Title: Episode 7. Dad, we need to talk ...

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Living Well, Dying Well

Interview Transcription

Georgie Vestey: This is a special episode of Dead Honest, a podcast where I talk honestly to the professionals who help us when we die. The last few months have been beyond extraordinary for all of us, as the Coronavirus is sweeping across the world and it's forcing us to look at many things, we've taken for granted. Perhaps the most confronting is the thought that we may lose people we love sooner than we imagined.

Truthfully, the chance of us dying of this virus for most of us is still very very small but we all have people we love who may be more vulnerable; elderly parents, grandparents, friends and colleagues who may have had serious illnesses or still be dealing with them. The brutal fact is this, that when they get really sick with this virus it's highly likely that we will not be with them as they die.

Here's the thing, we need to talk about death, not in the abstract sense but really practically. We need to step up and have the conversations about our last wishes with those we love, whilst we can. I know that sounds all good in theory, but for many of us actually doing it is almost too painful to consider and bluntly we have no idea how to start.

I hope this episode will help. My guest today is Hermoine Elliott, she is one of the UK's leading death doulas which is a bit like a midwife for the dying. In her long career she's been with hundreds of people as they die and one of her roles is to help families have these conversations, so I thought I'd ask her advice.

A quick caveat, this interview was recorded remotely as we are currently in lockdown so, please excuse the less than perfect sound quality.

Hermoine, you've been many families where they've had to have the death conversation because a relative is approaching death. I wonder how has it been after they've had this conversation?

Hermoine Elliott: My experience is that there's tremendous relief when we do finally acknowledge this. I've heard so many people who are dying say, "I'm so grateful that we managed to talk about it because it's given me the opportunity to say what I wanted to say. It's given me the opportunity to feel that I've completed with people".

All the time we're not talking there's a terrible tension, because sometimes it's the relatives that don't want the conversation and the person who's dying that does and we find ourselves in a situation where everyone is trying to protect everyone else. Sometimes it's important to have courage and to bring that elephant into the room or acknowledge that the elephant is in the room.

<u>Georgie Vestey</u>: What should we do if our relative doesn't want to have that conversation?

Hermoine Elliott: That isn't uncommon, and I think I would hopefully -- on one level respect that wish, because of course it's not our job necessarily to force people into having a conversation, but I would also recognise that I'm part of this relationship. To talk about it may be just as important as your need not to talk about it and I don't think we should be afraid to say, "Actually I need to speak about this, because if something awful should happen to you, I would want to make sure that I'm doing the right thing for you".

Georgie Vestey: What is the benefit of having these conversations for the healthcare workers who we may then come into contact with? Does it make a difference to them?

Hermoine Elliott: Yes, and an extremely positive thing to do. I actually had a conversation with my own GP the other morning to be very clear with him what my wishes are and he was so appreciative and said, "I wish all my patients would do the same".

Georgie Vestey: This is a difficult conversation for people to broach. A month ago, if we'd been in a similar situation, we would have been able to be in hospital, we would have spoken to health professionals, they would have guided us. People like you would have been on hand to give us the steer of what we need to do, but actually with Coronavirus the chances are by the time we end up in hospital, we are not

going to be able to take our relatives with us. We cannot have those conversations, so we have to have to them before they leave the house, to be blunt.

I wanted to talk about how we actually do that, really practically. How do I start that conversation with my relative? How do I open it?

Hermoine Elliott: It's a challenging question because obviously every family is different, the way they relate is very different. I would love us to encourage people to, "Come on, guys, we need to be doing this now", before we get into any acute emergency situation because the emotions run very very high. It's a desperate, desperate thing.

Georgie Vestey: I am going to give an example, because I always think it's really helpful to move from the theoretical to the practical. It's me, I'm having this conversation with my father. He's of a vulnerable age and could be one of those people who goes into hospital and doesn't come out. My view would be, I'd try and start the conversation with something along the lines, "Dad, I think we should have a chat about what's happening with the Coronavirus because of your age and your vulnerability, if you are admitted to hospital, you will be isolated, and I won't be able to be there with you to talk about the decisions you may want to have made at that time. So, I'm just thinking it would be a good time now for us to have a chat about that so that you maintain some control over that at a time when you won't have others around you who can help with that". Would that be one way of taking that forward?

Hermoine Elliott: Yes, beautifully put, absolutely.

Georgie Vestey: Then it's that thing, say look this is actually as much about trying to put my mind at rest to make sure I do the right thing by you, as it is about trying to make the decisions clear for you for your benefit. It's a way of you helping me deal with this as well, which I'd be really grateful for. I think sometimes parents find it easier to do things for their kids if they think it's going to --

Hermoine Elliott: Absolutely, right.

Georgie Vestey: Also, they recognise that they're helping the doctors to know the best way to act in those different situations. That is a great thing to say. "You are

playing your part in actually helping these incredibly overworked doctors and nurses do their job, you are making their job simpler by making your wishes known now, not just for us as a family but for them as well."

Hermoine Elliott: Yes.

<u>Georgie Vestey</u>: Then, if he said, "Well, what sort of things are you thinking about", and I suppose I'm throwing that question back to you. What are the questions we should be thinking about?

Hermoine Elliott: I think what's important to us, "How would you like to be cared for? What's really important for you at that time", because we can make sure that you're kept really, really comfortable and the doctors and nurses will do everything to make sure you're not in pain. Or, "Would it be important for you to go on life support?" If people say, "Yes", "Do you understand what that means?"

Georgie Vestey: What does it mean?

Hermoine Elliott: To be on life support will mean being attached up to a machine, that does your breathing for you. It means being sedated so that you will be pretty deeply asleep, maybe a little bit rousable, but being in a kind of suspended state. The aim of that is to allow the body to recover.

Very often if somebody does have a collapse or go into a cardiac arrest, in ICU, then the automatic thing is to resuscitate, as we call it, which is a pretty brutal procedure to try and restart the heart.

Georgie Vestey: Brutal in what way? What way is it brutal?

Hermoine Elliott: Simply that it requires a lot of pressure on the chest, repeated what they call chest compressions and obviously to keep the oxygen circulating somebody would already have a tube into their lungs, into their throat with oxygen and that kind of thing, so it's a very dramatic procedure. A bit frightening for anybody, it's frightening as a practitioner, it's frightening for family members, it's frightening for the person receiving that.

Georgie Vestey: It's no guarantee that you are going to come out of it.

Hermoine Elliott: No guarantee, broken ribs, all kinds of things so there's no guarantee that you come out of it, and there's no guarantee that if you do come out of it that you will be as you were before.

With much younger people there's a much greater chance of recovery, but the statistics show that it's still pretty small numbers of people who come back to full functioning after CPR.

Georgie Vestey: So, if my father was to say, "I don't want to have those interventions, I don't want to go to ICU. I'm of an age where I've had a good life and let that precious bed go to some other person who still has many years ahead of them, I just want to be left alone to die peacefully as possible, and as quietly as possible". Is that what you call comfort care?

Hermoine Elliott: That would be what I would call comfort care.

Georgie Vestey: So that is the least amount of intervention.

Hermoine Elliott: Yes. It would be managing symptoms; it could also be called palliative care. Palliative care is making life as bearable and as comfortable as possible, however long they're in the dying phase.

Georgie Vestey: If my father is taken to hospital and he's of an age and frailty that he is unlikely to be offered one of these precious ICU beds, and that's the reality now, then I want to know what's his death going to be like?

Hermoine Elliott: Dying is different in every situation. There's no one way of dying. My understanding is that the death from Coronavirus, a large part of the process is difficulty in breathing. If someone was in a situation where they were receiving comfort care, the chances are that that person would receive oxygen and sedation and pain relief. The more distressing symptoms would be managed very well, but we can never know what that process will be like. It's likely to be very individual, depending on people's condition before the illness. It would be about making life comfortable and as good as it can be for the duration.

<u>Georgie Vestey</u>: If we have relatives who have entered hospital who are very infirm and vulnerable and likely to fall into the same category as my father, that there is some comfort in knowing that there are procedures in place to keep our relatives,

even if we can't be with them, to keep them as comfortable as possible, as supported as possible. Then as we actually die the physical dyingness of dying, the shutting down, is that quite a peaceful ... ?

Hermoine Elliott: In my experience it is. I haven't been with Coronavirus deaths, but I don't see why it would be especially different. For me, the deaths I've witnessed and been involved with are very much about a change of state, so there's a shutting down that will happen and a withdrawal very often. We may become sleepier and sleepier, less and less able to communicate. We wouldn't be able to eat or drink anymore, that's a normal letting go that the body doesn't need sustenance and gradually the systems of the body that sustain us, will gradually lose their function.

As we perhaps then slip into unconsciousness our breathing patterns would change and it almost feels as though people are moving in and out, if you like. There's a sense that they're here and not here, here and not here until the moments that the next breath simply doesn't come.

<u>Georgie Vestey</u>: That's quite comforting to think that even if we can't be with our relatives at the very end, that it is a process which is very peaceful and that their awareness of us being there or not being there is not going to be that acute.

If my father wants to make his wishes clear, what do we do next? What form do we fill in? It all feels a bit daunting but what can do practically to record those wishes?

Hermoine Elliott: Because we're in such an unusual situation many GP surgeries have stepped up and are doing a very fast track form which is very very easy to do, because this is such a critical time. This is what they call a respect form, it differs, it's in different format in different areas but I think most surgeries would welcome you calling to say, "I'd like a telephone appointment to discuss my advance decisions or my advance plan". If you don't want to talk to your GP, you can go online to an organisation called Compassion in Dying, where they have downloadable forms.

The most important thing is you tell your family that you've done this, that they're aware of it and that you give a copy of this form to your GP. Everybody needs to know that you've done it. If you feel you need a hand to talk it through because sometimes, we don't always know the consequences of our decisions, then the End

of Life Doula Association have a whole raft of end-of-life doulas who are working with people remotely to help talk it through, just to demystify it a little bit.

Georgie Vestey: Can I take you back to another aspect of this though which is the fact that we're not just trying to identify medical wishes but how do we have those conversations with our relatives that are what I call the goodbye conversations? What would be your advice on that? How do we approach that?

Hermoine Elliott: One of the things I always tend to think, "What would I regret not saying if my husband were to die tomorrow?" To some extent I try and project myself into the future a little bit to imagine how would I feel if I didn't say these things.

<u>Georgie Vestey</u>: I am being fiercely practical about this, because again I always think it's really simple to go, "It sounds like really good theory, but the actual conversation's a bit tricky".

Hermoine Elliott: Yes.

Georgie Vestey: With my dad, it would be that thing to say, "We don't know what the future's going to bring for any of us, but maybe now is a good time for us just to sort of say the things that we want to say and I know you're going to think I'm being silly or you might think you're about to drop off your perch, but I'd actually regret the fact that I hadn't said it more, than if I maybe make you feel a bit uncomfortable for the next ten minutes while I tell you a few things and just make it a bit light-hearted".

Hermoine Elliott: I think the light-hearted approach is really important. I had a conversation with my mother probably about six months before she died, even though she wasn't dying. I didn't know she was dying, and I just told her all the things I was grateful to her for, and we weren't a family that shared intimately or deeply very much, and it was the most beautiful conversation I've ever had, I think.

She was very overwhelmed, and she recognised that she'd wished she'd had the capacity to talk more on that level as we were growing up. It was very special, there's something about gratitude and acknowledging what's been special for us in any relationship. I think that's very important.

<u>Georgie Vestey</u>: Is it something which if we don't even feel we can have the conversation face-to-face and in times like this we may not get that chance because

we're isolated to have those conversations face-to-face, that we can always write that down.

Hermoine Elliott: Absolutely right, that's what I was going to say. Writing a letter, doing an audio, recording something, just to remember that family life is such an intimate thing, it's not always a happy thing and it's sometimes jolly difficult but there will be threads that we can draw on to connect us into an intimate moment.

I don't think there's anything wrong with saying, "These are the things that I'd really wished I'd told you earlier", or, "Do you remember the time?" Reminiscence is a beautiful thing to do. "Do you remember the time we all went off to the beach and we just larked about in the pebbles and the sand?" "You were a great dad", just those simple, simple memories are very, very powerful.

Georgie Vestey: We've got time now on our hands as we're all isolated, to maybe write that letter or have that phone call or just extend the sort of tenderness that we feel for each other

Hermoine Elliott: Can I say something else, because I think also as British people, we tend to be a bit dismissive often of that kind of conversation and I can just imagine a stiff upper lipped dad say, "Oh stop it", brushing it off, but I don't think that means we should stop. I think we need to make it work for us and say, "I know this isn't comfortable dad, but I just need to tell you this". There's something about insisting upon being heard sometimes that I think is really important.

<u>Georgie Vestey</u>: We're living in really extraordinary times, we don't even know quite how extraordinary they are or will be going forward, but I wanted to ask you how will it change how we talk about death in the future, do you think?

Hermoine Elliott: Gosh it's very hard to predict but I really, really hope that it's brought it into the living room. Everyone is talking about the virus and really the next step is to talk about the what ifs and that does mean talking about death and dying.

I hope these conversations are going to continue and that we create an easier way for us to engage with it and to talk about what it is that we might want when our time comes. Georgie Vestey: My thanks to Hermoine Elliott from Living Well Dying Well for being so generous with her time. She mentions two organisations in that interview with regard to making your final wishes and if you grab a pen, I can give you their web details. If you can't find a pen don't worry, I'll also put their details on the show notes of this episode. The first was Compassion in Dying which offers forms about advance wishes which you can download from their website www.compassionindying.org.uk. If you have any questions about your wishes and want to speak to a death doula, the other organisation she was mentioned was End of Life Doula UK and their website is https://eol-doula.uk/.

My apologies once again for the variable quality of the audio, it was my first remote recording ever, but I hope, given the importance of what we've discussed, you'll forgive me.

If you have friends or relatives or colleagues who may benefit from listening to this episode, then please, please share it, we all need to have this conversation. In the meantime I'm sending you all my best wishes.



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