**NHS Education for Scotland**

**Talking about Bereavement Podcast Series – Transcript of ‘Valuing the time after the last breath: the ongoing caring relationship’ Podcast**

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**LI:** Hello and welcome to the Talking About Bereavement Podcast, which is brought to you by the Bereavement Education Programme in NHS Education for Scotland. I'm Lynne Innes, one of the educators in the team, and in these podcasts I'm going to talk about bereavement with our guests who will be sharing and reflecting some of the work and learning they're involved in as they talk about bereavement.

**LI:** Hi and welcome to this episode of the podcast. I'm delighted to introduce my guest today,
Kate Clarke. And Kate has 20 years experience in palliative and community nursing for the NHS and Marie Curie. But she's also the co-author of the book ‘Slow Down When Someone Dies’, which in essence is a call to everyone, and particularly carers to think about how their long-term wellbeing is affected by what they do in the days after someone dies. And Kate, I know you've told me a bit more than that about your, the background to how this got started. But actually, I thought it'd be really good to hear that from you rather from me. So, I wonder if you could just tell me a bit more about how you came to, well, write the book but I know you've also started a charity. So lovely to have you with us today and welcome to the podcast.

**KC:** Thank you very much, Lynne. I started getting involved in education about this issue really quite a few years. But it was after my auntie died, who I was very close to, and I spent time with her after she'd died and, which was very important to me. And it really, it made me realise that other people were not getting this experience. My other family had died at home as well and they had, I had spent time with them and that was just our family culture really. I think that was from the days when it was just the, the usual thing to happen here in Scotland. But through my nursing I've realised that for most people it's quite different. And so I set up a charity with some friends up in, I'm up in Moray, to just to highlight and educate people about the options that they have when someone dies and the importance of what we do in that time, how it can affect us.

**LI:** Thanks, Kate for, for telling us about that and I've obviously, I've chatted to you before and was really interested in hearing what the charity actually does and, and how you make sure that, how you ensure that people are aware of, of what it is you do. And I wonder if you could just tell me a wee bit about that. What is the charity's kind of, I suppose, main purpose to an extent.

**KT:** Really the, the purpose is to, to let people know that they are able to do things and be close to a person who has died for the first few days or even up until their funeral, if, if that's what they want. And because it's, it's not, it's not well known in Scotland now that that is possible. You know, generally people are advised by health professionals to contact a funeral director when, as soon as someone dies. And that is, can be a good option for people and, but it's not the only option. So especially for carers, we feel that it can be very helpful to have a slow, gradual release from that relationship and the caring relationship, but, and also the personal relationship that has built up over can be over years now that, that, that someone can be caring. And so, we're trying to raise awareness of the importance of taking care of all our relationships, but particularly the caring relationship when someone dies for adults. Now for, in children's nursing policy Lynne they, you know, it's, it's understood now that parents will continue that caring role after a child dies or a stillborn baby dies. It's now recognised. But that's quite recent. Well, maybe the past 20 years really that, that we have understood that and parents are supported to still spend time with a child if that's what they, they want. But there's no recognition of that with adult nursing policy or adult policy generally that, that relationship needs to be taken care of. So, we're educating, we we've educated hospice staff and also the nursing students now we're working with up in Inverness. But it's, we're Scotland wide so we've workshops at conferences or, and we also run a course, an online course ourselves for the public and anyone that can, can attend that. So, it's, we provide education that's suitable for everyone.

**LI:** And is your online course, you said it's, it's available for everyone. Is it a kind of, is it a few weeks or is it one day or how, what does your online course look like?

**KC:** Well, we have a course which is, which is over 9 weeks.

**LI:** Okay.

**KC:** So, it's kind of self-taught, you know, by emails. And we have live sessions, people like the live sessions to discuss. So, what that looks at is the value of a time between someone's last breath and their burial or cremation or their funeral. How to take charge of that time yourself, if that's what, that's what you want, how to care for someone's body and also how to look after each other. There's so much happening in that time, or there's so much can happen in that time in terms of reconfiguring relationships and starting to just for everyone to live without the person who has died and reconfiguring our relationship to the person who has died as well.

**LI:** I hadn't really thought about that before, but that kind of reconfiguring of that relationship to the person that has died seems kind of something intrinsically that we should be doing, doesn't it?

**KC:** Well, that, yeah, that's what bereavement really is, isn't it? In a way, there's that's a big part of bereavement. But there's in those first days, there seems to me quite a, you know, a special time for doing that. We're not really connecting to that. Generally, I, I hear people say, oh, I just want to get through the funeral and then I'll sort of start thinking about things. But that's a kind of missed opportunity to me, I think. Or if you think even, even about, you know, words in stages of mourning, believing that someone has died is a really important stage of mourning. And there's a lot that can happen in those first few days using our senses, even just you know we have our senses to make sense of the world around us. And so just using our sight to see that someone has changed, you know, hearing that they're not breathing anymore, hearing the silence, touching someone to feel that they're cold, that's all information that maybe sounds kind of simple, but it's really helpful information for embodying that someone has actually died.

**LI:** Yeah. Just thinking about often people, I will hear people say I can't, I can't quite believe they've died. And I suppose that might happen maybe more than a sudden death, but, but not always in that kind of disbelief that after all this time someone has died but then they don't see them again. And so I hadn't really thought about how they kinda reconcile that kinda of visual aspects of seeing that their family member has died can impact.

**KC:** Yeah. And it's not that everyone needs to do that. I mean, there's not that much research in this area, but the research there is, is that not everyone needs to see someone or be around someone after they've died, but many people do and many people do want to see and it's an instinctual thing. That's the way we, you know, we deal with the world. But for the people that do want time, it's very important that they get it and they can have, you know, long term difficulties if they don't get that time and long term regrets. And, and our experience is particularly, it does depend on the type of relationship, but it's particularly for people who have been caring that, you know…

**LI:** Okay.

**KC:** …when you think about the intense, the intense relationship, you know, that people have, even maybe if it's just for the last week before someone's died, you know, waiting for someone's last breath, it's an emotionally intense time often. And so just to gradually, you know, release from that, it's very unusual actually in Scotland just now what's happening. We think it's tradition, we think it's normal, but it is actually very unusual that often now people are taken away from their, I'm going to say relatives during this conversation, Lynne, because you know, it's that could be friends or close family, whoever has been close to the person when they're, they're to be taken away so quickly from relatives after they've died. It's quite unusual. Do you know, it's quite unusual in terms of what's happened in Scotland historically, you know, it's only in the past, maybe 60 years. And also, what happens in other parts of the world, you know, to be taken out of some, out of someone's family and community, it's quite unusual. And it’s, it's in our experience that what we, what we're looking for, for people I think, just from our experience, from stories people have told us is for someone to be ready to hand the person over. That's how, that's the best words I can come up with. And that's kind of for children that, that's…

**LI:** Yeah.

**KC:** …what the sense is giving parents the chance to say, okay, I'm ready to hand the child over. We would like to see that for adults as well, particularly, you know, people have said to me, I felt like he was ripped away from me, that, that's when, that's words that more than one person has used people with the best of intentions and it's not that anybody's trying to cause any harm here. I think it's a lack of understanding with people who maybe, maybe like that someone in, in a sort of group of relatives, there's someone that wants to do something when someone dies. So, they phone the funeral director because that's something they can do. Maybe they've not been able to do any caring or, you know, they've not been so involved, but now they can do something. And yet the people who need a bit and more time and a bit more quietness, maybe, and to take time to change that relationship, they then lose their voice. You know, they don't have a voice cause’ they're in shock. They're numb. They're exhausted often, you know, if it's someone who's been caring, they're exhausted. So, yeah. And then, and then funeral directors, they want to take someone's burden away, if any you know, that they want to help. And that's what it seems that it can help you know I can, you know, make it all better. But that's maybe not, maybe not the best way in the long term.

**LI:** Yeah. It's interesting that, you know, it's, it's changed. As you were talking there, I was reflecting on, and this is just my own experience, I remember my granddad dying in the house and that was 1979, and him lying in the house until his funeral, which was probably quite a few days later, not lots of days later. It seems to be longer now for funerals than it was then. I think it was maybe about 3 or 4 days then and he was in the house. And then my other granddad died in 2000 and he, he was in the house as well. So that doesn't seem that long ago, but I can't really think of anybody since then, certainly within our own family that has my own experience that the family member has stayed in the house. But up until that point, I remember it was unthinkable that both of my grandfathers wouldn't have, wouldn't be in the house. You know, that was just not, it was just, that's just what, what, what happened. But, but so in the last 20 years or so, has there been a definitive shift or, or, or do you know, or.

**KC:** My sense is it's a little bit more than that, you know, that the shift has happened, and it is partly with people, more people dying in hospital, you know, now about in Scotland, about quarter of people die at home, half of people die in, in hospital. So, with that shift, I think maybe that has caused it. But in our, in our experience of what, what people have said only, I've only realised this myself since starting Pushing up the Daisies really that stories people have told me it might actually be more important if someone dies in hospital to take them home for a few days, you know, after they've died. Could be a funeral director that does that, it doesn't need to be the family doing that themselves, but to take them back to somewhere within their community, within their sort of fabric of their society so that they can then leave home again. And that, that can be helpful. There's people who, you know, do believe that that can be helpful for the person who has died to orient them. Because often people die in hospital not by choice, but because, you know, they've been maybe taken there in a crisis and, you know, they haven't been expected to die there. And they haven't expected to die there, but they just haven't been able to get home. And so again for carers who may, who say to me that they had promised a person, you know, not that they would look after them, they would never have to go into hospital. And so, and when they hear that they could have taken them home, they have big regrets. If only they'd known, they could have done that and they could have cared for them for the last time and been the last person to care for them, that they would have really liked to do that. So, so again, that's something that you know, we would like to raise a possibility of that with staff to be able to give people that opportunity. And even, you know, staff have a duty of care we believe to give people their options, to give people the correct information about what can happen when someone dies. Because generally, in my experience as a nurse, staff say could contact a funeral director now they'll keep you right, you know, they'll tell you what to do next. And that's not actually, you know, very, well it’s not correct, well it is, it's not incorrect, but it's like not all the information, you know, that people can do something. So, there's a great opportunity here for staff to advocate for relatives in terms of improving their longer-term wellbeing.

**LI:** Yeah and, and so there’s a couple of things I want to kind of pick out there. One is about you've got a little kind of information quiz I'm going to call it on your website. I think it is a quiz and, and I did it before meeting you the last time and was kind of amazed at what I didn't know. And I have worked in the, you know, I'm a nurse as well. I've worked in health care for a lot of years and I didn't know kind of most of the information that was there. So there's that aspect. So there's a bit of about, you know, the information that people that probably health care staff aren't really aware of either. But the other thing that I wanted to pick up was the wellbeing aspect of the kind of the people that have been caring for the person that has died. So just kind of I don't want to forget to talk about that. So, I wondered if you kind of wanted, maybe talk about your, your, I’m going to say your quiz first of all, and how, and how people can find out a bit more about what is okay to do and what, what's you know, what's legal and, and that kind of thing.

**KC:** Yeah. So the quiz can be downloaded from our website. That's, that's got questions and the answers on the back. And that, that's just about the legalities really. And, and basically in Scotland, there are no legalities about what people can do after someone dies really.

**LI:** Okay.

**KC:** So, so we are much more free to do what we feel our instincts, you know what, what we want to do. So yes, so, so we can, I mean, and people do move, you know, we can move people around ourselves, take, take people home from hospital. We can look after people ourselves. We can arrange or a burial or a cremation ourselves. And so we can take complete charge of the situation ourselves. We're not necessarily advocating that because if someone doesn't have experience and it's the first time, you know, they really have experience of someone dying and if unless they have a good network of support around them, you know, that can be a lot to take on yourself. So we're not necessarily advocating that people do it all themselves, but maybe there's things that they really want to do and it is surprising when you speak to people and ask that question. Is there something you would like to do, you know, particularly for the person who has died? People do have instincts and they do have things, you know, and it can be all different. And sometimes it's I don't want them to be left in the, in a hospital. We're working with somebody at the moment who's her main concern is they don't want them to be, to have to leave them in the hospital once they die. And so, you know, how can they then pick them up directly from the mortuary? Do you know, and, and take them home?

But then there's some people that, that don't mind someone being in a mortuary, but they really want to take them home at some point before, before and then there's some people that don't mind at all. Do you know, that are quite happy to take somebody, but they want to do it themselves. So they want to take somebody directly from the mortuary to the crematorium, but they want to do it in their own van or their own car. And now, now there's also another issue in, in which is growing, isn't there about, about debt and about the cost of someone dying and how to pay for that? So there is an issue there that, that, that we do all need to be as health workers taken, taken account of that saying to someone contact a funeral director is actually, you know, a big cost for them. And even just taking the time to decide what is it you want a funeral director to do and what can you do yourself, you know, is and maybe, you know, maybe half and half sort of thing. The difficulty with that at the moment in our society is that funeral directors tend to offer a package of care. So it's a one price. And so it's finding, but, but again, if you take the time to shop around, you'll find a funeral director who will just offer you maybe, you know, transport or will, you know, just offer to maybe arrange a cremation. And now there's also a direct cremation. But you know, so that's an option as well that people have now if they don't want to get involved in filling in forms for, you know, or organising something, then they can, you know, that there are companies who will just take someone for cremation, but they can still have all the benefits of still having someone at home for that time.

So our quiz, our quiz is on the website for anyone to download. There's lots of information on there. There's also stories, there's videos we’ve quite a few videos now of stories from people, but also, there's also on our YouTube channel, which you can, the easiest way is to link through from the website. There's a video that we've made for empowering health professionals. It's just a short five minute video, which was kind of for like sort of team training or for, you know, for anyone who was interested to tell their colleagues about it. That's on, that's on our YouTube channel as well. And yeah, and there's, there's a lot of little, little quite short videos there to watch.

**LI:** And in terms of people's wellbeing, you kind of talked about that I think at the start about the importance of, for people's ongoing wellbeing that they're able to bring someone home or care for them at home after they've died or, or whatever, whatever that looks like for them and what, what works for them. Is there any kind of research around that?

**KC:** Well, the research, the research is that, that some people, it is very important to see someone after they die and it's an instinct and if they don't do it then they have regrets. They can and it can be long term regrets. Also, the other wellbeing issue is, as I said is, is knowing that someone has died, knowing that person has died and, and feeling what, what seems to happen is it, it's usually is three days, actually two to three days. It takes someone to realise that, and that was my experience as well. And I know that three days comes up in sort of old, you know, like the traditions, spiritual traditions as well. Three days is a time. So whether that is, you know, I don't know. Is it the way our, us humans are made? But that seems to be the time it generally takes for someone to get to the point of feeling like, yes, they've died. I remember going into the room when my auntie died after three days and just thinking, yes, she's died and it's okay. It's like, that's right. There's not a wrongness about it. Okay you know, there's still a grief process to, to go through and terms of, you know, missing someone and coming to terms with the grief of, of losing them. But to know that it's, that it's actually okay, I think is a big help in starting that process. That, that, that's what my understanding is. But and it doesn't take, and I think there's a worry as well that with people who, who are, who don't have the need to be with someone for that, if someone does, you know, if they'll, if they’re saying oh I don't want to let them go, you know, maybe that first hours after they've died, then people think, oh golly but if I don't take them away now, you know, they might never let them go. That's just not the way it works. Do you know that, in all, well it's certainly in all my experience, you know, generally after three days, people think, yeah, they're ready to let go.

**LI:** Right.

**KC:** And that's where certainly the people who've, who've talked to me about feeling like someone's been ripped away from them and they've just never really come to terms with, with, with the person's death. There's a whole bigger issue about the way we, we relate to death in our society here, you know, like, like the Lancet Commission report on death. But, you know, that's what, that's what they've said it's about what they're looking at bringing death back into life and valuing us, understanding the value of death. That's what we've kind of lost. And that's what they're looking to do is to rebalance, rebalance death, they say, because they, they feel that relationships and networks are being replaced by professionalism and protocols.

**LI:** Yeah.

**KC:** And that's, that's maybe that's kind of what we're addressing as well. And that, that dying be understood as a relational and a spiritual process rather than simply a physiological event. So a lot of what's in the Lancet Commission report, I think it's what we're addressing here, you know, sort of person, one death at a time really.

**LI:** Yeah. I hadn't really, I suppose thought about that, but, but, but talking about death as a, as a relational, is very much a relation, relational kind of process or activity or how can it not be, you know, how can it not be? And yeah, I suppose not being completely aware of how that, how that's changed and, and how there's, how we've, we've, we've maybe moved into professionalism and processes. And it’s interesting now and I also think about so my aunt died a year and a half ago in hospital. And I was really aware that we spent a lot of time in the room after she died and various relatives coming and going, we’re big family and lots of nieces and nephews coming and going to see her. But as a nurse, I became aware that we were taking up this single room in a very busy part of the hospital and starting to feel slightly uncomfortable that we kind of needed to move out of the room because they were probably needing the room for other people. And became a bit, I’m going to say obsessed by that and thinking we should really go, we should be going, we can't stay here any longer. Not that any of the staff at all at any point said, look, we really need the room back. They were absolutely great actually. Nobody ever said that it was my own kind of my, I brought my own kind of bias towards it really. I don't think bias is the right word, but my own issues around it. But nobody ever said that we needed to leave the room. And, and now when I look back, I think, you know, why, why was I so worried about that? Why did that, why, why was I taking on the businesses of the hospital after I had just been, you know, bereaved very kind of suddenly, actually and, and, and quite tragically.

**KC:** That's the nurse, the nurse in you.

**LI:** Yeah, it must have been, must have been. Yeah.

**KC:** Yeah. When I speak to staff about this, they often say, oh, but people, you know, people didn't want to stay long with them, you know, in the, in the room when they died in the hospital. But I think that's not really the point because, there is a video on our, on our channel as well about how our brains work, you know, and when, when someone dies, how our brains respond to that, even, even if it's somebody's been expected to die for a long time, we still go into a state of shock. And, and that's, that's the other reason why we, unless we're very, very well integrated in our brains, our limbic brain will take over and we really don't have access to any sensible thinking, thinking processes and that's the way that humans are made, you know, and we just have to live with that.

But the way to, thing to be aware of, I think is that, that that's why we say especially for carers again, for anyone really close, have a sleep, have a rest before you make any decisions. And in if someone's died in hospital, that's perfectly possible. People can go home. Someone can be in the hospital mortuary, you know, overnight until they make decisions about what they want to do. Because in those first few hours, it's not the time to be making decisions. You know, you're not thinking, you're not getting access to your higher functions, which in terms of fearlessness as well of moving forward, you know, you don't have, you don't have a access to that. So people are in a state of fear about their survival really, which if it's someone very close to us that has died, you know, that can be a, you know, a threat to our survival on some levels. You know, so that's how our brain reacts initially until we get a chance to sort of integrate and, come to terms with things and make, make sensible decisions for our longer-term wellbeing, which might be to spend time with someone or it might, it might not. But, but generally in our experience, you know, people, the people that need the time are the people that are quiet when someone dies. We call them the quiet, we call quiet voices. People have told me stories, particularly women actually is the reality who are not, not have no difficulty standing up for themselves or speaking out normally who have wanted, I'm thinking particularly right now Lynne of a woman who, who's, her gran died in hospital and she, her gran had said she wanted to be taken home. She was quite clear about that after she died. But when, when she did die, the hospital staff were saying oh no, you know, you can't be doing that. And, and her mum and auntie who didn't want to cause a fuss, they said, oh no, no, no, no, we won't make a fuss, you know, just forget about it And so she, she just went along with that and, and then it was a few years later that she spoke to us, saying how she was still regretted that she hadn't done that for her gran. And she's not, she's not somebody who has any trouble speaking up for herself or anything normally. But, but it's, it can easily be overruled, you know and...

**LI:** Yeah.

**KC:** …there are compromises to be made within a group of people of course, you know, there's compromises and negotiation to be done about what happens. But given the research that it's the people who want to spend time that have the regrets, the people who don’t…

**LI:** Yeah.

**KC:** …want to spend time, they just carry on, you know…

**LI:** Yeah, yeah.

**KC:** They don't, they don't need to be involved. It's the one, people who have regrets that we're trying to speak up for.

**LI:** Yeah.

**KC:** In, in terms of what, you know, wellbeing of our society really.

**LI:** That feels like, I know we're coming to the end of the podcast and I'm just wondering that seems like a really kind of lovely place to end where you've just said there the wellbeing of our society and that feels like a really, you know, good place to sum up this conversation. But before we do that, is there is, there anything that you've wanted to say that we've not captured that would be, that you'd want to kind of mention before we finish off?

**KC:** I guess, Lynne, just to say that if there are any, any staff listening to this, you know, who, who do say have any sense of the importance of it, that we are here to support them to have conversations if necessary.

**LI:** Okay.

**KC:** If, if they have a group of relatives, you know, this is really something that, that's easier talk to, really better talked about before someone dies.

**LI:** Yeah.

**KC:** Even if it's only in those in those few days leading up, you know, someone's maybe sleeping more, maybe unconscious. And those few days where, you know, waiting for someone to die and you're with family and thinking you're seeing a group of people, you're seeing somebody who's been caring for years, you know, having a conversation with them. You know, what would you think if it was possible for you to maybe take your mum or whoever home after they died for a few days, would you like to do that? Would that be important? Do you think that would be important for her? Do you know and just starting, there's a great opportunity for staff to be helping family with that negotiation. So if they're then seeing a person who's likely to be wanting to be busy and wanting to disengage and contact a funeral director, maybe just say, look, you know, you don't have to do that straight away. You know, you can look at your options, look at the costs even, contact funeral directors and see how much it costs. Think about, would it be possible for it to take, have you got somewhere to take someone to do you know, and maybe you could contact a funeral director and ask them, would they do it for you, do you know? So there's, there's stories in our, in our book as well, well, our book is written really for stories to inspire people, but also it has got all the information, all the practical information. If you do want to do this yourself, step by step, how to do it. So then people can think, okay, I might want to do that. I might want to do that myself. I wouldn't want to do that, you know. And so staff, there's a great opportunity for staff to be advocating here, you know.

**LI:** Yeah…

**KC:** For people…

**LI:** Yeah.

**KC:** …to get, get what they need. So, and we're here to support, you know, if one of the reasons really I started Pushing up the Daisies was because I knew as a member of staff, you know, I might not be on shift when someone died or, you know, so even if I'd spoken to them about this, I wanted some charity that I could say, okay, contact, contact Pushing up the Daisies. You know, they'll, they'll help you. And we, we support people right through the process.

**LI:** Okay.

**KC:** We can, we can discuss their options before someone's died or we also help people plan, you know, if there's people that, that want to plan for their own, you know, after their own death.

**LI:** Oh, right okay.

**KC:** We can, we can do that. The one caution, the last thing I'll say Lynne is that in terms of planning because now there is people are sort of doing more funeral planning. People don't tend to, it tends to be all about the funeral and they tend to maybe not want to be a fuss or they, they want to be just make it as easy as possible for their relatives. And so they, people generally in our society don't have an understanding that actually the relatives might want to be taking things slowly and spending time with them.

**LI:** Yeah. Yeah.

**KC:** So if, if anybody that's supporting funeral planning we would just say, I mean, again, on our website, what we do is encourage people to write letters and be not so specific. Maybe there's some things you might want to be so specific about, you know, especially like burial or cremation or, but not to be so specific that it doesn't give relative space to do…

**LI:** Yes.

**KC:** …what they need. So that, that’s our kind of concern about this planning that's going on that, that it can actually, you know…

**LI:** Inhibit…

**KC**…limit people…

**LI:** Inhibit. Yeah, yeah.

**KC:** …limit people, inhibit, inhibit…

**LI:** Yeah.

**KC:** …yeah, but certainly we're here and we're up for speaking to teams. We're doing that already actually in the NHS.

**LI:** Okay.

**KC:** We speak, speak to team meetings and anything that we're here…

**LI:** Okay.

**KC:** …to support.

**LI:** That's been really interesting. Kate, this is the second time I've spoken to you and I've, I have find, I've found it something that I haven't thought a lot about and I kind of work in bereavement. So it's been really interesting to, to talk to you again. And, and certainly hope that people enjoy listening to the podcast and finding out a bit more about it. So, thank you so much for your time today.

**KC:** Thank you.

**LI:** Thanks, Kate. Bye, bye just now.

The podcast was recorded in January 2025 and can be found at <https://www.sad.scot.nhs.uk/podcast/> or <https://open.spotify.com/show/11AORpjHqbsYwgg1DJUtLk?si=687dba351d1f45d4>

For more information visit [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk) or contact supportarounddeath@nes.scot.nhs.uk

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