

Title: **Episode 4. Meetings at the Edge**

Speakers: Georgie Vestey, Dead Honest & Lizzie Neville, Death Doula

Interview Transcription

Georgie Vestey: What happens if you tell you people, you go to a party, and you tell people what you do; how do they react?

Lizzie Neville: So, you'll get those that are really interested in it and will want to know more, and then you'll get others that eyes will go like saucers, and they'll suck their teeth in and go, "Okay", and then change the subject or walk away; there's no middle, no middle at all.

If they do talk about it, their answer straightaway is, "I couldn't do that. That must be a really sad job to do. Why do you do it?" And it's like, "No, it's a really happy job". Then they're like, "Well, you're a freak, because you really like death!" It's like, "No, no, I can handle it. It's normal; it's a part of life. It's no different to the midwife bringing somebody in. We are the death doula taking somebody and journeying with them on their way out".

Georgie Vestey: I'm Georgie Vestey and you're listening to Dead Honest, a podcast where we talk honestly about death. Now this week, it's the turn of Lizzie Neville who you were just hearing. She's a death doula, which is a bit like being a midwife for the dying. She loves, just loves dying people, and not in a worthy, hand-holdy, patronising, "There, there", sort of a way, but in a really proper, "This is the biggest journey of your life and I'm so pleased to be sharing it with you".

We start by discussing what skills you need to be a death doula.

Lizzie Neville: Doulas are very grounded people, very grounded. You've got to be able to deal with people's emotions, and they may range from being really sad to being really angry. I don't think you can learn it; it's doesn't come from the head, it comes from here, your soul, your heart.

So, I always imagine it like there's a hurricane coming through that family and it's ripping everything apart, but the one person that's going to stand still and not move

and be constant is that death doula. I think, for yourself, you've got to very comfortable with death and dying.

Georgie Vestey: How did you get so comfortable?

Lizzie Neville: I was with a friend who was dying, and it just felt comfortable talking to her. Nobody else would talk to her. They kept saying, "Come on, you can beat this", and she couldn't; she knew she couldn't. She needed to tell somebody she was dying and for somebody to validate it and validate her feelings and thoughts and to just talk about it, and I was able to do that. I realised that I was very comfortable with it, and it felt right.

Georgie Vestey: Do you ever attend a death when the person is on their own because there aren't family members or friends around?

Lizzie Neville: Yes, I've been with somebody who's got nobody about and you can just sit there and be quiet with them really; they don't need a running commentary. People who are dying really need to concentrate on dying in a way. Sometimes I use a recording of the sea, because the waves are in and out and it's quite rhythmic and it's a bit like breathing really.

Georgie Vestey: Have you worked with anyone who has got family and friends, but actually wants to die alone regardless?

Lizzie Neville: I think you should honour it if that's what somebody wants, and that's when you talk to the families and say, "This is what they want". So, I've been with lots of people who have sat with their family for a day, two days non-stop and they just say to them, "I'm just popping out to get a drink", and the minute they pop out they die.

Georgie Vestey: Why is that?

Lizzie Neville: Lots of people are very self-conscious. It could be that they don't want to be watched dying, it could be that they're trying to protect their loved ones from seeing the actual death; it happens an awful lot. If that's happened to you, don't feel guilty that you missed it, it's perfectly normal for that to happen; they're just doing it when they want.

People die how they lived. So, if they were a very calm person while they were alive, they're probably going to be very calm when they die. If they're quite a hothead and a grumpy, they'll probably be hot-headed and grumpy on their way to dying. People don't suddenly change because they're dying.

Georgie Vestey: Do you think some families though want their family member to die in hospital, because the responsibility of having them at home feels too daunting?

Lizzie Neville: It is daunting, it is. I'm not going to say, "Oh, no, it's fine", it's not, it's really hard. Having somebody dying at home is hard. It's lonely; the responsibility of it all is huge. Yeah, you've got to be informed and know what you're doing or what's likely to happen.

Georgie Vestey: But I can imagine there might be occasions where somebody's explicit wish is, "I want to die at home", because that sounds so nice, and the person who has to do the caring for them may not feel comfortable doing that. Does that ever happen in your experience?

Lizzie Neville: Yeah, that happens quite regularly. So, that would be a conversation that we would have, maybe I might have it on a one-to-one with the person who's dying first and explain that it's quite hard for the person that they're with to deal with it. How would they feel about perhaps going to a hospice, or whether we can get a live-in carer to come in and help, or whether they're okay with just having an end-of-life doula there?

Then, I'd bring in the other person and then we'd really try and bridge and come to some sort of happy medium that they're okay with.

Georgie Vestey: Tell me, what happens when people die; are there any common themes that you've observed?

Lizzie Neville: Yeah. People start talking in a different language. So, you'll hear somebody say things like, "Where are my shoes? I need my shoes. Do you know where my suitcase is? Have you got the tickets; have the tickets arrived yet?" So, it's all about travel, all about moving on.

So, if I'm with a family and they're like, "What is he on about? Why does he need a train ticket?" I ask them to go with it, "Just tell them that you're arranging it, it's

coming", because they are going on a journey. We don't know where they're going, I don't know where they're going, but they're going on it and it's a real common theme.

Georgie Vestey: You're in a position where you see things happen again and again, and what we might see at being idiosyncratic to the person that we love actually is quite common. Are there any other examples that you can think of that you recognise, "We're at this stage again"?

Lizzie Neville: People pick, we call it picking, so with their finger. So, it'll be the thumb and the finger, and they'll be picking at the clothes and people think they're agitated, and it's actually just a normal sign of things slowing down towards death. Or sometimes they'll be reaching out in front of them, and their hands seem to go up in the air, and it's just one of those things that frequently happens. So, when it happens, you can say to people, "Do you know what, that's normal, that's okay; we were expecting that".

I think the biggest one is the death rattle that everybody seems to go, "Oh, you hear that, you're a goner". Yes, you are dying with it, but it's not hurting them. Sometimes it can be quite daunting when you hear it, but if you actually watch the person, they are unconscious, and that bubbling noise is just mucus or a little bit of saliva just stuck in the back of the throat, and because they're not swallowing, it's just sitting there so the air's just bubbling through it.

When you can explain that to somebody, it's a lot easier, and you can say, "Look, they're perfectly calm. It's not hurting them; they're not distressed. Maybe if we just turn them slightly, that might ease it".

Georgie Vestey: So, when a death happens, tell me what you do when you walk out that door.

Lizzie Neville: Okay. So, when you've left the family, you normally get in the car, you drive round the corner and then you let it go and you can cry and really let that hurt and emotion out; you've got to let it out. Then you go home and then you take all your clothes off, you get in the shower, and you wash it away, and then I will sit down and write reflections of the day, of what's gone on, what's happened, how I'm feeling.

Maybe a day or two later, I will speak to a mentor and then talk to them and say, "Hey, this one's really affected me; I need to talk about it".

Georgie Vestey: When you've gone back to your mentor about the ones that have hit you particularly hard, what is it that has hurt?

Lizzie Neville: It is when you could see yourself in that same situation. So, it could be a young person that's the same age as yourself, it could be that they've lost a child, it could be that that person actually reminds you of somebody that has died. You might have had a really long relationship with that person, and without realising it, become really quite fond of them. Yeah, you have to be really careful, and you have to download this to your mentor and really talk it out.

Georgie Vestey: Tell me about the death that's taught you the most.

Lizzie Neville: That would be somebody who was quite young, who had a young family, who was going through mental hell I'd say, that it had happened to him, why him? He kept a lot of anger, he tried to be very brave with it and he wasn't letting go, and his wife said to me once, "Can you please try and help him go?" So, we had a really long heart to heart with it. I eventually got him to let go and tell me what his real fears were.

Georgie Vestey: Can I ask you what that fear was without compromising that person's confidentiality?

Lizzie Neville: It was leaving his child behind without a father figure, and that he had failed as a father for leaving him.

Georgie Vestey: It makes me think that it's really important you come in early in the process, because from what you're saying, these conversations will take time; they're not going to be just one conversation. Where would you say a good place to start is to bring in a death doula?

Lizzie Neville: Gosh, it really depends on the families. I think, certainly when communication breaks down between partners, that we can bring them back quite quickly.

Georgie Vestey: Is that quite common?

Lizzie Neville: Yes, it is. There's a lot of anger between both sets. There's a lot of fear of what's going on. One becomes the carer, so you can you lose the partnership. So, you'll end up having a carer and a patient and then they don't speak to each like they used to; you lose your lover; it may be that that person that's dying used to be the head of the household and used to run it, and now they're playing second fiddle and they're getting used to that.

It's so enormous what goes on that to just have somebody else there that says, "Hey, have you thought about this?" or, "Let's try and do it a different way", and just bring everybody back up to the same level again.

Georgie Vestey: We often take for granted we know what our partners want, in long-term relationships; how accurate is that? In my experience when I've talked to friends, deeply close friends about their wishes, I've got it really wrong and I'm curious about that; is that quite common?

Lizzie Neville: Yes, it's very common. We tend to think, "Oh, well, they're like me. We lived together for 40 years, we think the same", well, actually you don't. So, it's very important that we get this out before things get too far down the line.

So, it's much harder to talk to somebody if they're in the last week of dying than it is six months before, because they're out and about and they're still quite energised. And once it's done, it's done; you don't need to worry about it anymore, it's finished with. Let's get on and live.

Georgie Vestey: Does it give people a sense of relief once they've done it?

Lizzie Neville: A huge amount of relief, huge. Also, you're not asking your family to make decisions on your behalf, and that's the big thing, especially with medical procedures. Say you're taken into hospital, because you're quite poorly, and then the doctor's saying, "Well, we could do this, or we could try this invasive treatment. What do you think they'd want?"

Suddenly, all that pressure is put on your loved ones to decide, "Do we really want that to happen to you or not?" Now, if you'd written about that beforehand and said, "Under no circumstances do I want this done", they've got that to go by.

Georgie Vestey: What are the most important things we need to know about advanced planning? What would be the things I need to get done?

Lizzie Neville: They would be what you don't want; so, what interventions you do not want. So, that would be intravenous fluids; whether you want to have a breathing tube; any more chemotherapy or radiotherapy right near the end; CPR; whether you want that or not; where you want to be when you die. Do you want to die at home; do you not want to be hospitalised? You don't have to be. If you've got it in writing, you don't have to go.

Who do you want with you; who do you not want with you; who do you not want to see? That's just as important. Do you want to be near a window; is nature very important to you; do you want the window open? The little things are the really important things.

Are there any pets; do you want your pets with you when you die? What sort of funeral would you want; do you want a funeral; do you want a casket; do you want a green burial; do you want a service? Who do you want to talk? Is religion important to you? There are lots of options, and if we can get as much information out of you of what you want, it helps the family.

Georgie Vestey: You strike me as having two quite distinct roles; you're the person that we should call when we want to do our planning, like we would a solicitor about our will, and that can happen now; and then you're the person who comes and helps towards the end.

Lizzie Neville: Yeah. So, I would be quite comfortable going to see somebody who's in their 20s, 30s, 40s who's fit as a fiddle to help them plan and say, "Yeah, cheerio. I hope I don't see you for a very long time", and others, we might do their plan and I might see them in a year or two.

End of life doulas don't say, "That's my job, I finish, I'm out of here". When somebody dies, we don't just stop the minute somebody dies; we'll stay with the family for however long they need, but not so long that they become dependent on you.

Georgie Vestey: How do you manage that, because I can imagine you are a very comforting presence, and you are also a link to the person who's died; how do you extricate yourself?

Lizzie Neville: Yeah, it's tough; it is hard. So, when you first go in and meet the family, you make it quite clear that this is your role and that you will be there afterwards, but there will be a time when you won't be. When you get the other side, it may be that you say, "Right, okay, I think our time together is coming to an end. Let's meet up and go through it and just talk".

Georgie Vestey: Last year, I know your mother died and you were a doula for her. Tell me about that experience.

Lizzie Neville: I'd actually come back from doing a piece of training and I was on a real high. My sister rang me, and she said, "There's something wrong with Mum". So, I rang her, and I said, "What's going on?" Then it started to come out that, actually, she'd had a scan and that there was a growth.

So, straight into doula mode, "Okay". So, I went over and saw her and then it was just the enormity of it all, of realising that, actually, the person that you thought would be there for years to come is suddenly dying and now I'm on the other side of it.

She taught me so much through it, how she felt, how other people were treating her, what medical things she did or didn't want. I was able to go with her and journey with her.

Georgie Vestey: That's what I'm curious about. How did you balance the role as a doula and as a daughter?

Lizzie Neville: It was a learning curve. I'm not going to say I did it perfectly, because I probably didn't, but I said to her that, "I'm trying to be both here and it's difficult". I was open and honest with her with it, and she was very honest as well, so it worked really well. It was one of the best experiences because she taught me so much. She loved the fact that I was an end of life doula, loved it.

Georgie Vestey: Do you ever have clients who come to the end of their life and just say, "That was a great one. I'm okay with where I am and I'm happy to go forward"?

Lizzie Neville: Yes, and it's lovely when you get a client like that, because you can really work with them, you can have a really honest, chunky conversation about death and dying, and you can ask them all sorts of things and get really good answers back.

Georgie Vestey: Is that an uplifting death for you?

Lizzie Neville: Yeah, because they're teaching you all the time. Every death that I witness, that I'm with the family all the way along, I'm learning.

Georgie Vestey: Tell me about how you would like to die.

Lizzie Neville: I would like to die at home, as long as my family are happy. It depends on how far away it is, but if it was happening now, although I would like to die at home, I'm very conscious of my children, who are early 20s, and the impact it would have on them of me dying at home. So, I would want to talk to them, how comfortable they are with it. If they're not, I think I would probably want to go to a hospice.

Georgie Vestey: Are you going to have a death doula?

Lizzie Neville: Yeah, I would have lots actually, because it's really lovely. When the death doulas are together, there is that just lovely, warm, safe feeling. I always say it's going back to a womb when I'm with all the doulas.

Georgie Vestey: So, Lizzie, what is a good death?

Lizzie Neville: So, a good death, to me, is that you are in the place that you want to be, that you have the people that you want around you, that you have said what you needed to say. That's really important, is that people talk to one another before they get to that end stage and to say, "I'm sorry, please forgive me; I forgive you. I love you, and thank you".

Georgie Vestey: How common is regret amongst the people who are dying?

Lizzie Neville: Very common. "Why didn't I do this earlier?" I've often heard people say, "We kept saying, 'We'll do this when I retire', well, I've just retired and now I'm dying", or, "I worked so hard, and I missed the children growing up". "Why did I worry about other people's opinions of me; why didn't I just go for it? Why didn't I

become the nurse I wanted to be, because somebody told me I wasn't good enough? I am good enough but it's too late". It's your own mind telling you that other people don't think you're good enough to do something or you've got plenty of time to do it in the future.

So, how I live my life now is, if there's an opportunity, even if it's really scary, do it, and you'll learn along the way. I am forever out of my comfort zone now. Yeah, I get really scared but it's a ride and you've got to go for it, because you never know what's round the corner.

Georgie Vestey: My thanks to Lizzie Neville for being so open and honest, and if someone close to you is dying and you think, "Gosh, I could really do with a Lizzie", then contact the organisation that trained her, [End of Life Doula UK](#). Now, they're a wonderful resource and they can put you in touch with someone who can help you in your local area.

As ever, I'll put a link to their website on this episode's show notes, which you can find on our website, [deadhonest.com](#). So, until next time...



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