think at the time, and everyone's like, oh, make sure you look after yourself, make sure you're eating. And I'll be honest, it's your last priority.

**Kayleigh:** You go on autopilot, don't you, to just do what you need to do.

**Gail:** Getting through – I think I don't think there is a right or wrong way for that – you just learn to get through. And I always remember there being knocks at the door, and there was food deliveries. And although people never said, it just turned up. And at that point, I think it was quarter to seven one night, and my children were there and I still hadn't had the opportunity to feed them. And those deliveries, were just amazing. To hand over to the children so they could sit down and have a meal. Not that I'm saying everyone should go out and order food for everybody! But I just remember at that point that someone sat so far away and couldn't be near and knew they couldn't help, but just did an order for the children. And it was a massive, massive, massive help.

**Kayleigh:** It's just those little things isn't it? That makes it a little bit easier.

**Gail:** Yeah, it really really is.

**Kayleigh:** It's good, it is. It does make such a difference. I remember when I went and picked Mart up, like you say, things change so quickly. When I went to pick him up from hospital, the nurse brought him down to the entrance – exit – in a wheelchair with his two bagfuls of medication. And I drove to that hospital and I was absolutely buzzing. I was like, I'm gonna get him home. Things are gonna be – I knew he couldn't do much, but things were going to be a bit more normal I guess, being at home together. And we could barely even get him in the car. Because he had this brace on, he couldn't move. So it was up here and we had to get him in at an angle, had to put the seat right back get him in an angle. And I thought, this is it. I've driven here as your girlfriend and I've left as a doctor, a pharmacist, a nurse, a carer, like everything kind of all rolled into one.

And I kind of wedged him in, drove back and I don't even think we spoke to each other because I was overwhelmed with everything already and all I've done is pick him up and sat him in the car. And we got him back. And he kind of waddled or shuffled into the kitchen and sat down. And

then we realised straightaway how difficult things were going to be. He couldn't even sit on a chair properly because he couldn't bend, and the brace was so restrictive because the seating was too low.

And then I emptied out all his medication. And just panicked. Because I was like, do you know which ones you're taking? He said, oh, no. I was like, great. How am I going to not overdose you? He said, oh, don't worry, there's a list. And we did have it on a list. But I phoned my mum that night and I was like, what do I do? And she was like, you don't need to know what you'll do. You'll just do it.

And the amount of medication and things! And then he couldn't get up the stairs. So he had to sleep downstairs for a bit. The only time he wasn't allowed his brace on was when he was laying flat. So we then had to get physio to order a chair raiser for the toilet, another chair for him to sit in because the sofa was too low. Like you say, you don't expect to have all these kind of extra bits and pieces. And the first night, he woke up in the night and he needed the toilet but of course we had to get this brace on and it took 40 minutes to get his brace on. And I thought how? In the end, we could do it in five minutes and but at the beginning I was like, where does this bit go? Where does this fit? Is it right? Are you sure you're able to move? I don't want to do any damage.

And in that moment, everything just changes. One day, you're this person and the next day, you're someone completely different. But I don't think you can ever go back to being that person you were before. Even though now, I don't need to look after Mart. Well, I don't really need to look after him. He can do his own medication. He's out of his brace, he's back at work. But I don't think that you can step back because I always feel I need to be his little bubble of – I need to protect you and I am more aware of things, a lot more aware of things than what he is.

**Gail:** Because he was completely out of it, I felt that I was his only advocate. So, I mean, I'm not proud of it, but I think I literally fought with absolutely every medical professional because I literally, whenever I could, whenever he slept, when I should have been sleeping, I researched for answers because I needed to know that everything was going to be OK. So my way of knowing that things might be OK was researching. And so I was researching things that worked. Because every time he got treatment, which was supposed to make them better, it was making him worse. And by the fifth treatment, he was admitted and we were told literally that we'd be lucky if he made it through the weekend.

And that was because although the chemo was working to get rid of the cancer, it had that much of an effect on the rest of his body, it was shutting down. And then he needed an emergency

operation which they couldn't do because he was neutropenic, and he wouldn't have survived the operation.

And I just felt at the time that all I could do was, you know, like, there's got to be something! so I would literally look for things, fight with people like literally there has to be answers. Look for a way. And I felt that it was I was constantly fighting for his life as such.

So then obviously he's doing well now and he made it through the weekend, and spent many weeks in hospital and we got him home, it was how do you step back from that? I've literally been shouting from the rooftop doing everything for you, seeing to the children, had our own little bubble, nobody could come near. And how do you switch off from that? And I remember sitting crying to my friend one night, and I think it was two, three o'clock in the morning. I'm sitting crying to her and I was going, who am I anymore? I literally was like, I actually, I've lost myself somewhere along these six, seven months. And I actually don't know who I was, who I am, and where I go next. And I think that was a massive eye opener, at that point.

**Kayleigh:** I think where we are now – a stem cell transplant is deemed the be-all and end-all and you've got to get to that point. And I think working towards that point, you're working towards that positive. You're gonna do your induction treatment, you're gonna to get this, this is where you're gonna be at the end, hopefully. But now we're there and we've done that, I almost feel I've been, myself, worse after it than before. Because I think we had so many appointments and everything leading up to it. You just, you just do day to day, don't you? When you go and you don't really think about anything else. You just wing it and you get there. And now because that's been done, it's like, right, so now what then? What do we do?

And with the myeloma we know it will come back. It's just a case of when. Whereas I think before when I was waiting for monthly appointments, I was like, right, what are the numbers this time. They're going down. This is amazing. And now I'm like, are they going up? How much are they going up? And they're not, which is great. And a couple of blood tests, after transplant, the numbers were a little bit up and down. And then I kept ringing his nurse. And I was like, is this OK? How long does it take to kind of level out? Has it not worked? Has it been a waste of time? And she was like, no, no, don't worry, just keep doing what you're doing.

There is nothing that we can do. We just have to go on their advice. And I found it a lot harder after [transplant] because it's almost like, you're just in limbo, waiting for it to kind of change course and what's going to happen. Our team are really good. And they do check in with me, as much as they do [with Mart]. Even when they have an appointment, me and his consultant joke. He had one on Friday. And he's like, is Kayleigh there? Do I need to give you the numbers? And I

was like, I'm here. I've got my phone, give me the numbers. Whereas Mart's like, can I start my next cycle? That's amazing. Thanks very much. Job done. I need to know the other bits and pieces.

**Gail:** That's where we're very similar. The consultant called last week. And he was like, Is Gail there? And are you okay with this?

**Kayleigh:** I've got a list!

**Gail:** And yeah, it becomes your new normal, doesn't it? But you see, the one thing I can say is that, even with remission, even with when they're doing well, you never ever return back to the person that you were. And I'm now in a much better place where obviously, I've moved forward and I'm not the same Gail. I'll hold my hands up. I'm nowhere near the same person that I was. It has completely changed me. For the better. Yes. Because, you know, things that used to bother us in the past, it's just water off a duck's back, you know, it's just like, really? Things that you just used to get worked up about, it just doesn't matter.

**Kayleigh:** Little things, aren't they? They're irrelevant now.

**Gail:** Yeah, absolutely. And that's the most important. And one thing that I will say is that, you know, everybody, celebrates when you get to ring the bell, you know, everybody celebrates when you finish treatment.

**Together:** But it's not the end.

**Kayleigh:** It's definitely not the end. I almost feel like it's just the start of the next bit. And Mart's kind of been worse, now, I guess. I think mostly it's because he's been back at work. So he's been around a lot more people. Going through treatment, other than his clot, he had no issues, no infections, no hospital admissions, nothing at all. And he went back to work in April last year. And then he got covid in June, which lasted two weeks. And then he had RSV in September, he had flu in October, he had another respiratory infection and then he had another one just after Christmas and he had a saliva gland that was infected. And every time you go into hospital it's like oh here I am, don't forget, you might be in remission but I'm still here to annoy you and kind of remind you that I'm still around.

In A&E, I know they're crazy busy at the moment as well, but you just don't want to go in there do you? I find it really hard being in there. When he was in with flu, I think anxiety now is just kind of through the roof. Is it going to be something else? Because ultimately he went into hospital with a



bad back and came out with cancer. Those two I wouldn't put together. So I'm like well you're gonna go in with this, what are you going to come out with next? And when he had flu and we were in A&E, I couldn't stay in the room with him. I had to keep going out because I was like I want to be in there because I want to know why you've got a crazy high temperature, why you've got this, but I don't want to know what they're actually going to say. And yeah, I was in and out, in and out and the nurse was like, you OK? And I was like, yeah, I'm OK. But I just don't want to know what you're going to tell him. Because I don't think anything can prepare you for anything now, not that it really can anyway.

**Gail:** No but, anything now, you think that everything's gonna return and you know, it's always always, every day in the back of your head. David's been unwell recently and we've (we!) he's been for a lot of scans. He's had hospital visits. We went in for one thing – for a check, for the scan – but it's come back with loads of other things. And, you know, it's just, it's constant. And although everyone was like, wow – and yes, we are delighted he gets to see his children every day (well, all I could ever wish for is one more day and every day we're grateful for), but when we got remission, it's been every day, he's on high amounts of medication. He can't physically get out of bed and do his day without his high amounts of medication. We used to be an active family, we can't do that anymore. Because he's in so much pain, daily. And that's from, you know, the course of treatment and things. He has low testosterone levels, which is a result. Sleep apnoea stuff and things that's going on and being checked for at the moment, because of the radiotherapy.

It's the constant things that come with the treatment, you know, which we're forever grateful for, because if you told me in the beginning, that you'd have this, this, this, this, this and this, but not the cancer, I'd be brilliant, swap it, you know? But now obviously moving forward and living daily with the amounts of pain and the constant – if you get a temperature, it's straight into hospital.

**Kayleigh:** It escalates so quickly, doesn't it? It's like, oh, it's just a temperature. But we need to...this is where we need to be. We've got to go in. And Mart's like, just half an hour more. Let me just...I'm like, we don't have half an hour, time is crucial! We need to get in. And I guess I'm more of a panicker now, that's the thing. And even when he wakes up in the night, I don't think I've slept a night properly since, because every movement and he will get up and I'm like, are you OK? I just need the toilet. Yes but are you OK? He's like, yeah, I'm fine. OK, that's fine. It's like having another child, isn't it? Like you're on high alert all the time.

**Gail:** It really is. I'm not very well. What's your temperature?

**Kayleigh:** That's how it starts straightaway. And then it's like, have you got? Do you feel sick? Have you got anything else? Any tummy issues? And he's like, no, no, I probably just slept on that ear. That's why my temperature was... OK, but like you say, I think people – and I guess my perception was as well, before I was in this situation – people get to remission and you're like, that's amazing. It's all unicorns, and it's all rainbows, whereas actually, even the maintenance medication now that Mart's on, it's all kind of weighing it up. Do you take it, because it hopefully will keep the myeloma at bay for a lot longer. But in the process of doing that, it drops your platelets, it drops your neutrophils, it drops your blood count, it gives you these infections, or it makes you more susceptible to these infections. Well, yeah, obviously we want to keep that [myeloma] away. But then it ruins everything else in the process. He's always tired. And then sometimes it's like, are you tired because you're back at work and you're doing 12 hours at a time? Or is it the medication? Or is it...is it just you? You just don't know, do you? And you'll never know. And it's always, is this the right thing to do?

**Gail:** I don't think there is a right answer for the right thing. We constantly – I will say one thing is when you're in this position with someone who's so close and a loved one – you're in a position of what is the right thing? And I think at that time, the only right thing to do is to survive, you know, and get through the day, knowing that you've literally done what you can and what feels right at the time.

**Gail:** So Kayleigh, I mean, one of the big things was obviously emotions and things and how we felt throughout. Did you manage to speak to anyone in regard to that?

**Kayleigh:** I think in the beginning, say the first year until we got to transplant, again you're just kind of on autopilot. You do everything you need to do. My manager – both our line managers to be fair – work were really good. So although not everybody knew, I had those few people that I could speak to and when I did go into work on a random day, they knew if I was going to go and have a meltdown, I would go into another office. And it's good to kind of get it out.

I don't really think I've ever massively spoken to Mart about it because I have this kind of thing – it doesn't really hold me back – but I don't want him to feel guilty for me being upset, or for me feeling the way that I do. And I've only just started a few months ago having some counselling because I do find it's hard and like I said before, it's harder now being on the other side of transplant than it was before because now I've got less to think about, I've actually got more time to think about the negative things or the negative thoughts, I guess, so to speak. And I kept changing everything round to a negative.

We'd be out in the garden centre at Christmas, looking at all the decorations. And I was standing there with like tears in my eyes thinking, well, there's going to be a Christmas when he's not going to be here. And what am I going to do about that? Or let the dog out for the toilet, and there's going to be a time where I'm going to come back in the house, and, and he's not going to be there. And I've never really thought about that before, it's only really been the last six to eight months really. So I guess I'm lucky that I'm aware that I have thought about that. And I don't want to waste the time that we have got thinking about the negative things. I want to, you know, focus on the here and now.

So I checked in with his nurse and his physio and I was like is there anyone really to help me? To send me somewhere? So yeah, I've been having some counselling and stuff, and it is just getting it off your chest, isn't it, and talking to people. But I find, again, it's speaking to people like you, when you know someone's going through a similar situation, you know that it's OK to feel like that, or however you're feeling is OK. That there's others out there that feel like that as well.

But emotion-wise, we probably have never really spoken in that way. Because yeah, I don't want him to feel guilty. It's not his fault. Nothing's his fault. But I know that he would feel he's like a burden. And he's put all this on me. It could be anyone that's the thing. It could be anyone.

So how have you found it?

**Gail:** I'll be honest, I kind of like really, really kept it shut down. I felt that at the time, I had a lot of worries. You know, at the point when we came out of the hospital we were given no options. And he was staying in and that night I was sitting thinking, seeing how quickly he deteriorated over days, I was like, if he only has days left, I could lose him soon. What on earth am I gonna do? I've got two kids upstairs. How am I gonna manage? You know, literally thinking about every little thing. How on earth am I going to manage two children on my own in this house and everything...work and...I was thinking about the completely the wrong things all the time, but I was thinking, What on earth am I going to do? How am I going to get through this?

And I put a front on, I'll be honest, which wasn't healthy. But it was my way of getting through because I couldn't let the kids see me getting upset. I couldn't let them see me worry because I thought, if they see me worry they're gonna know things are serious, and they can already see that things are serious. And it was already a daily challenge.

You know, my son, I was trying to drop him off at school – the school that I work at. You know, they were amazing – not only my colleagues, my friends, my family – and you know, they were having to get him out of the car. They were seeing to him, so that was one less thing to worry

about. And it was challenging. He weren't going to school and just cracking on like everything was fine. He was really struggling day in day out. And then I had my daughter who I hadn't realised at the time was hiding her feelings too, to save me from worrying about her. So she was going off to dancing and luckily she had a dancing school who were supporting her to put her emotions through dance, to create dances.

So that was a support, but what I found was, you know, it's only now when I can speak to you Kayleigh and others from the friends and family chats and things with Blood Cancer UK and in relating myself to other people's experiences that I can talk my way through it and accept that what I thought and what I felt was OK. Because I was almost feeling guilty for thinking, I'm accepting that he could die, and I should never accept that and you should never accept that and that's the kind of fight I felt that I was having every day. Don't accept it – if you don't accept it, it won't happen if you don't. And I felt like I was having these arguments constantly with myself. Don't ever, ever find that weakness because if you find that weakness you're accepting that this could happen. And it was like those. And it was an escape to the bathroom and the bath maybe, you know for the hour of the night that I would have my own arguments with my head, pull myself together and make more calls and carry on with the day.

**Kayleigh:** It's tough because it's quite a... well it is a traumatic thing, I guess, to see someone that you have spent your life with – they are your whole life – to have their life changed. When Mart came out of transplant, when I picked him up then, I looked at him and the first thing that came into my head was, you really looked like a cancer patient now, you do really look poorly. And then yeah, we got home and I remember taking a photo to send to everyone to be like, oh, he's home. And again, I looked at it. And I was like, you do...you look...you look really...this is it, you do look really ill now. And it's not nice for anybody. But it's not a nice thing to see someone like that.

**Gail:** But it definitely is traumatic. You know, there's no, there's no other way to describe it is there. I think everybody thinks – don't get us wrong, you know, the person that's diagnosed with it, that they're the ones that's going through the trauma, they're the ones that are having to face it they're the ones that – and don't get us wrong, you know, I would never take that away from anybody that's going through the treatment and seeing what they're having to go through and the pain that they're in, and you know, everything that comes with it, the changes. But the trauma for close relatives also, that's trying to hold it together as well. It's completely different, like it's a different trauma but it is, it very much is.

**Kayleigh:** Cos you're trying to support them as well as look after yourself and family. And where do you go? Where do you go first?

**Gail:** Did you find that you protected others? So when you updated people, I always found that, I always gave the positive side even though literally I was being told he would barely last the weekend and things, I was always giving a more positive side to it, with telephone conversations to relatives and things, than the true story.

**Kayleigh:** Because I don't think they'd ever realise how bad things would be. I say to people Mart's got a temperature and they're like, oh, he's got a temperature. And I'm like you don't know how bad a temperature can be. And I think even if you were honest, because they're not as close to it as you would be or they haven't physically seen it, they would never believe how bad it can be. So I'm grateful that you know, we're where we're at. It's just the journey getting there.

**Gail:** Looking back, is there anything you could tell yourself, is there any advice you'd give yourself now, do you think? When he was first diagnosed?

**Kayleigh:** Don't google anything. And luckily, I only did minimally. And don't compare your stories to anyone else's. Because as much as you hear everybody say, everyone is different, everyone really is different. And you can compare the small things and you know how people are going through different journeys, but you can relate to certain points. But just because someone's had one line of treatment and that hasn't worked, that doesn't mean that that's not going to work for you. Like there's lots out there that, you know, are available. But also rely on people like us, other people that are going through it. I think that where I've learned most of what I know, and have felt more comfortable with what I know, is speaking to people who are going through it themselves.

Google can tell you whatever it wants to tell you, but it's not a reliable source. I know it's really hard when you're up two or three o'clock in the morning to not get on the internet and start looking for things, but it won't tell you what you want to know. If you ask someone that's going through it, they'll tell you what it's more reliably like that way.

**Gail:** I completely agree. Like one big one was statistics. Do not look up statistics. Whatever you do, just do not look up statistics because it's just not helpful at all.

This, what we're doing now, talking to each other, the forums, that you can get through the group, massively. I mean, I didn't know about them immediately. And that's something that I wish I had had in the beginning, where I could go and ask a question, where someone could say they would chat to you. I felt that I needed that in the beginning, and I didn't have it. Constantly trying to google information that I just can't get answers to. And what will happen if...hanging on to an inch of hope for hours and hours and hours, whilst the forums could give you that answer straightaway. And these talks with other people similar. And everybody's story is so different. I

read about people who have had exactly the same diagnosis, and continue to work, go for treatment, the wives continue to work, the wives don't have to care for them. And it's just completely dependent on how the person reacts, you know, and other underlying factors and things like that. And also I think to accept what I did. Do I agree that everything was correct? No. Would I change anything? Probably not.

**Kayleigh:** Me neither, me neither.

**Gail:** Probably not. Because the journey that we've come through has got us so – we always were close – but it's got us so much closer. And I can now feel like I can give and feed back so much that I've taken from it to help others.

**Kayleigh:** Yeah, definitely. And I think that's like a massive thing. Like, I'm the shy person everywhere, and everyone's like, you're going out and you're doing these things? And I'm like, yeah, because people have had to do that, for me to know, or for us to know what we know now and to move forward. One hundred percent people deserve that, from me, to go forward as well.

And I will talk the ear off anyone about it now. Because every day Mart's like, oh, you're going to do this? Yes. Because people need to know, don't they? And it shouldn't be like a hidden thing. But if that's how someone wants to deal with it, that's completely fine. However you feel, you just need to know that that is OK. Your feelings, whatever, are valid to feel. If you're angry, that's fine. If you're sad, that's fine. If you're stuck in your positivity bubble, that's fine as well. You just have to wing it really, don't you, every day.

**Gail:** You really do. I found myself one day pacing in the kitchen. I think I paced for two and a half hours. But that's OK. Because that got me through two and a half hours. And I think it's just accepting everything and things that you do, there's no right or wrong way. There's no one path that everybody should follow. But we've just got to be true to ourselves and not over expect as well. Because I mean, I know you Kayleigh, from what you've spoken to me about here, that we have put far too much pressure on ourselves.

**Kayleigh:** You definitely do. Yeah. And you kind of forget, look at everything that you've been through from the beginning. And you've done it because you could. And if something happened again, you'll deal with it. Because you can deal with it. But at the time you just think oh my god, what am I gonna do? But you will, you will deal with it. In whatever way is right for you.

**Voiceover:** We hope to bring you more episodes of Blood Cancer Heart to Heart later this year. Until then, head to [bloodcancer.org.uk/heart-to-heart](http://bloodcancer.org.uk/heart-to-heart).

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