Transcript

A gift at the end of life

[Music playing]

HELEN: When Alice was eight, she was very ill. And eventually, we got to the Children's Hospital in Birmingham. And they diagnosed her with type 1 diabetes.

JAY: We went through quite a few years of IVF, which is probably more hard on Sina than it was on me. But we were very fortunate to have Ari in our lives.

HELEN: I was used to being with Alice within the hospital environment. I was used to seeing her wired up. I was used to seeing her on drips. I was used to talking to medical staff. I was used to the smell of the ward.

JAY: He was truly, truly caring and compassionate. He could read a room even at three and a half.

HELEN: And she was up for anything really. She just had a lovely sense of adventure, and she never let the diabetes stop her in any way.

JAY: Me and Ari had just been spending the whole day together. So, I got all of my young ‘un, I put them in front of Peppa Pig, and then I just carried on doing what I was doing around the house.

HELEN: I'd finished work that day for the Christmas holiday. And I'd been shopping. I'd come home, and my sister was coming. And I'd had a couple of gin and tonics in the afternoon. Hey, you're on holiday. And my brother came over. And about six o’clock my daughter rang and said had I spoken to Alice today because she'd sent a funny message and didn't know what it was. So anyway, then all the phone calls started.

SINA: And then, when I went into the living room and I saw-- he was actually standing up. So, I just thought, he's being very still, and I thought, you're trying to pretend that you're being like a statue. No response. And a three, three and half year old is going to flinch, move, couldn't be that still. So, I thought this is a bit strange.

So, as I went closer towards him, I kept on calling him Ari, Ari, why aren't you moving? And then, as soon as I went up to see him face on, I saw his face. And it looked completely different. And then, a few seconds later, I figured out that he was-- literally, his chin was resting on the blind cord.

HELEN: I said to the consultant, do I need to be there because I didn't know if she was having her hypo, which would have knocked her out for a while, or if it was worse. He said, no, you need to come up. As a parent, you need to be here.

IAN: We have pathways through the hospital that start, in some cases, in the prehospital environment that alert the emergency department that maybe there's been a road traffic accident with somebody who's been significantly injured coming into the emergency department.
We are then notified of that in the intensive care unit so that we can make preparations in expectation that that patient will be transitioning from the emergency department through to intensive care with whatever other intervention they may need.

HELEN: The blood sugar dropped to 26. So, they're trying to stabilise and get her comfortable.

JAY: I can't remember how many doctors and medical professionals were around her, but just to see it was me and Sina and then just people, and they're doing their best to try to resuscitate him.

HELEN: They found us at midnight and asked us to go back in, and that's when they said the MRI scan had shown there was about 20 stroke sites.

[MUSIC PLAYING]

IAN: When a patient has been admitted to the intensive care unit and undergone that period of observation and we have the certainty that, sadly, this is an injury or an illness that is going to result in their death, then at that point, we explore end-of-life choices.

ELAINE: The consultant will talk to us and say that they're going to have breaking bad news conversations with the family, that they're reaching end-of-life care.

IAN: And then we will, along with the bedside nurse, we'll have a preparation meeting before going to meet the family to ensure that the patient is eligible to be considered as an organ donor.

JAY: I remember Sina saying then, so why don't you just save every organ you can, and why don't we donate his organs?

HELEN: We had talked about it as a family, and when she signed the register, she told me that she'd done it when she was at university. So, I knew that she would be happy with it.

LEANNE: The types of organs that people can donate varies hugely on lots of different things. So that's their medical history, their age, medications that they can be on, and actually what's brought them into hospital this time. Have they had an accident or something? So, this varies hugely, but what it's really important to say is that the families have control, and they need to consent for each specific thing.

SINA: We agreed to donate all of his organs. For some reason, I decided not to donate his eyes because he had this huge, brown eyes.

HELEN: We all agreed on one thing that there was no way that her face was going to be touched, no corneas, nothing. Her face had to stay pretty.

SYLVIA: So, before we start the operation and before this goes ahead, we'll have a minute's silence.

HELEN: So, you still have that-- the surgeons still have respect. So that was wonderful to know that it put me at rest.

JAY: I think he came out of theatre probably about five or six hours later, and we had the opportunity to sit with him after that in privacy with our entire family. I think we put clothes on him. We held him. I've still got photos of us holding him. I think the best way to describe it was he was a little lighter and had two surgical cuts, which you couldn't even see.

SYLVIA: When you leave the hospital that day, you will have a plan about what is it you want me to do now? Do you want us to phone you the next day? Some families would like a phone call in the morning after the surgery's all finished to let them know what's happened.

ELAINE: And then we will send a letter with outcome information letting the family know about the individuals that have received transplants.

SINA: And we are waiting and waiting just to hear anything. But then when the letter actually arrived-- and you get prewarned that there is a letter coming. I think we just sat there. We sat on it for about a week because you just had to find the right moment to open it.

HELEN: The letter started, "to the brave family of my brave donor." And it was talking about everything, how he appreciated Alice and he can't believe his luck. And it's sad that she's died, but he will always remember her.

And at the end of the letter it says, thank you, thank you, a million times thank you.

JAY: We know the girl had an external mechanical heart. She only had one month left to live. And this truly did save her life.

[MUSIC PLAYING]

I kept on asking myself, and I don't know if I ever asked Sina, but how do you deal with the death of a child? Just not the organ donation part, but just the death of a child.

HELEN: I had about 16 months of bereavement counselling up in Birmingham.

JAY: I'll never forget the psychologist that helped us. She just said come and see me, both of you. And we went to see her every two weeks for just under a year.

HELEN: It's what I call the oxygen mask theory you get on an airplane. In case of emergency, put your own mask on first and that's safe. If you don't look after yourself first, how on Earth are you going to look after everyone else that needs you as well? So, I decided from day one I was either going to sink or I could swim, and I chose swimming.

JAY: What people don't realise is that, by Sina and I talking about it, it actually helps us grieve. It's really been helpful where we can positively talk about our experience.

HELEN: Obviously, I'd rather Alice was here, but she's not. So, this is the next best thing I can do to remember her. And I talk about it all the time.

[MUSIC PLAYING]

JAY: You never get over this, but you'll start learning to live with the pain every day.

HELEN: Some days, the grief is debilitating some days. Just can't do it, but I know I'll get through it. I've learned that I'll get through it.

SYLVIA: I don't think that huge amount of grief changes its essence. I just think you're going to grow around it. And how you live your lives and move on, I think it changes.

JAY: If we didn't make that decision to donate his organs and we chose not to, he would have just died. But now, we can sit here talking about Ari and how he's left a legacy that is not just the legacy for those children that are recipients of his organs, but also a legacy for our entire family.

HELEN: It's like-- it's like the club that any parent doesn't want to be in. But if you're in it, you might as well make the most of it. If you're there, then just see all the positives in it.

ELAINE: I think, if families don't get given that choice, we're denying them them that hope, that future. We're denying recipients the chance of a transplant.

[MUSIC PLAYING]