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**Talking about Bereavement Podcast Series - Transcript of ‘The Individual Compassionate Space in Bereavement’ Podcast**

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**Speaker**: Sandra Campbell, Macmillan Partnership Nurse Consultant (Palliative & End of Life Care), Scottish Ambulance Service

**LI**: Hi, I'm Lynne Innes. I'm a Senior Educator at NHS Education for Scotland, otherwise known as NES, in the Bereavement workstream. In this podcast, I'm going to introduce you to the work that our team does, share what we do, and also share our learning. So what is NES Bereavement? When I ask this question, sometimes people aren't sure what we do. However, in essence, it's putting people at the heart of bereavement care and our aim is to support health and social care staff to do that for the people in their care. We know that evidence suggests that person centered care and bereavement matters as it improves people's experience, and bereavement care and the communication around that with those who are bereaving is core business for many staff groups across health and social care. It's also known if it's poorly handled, there can be the risk of causing additional harm and that subsequently might have negative impact on staff wellbeing. This is a short introductory series of podcasts, which will look at the compassionate space and bereavement. I'll introduce three guests from different parts of Scotland who are all working in health and social care and ask them to share their thoughts and reflections on that space for us as individuals, teams, and organisations.

**LI**: With me today for our first podcast in the series on the compassionate space in bereavement is Sandra Campbell. Sandra is a nurse and is currently working with the Scottish Ambulance Service as Macmillan Partnership Nurse Consultant in Palliative and End of Life Care. Prior to that she was Macmillan Consultant Nurse in Cancer and Palliative Care at NHS Forth Valley. Sandra has had a long and extensive career. She qualified in 1981 and has gained lots of experience in a variety of care settings and throughout that developed a passion for cancer and palliative care, with a particular interest in the value and power of good communication. What she found was that in her strategic role as Nurse Consultant, both in her previous post and her current post, allows her to fulfil a vision of really making a difference to patient care by working with many teams, providing leadership on initiatives in cancer and palliative care. She studied at doctorate level for five years and served on the UK Oncology Nursing Society Board for six years. And she was also on the Board of the Scottish Partnership for Palliative Care, and she's currently on the Committee of the RCN Pain and Palliative Care Forum. She believes strongly that kindness and compassion are at the heart of the human connection. And throughout the pandemic, she's been really touched by the despair that she sees in bereavement, but she believes strongly that nursing can be the voice for those whose lives have been so damaged by this tragedy. And so we will go on to talk with Sandra about, how she sees the role of self-compassion and the bereavement space.

**LI**: Welcome to this first podcast on compassion and bereavement. And I'm really pleased to be joined by Sandra today, who is going to focus on self-compassion and bereavement. So welcome Sandra and thank you for joining us. How are you today?

**SC**: I'm very well thank you, and thank you for giving me this opportunity to speak about bereavement, something I feel very passionate about. So, thank you very much.

**LI**: And as, have you had a good morning today?

**SC**: Yes, I’ve had new sofas delivered this morning and I've put my dog in the crate, so we should get nice peace and quiet for the podcast.

**LI**: Hopefully your dog will get out after the podcast is recorded.

**SC**: Certainly will.

**LI**: Thank you. So, I suppose what we're thinking about is what is compassion in bereavement, and particularly for health and social care staff who are often dealing with bereavement on a daily basis and their different roles. How can we support them or enable them to be self-compassionate in bereavement care?

**SC**: I honestly believe it's about letting people know it's okay not to be okay sometimes, and to be distressed perhaps, that when someone dies who they have cared for, for a long time, or even for a short time, or if they're particularly affected by a particularly difficult death or whatever. I think raising awareness about the, the potential impact that bereavement can have on people, and I think you know, it's important to, you know, have education around bereavement and it's yeah, grief is normal, however, it certainly doesn't feel normal to people when, you know, when when people experience intense grief. And I also think that there's no words to describe it, to be honest, for some people. There are no words to describe that intensity or the depth of the, the sadness or despair for some, or the impact for some people. So I think that raising, to raise awareness around bereavement is really important and the potential impact on on people and you know, if we don't support people, if we don't provide support, if people are are not given that space or that time to talk about the individual or talk about how they feel around that loss that that, you know that horrendous loss sometimes, then the risk is that we will lose more staff. You know, people will leave and and we know that from different reports that people, you know, people do, they will leave, they will not continue to, you know, want to work in some places if they are really struggling. And I think that it's important to be able to provide support somehow to allow people the time, the space to talk about their, their experience and to share with others, you know, and to know that they're not alone in that, in that grief or that horrendous experience, especially what we've seen throughout COVID and the multiple losses that some areas have have experienced. I think it's vital that we have networks in place, that we have, that we give people the opportunity to be able to talk and to understand that sometimes it is difficult to face the day around, you know, potential for, you know, for other people are going to die, and they’re, they’re in place of, wherever they are working.

**LI**: And one of the things I noticed you said, you said it a couple of times there is about picking up on how, that people have the space to be self-compassionate to themselves and in a busy, you know, NHS or healthcare environment, we know that, you know, we know just now that that's hard for people to find the space. So, I suppose I suppose that's how how do we support them to find that space?

**SC**: Sometimes it's even even just allowing someone to, you know, if you're over a cup of coffee, it doesn't have to be a formal thing. I think that, just when people feel, don't push or pull, you know, allow people that, just the opportunity to talk and certainly not to ignore, you know if something. I think the really sad thing is in health and social care is that, you know, a member of staff or someone may be dealing with a really difficult death, or a, or something they feel really struck by, really sad by, or sad about rather, sorry, but then they're off to the next patient, they're off to the next client, they're off to the next person and there's no time to really process that. And I think that if it's, if managers could possibly just, just allow that bit of flexibility for some staff because, and just check out that people are okay and that that they're managing. And I think sometimes if you give that opportunity, then perhaps people will feel less pressured if you like, if they do need an hour or two off, or just a bit of a break, if it's possible. I fully understand with shift, rotas, etc etc it's not always possible, but I do think that we could build in a bit of flexibility around bereavement and recognising that if we give the right support around the time or provide that space or whatever you want to call it or, you know, around that individual, then it does allow them to function in social, you know, socially better in months and years to come. If we don't provide that correct support, then the the impact on society as a whole, you know, there's increased visits to GP, there's increased anxiety, there's increased stress, increased mental health and poorer quality of life for people.

**LI**: Yeah, I suppose it's thinking about that space and about maybe, people being able to support them, to have some time out or whatever it is. How, how do we, kind of ensure that we do that well? And I know that we've had the UK Bereavement Commission recently speak about some of this in their report and we've got recommendations specifically in Scotland. But, it’s that kind of, how do we, how do we do that well as a, as a, as healthcare staff?

**SC**: I think it's about, about being open and honest with people. I think the Bereavement Charter will definitely help if organisations sign up to that, I think that's, and it it, it definitely is about raising awareness, letting people know what is available, if they, if they did feel they required more formal support. But if people are given the, if people are given the right support around the time of that death, so if they lose a member of their significant, loss within their own family, and that perhaps they've got some time off. If we could be more flexible around that and allow them to, you know, if we could just take a bit more of a flexible approach to how people return to work or, or are in their workplace. Clients, community clients, some of the you know, some people are working with, you know their clients, they have their clients for many, many years in some cases, and then that person dies, and there's a real attachment there. So, so it’s how do we, you know, prepare if we, if we are having, you know, if we've got staff who are managing the care of the dying for example, then have have them included in that process around the conversation and preparation around what we expect to happen around the time of death. So that's in a, in a more, in a more controlled thing if you like, where, where where there's you know, people, I’m thinking of people in the community, we're perhaps working with people for some time and involve them. I think if they're involved and they, then that would make a difference to how they, to how they cope perhaps, and if they're more aware of what to expect. I think if we support staff in understanding, you know about care of the dying, about how to, how to manage the time of day, how to have conversations. If we could support our staff to have these conversations and to be able to care in that respect, then that will help. I do believe that will help them. But equally we need to be able to support them as a human being themself, and each experience is unique to that individual. So, so even if you've experienced, you know, you know, even if someone has experienced a a particularly difficult death within their own life, it does not mean to say that, that person they're working with or or or team that they're working with will be will experience it in the same way. Each experience, each experience of grief and bereavement is unique to that individual as a human being. And, it's about recognising that, you never know how someone else feels but, but we can certainly, that compassion and understanding of how difficult that might be, for that family or that person is is important, but also how is it for you? You know, how is it for you as an individual? How do we help them to to to seek support if that's, if that's required? Or as I say, just give them that space, even over a coffee, time, time out, whatever it might be. But raising awareness within the organisation, whatever organisation that you know that people work in, if managers, if senior people can, can have a culture. It's about culture really, isn't it, it’s about a culture, a cultural shift.

**LI**: Yeah, I was just thinking about you talking about the, each, each bereavement is unique and individual. And, but there's something about keeping the person at the centre of that,

**SC**: Oh, absolutely

**LI**: isn't there? That's, what's what's kind of fundamentally important, and and maybe reacting or not reacting, responding to that person and and, their, what they need at that moment in time. And we talk about bereavement on grief, not well, grief specifically being a process, that's not linear.

**SC**: Yeah, absolutely

**LI**: We hear that a lot, you know, where we, and it doesn't follow follow any kind of hierarchy either around it, then it might be, it's very different for different people and I, I just wonder suppose if that's a, an element of helping people to be self-compassionate,

**SC**: of course it is

**LI**: thinking about grief in that way?

**SC**: It’s about understanding there's no right and wrong way. You know, I'll say to people there's absolutely no right or wrong way to, to grieve or or what you know, what what what you feel, there's no right and wrong there. And it's okay to feel as if you're going off your head sometimes in fact, you know, and sometimes, you know, we say take one day at a time, sometimes when they're in that really dark hole, that really dark place, it's about an hour at a time, it's, you know, not just a day at a time, it can be an hour at a time and it's about trying to find something to find some hope, somewhere, you know. And some purpose, because sometimes there's a complete loss of purpose for some people. What's the point? There's no future, if they've lost their, you know, lifelong partner, or they're left completely alone. Loneliness is a massive problem, and we know that. How do, how can we help people and make that move? It's how you support them to be able to do that, you know. I, I think that it's about noticing. I, I like to think about compassion around it's, it's about noticing, feel that you notice that someone is distressed, or yourself. You could treat yourself in the same way. You notice there’s something not right. It's about what, and you feel something about that, but then you need to respond as well, not to ignore it, you know. So, it's about understanding and helping. If we could just raise awareness across society really about the importance of talking, not ignoring when someone has died, because often that you know, you know, that's often what people say. Oh, nobody, they didn't know what to say, or they crossed the road or felt ignored. I felt embarrassed or whatever. And and I would also say to people, this is from a personal experience, often people will say we'll go for a coffee or a coffee and a cake or whatever and and you find yourself in the middle of a restaurant or a busy cafe, and then tears will come and go because they'll be in that grief moment, there will be tears one minute, there might be laughter the next because it's the, you know, the emotions so up and down. And I would advise to sit in the corner. Don't not go in case you're going to cry, but sit in the corner. It's quite okay to, you know, to have tears. Just make sure you've got a tissue, and and and be in the corner where it's not so public. Because, you know people will be, you know, you don't you want, you don't want people to feel you're being stared at, or people being stared at. However, people are kind and I think that kindness, you know, kindness and compassion really go hand in hand, don't they? And we all need that. Everybody needs that. We need to show kindness to other people, but we also need to be kind to ourselves. If it's too much effort to do everything in one day, just small goals. And I would say that to people. I’m not a Counsellor, a Bereavement Counsellor, but certainly a lot of work with people and spoke to a lot of people who've been bereaved over the years. And it's about small steps, baby steps sometimes, just small goals. Set yourself a small goal. They’ve maybe not been able to go out because they're frightened they’re going meet people that they've not seen before or seen since their loved one has died or whatever, and they just can't face another day of these questions ‘oh how’s so and so’ and you know, so, but it's just about small baby steps and about goals and, I also say to people, you know, life’s a journey and I know that sounds a bit twee, but actually, you know, life is a journey and none of us really know what's ahead on that road and we can be ticking along just fine and then all of a sudden, something happens - there's a major trauma or someone dies, a a tragic bereavement or a diagnosis of a terminal illness or, or something that's very unpleasant and we're on a different path. We find ourselves on a different path of life. And it's not one that we would choose to be on, but you've got no choice. So, it's about how you find coping strategies, whatever that might be, friends, family, good supportive work colleagues, whatever it might be, we find some way to be able to cope and get hope in amongst there. You know, there has to be hope and purpose for someone's future and try and improve their quality of life as much as possible. And their ability to function socially, you know, as well. You know that, I mean, we all know that, if you don't get the right support then people will not be able to function in society and get the best out of life. And it's about learning to live without that person, you know, and so.

**LI**: Yeah, I'm really struck with what you're saying about hope and purpose. Obviously, I work in spiritual care as well, and so that's a lot of what we do is around helping people to find hope or or explore their hope or their purpose, but also the other thing you said there, which I thinks really important in self-compassion, is listening. You didn't say listening, but you were talking about listening, you know, in the coffee shop or with your colleague or with your friend. But that kind of real value in listening. And that’s, enabling people to have self-compassion when when they can listen with one another.

**SC**: Yeah, yeah. I teach about listening too, I can't believe I forgot that, to say that, that's terrible. But actually, yeah. And it's about actively listening as well. It's about listening to what they don't say as to where, you know, as you, what is, what's their body language telling you? What are they, you know, saying with their hands or even their face, or their eye contact, whatever it might be. So, all those, all those skills, if you like. But they come naturally to a lot of people as well, you know. I think it's that, it's having that human connection, I think if you can make a human connection with somebody that makes all, that will make all the difference. And that will help that person on their darkest days you know, if they're having a real struggle, if people are just kind and and and as you say, it's that listening. Let them talk about the the person, the individual or whatever, you know.

**LI**: Yeah, yeah.

**SC**: And not to be, the other thing as well, if we're talking about work-related things, I think, I don't think we should be, well, we definitely shouldn't be critical of things that have maybe you know, say there's a traumatic thing or something that should have been really difficult for the staff, let's not be critical about it. As you know, reflective practice, we learn from things, but don't beat ourselves up. You know, we've all, I've came away from situations and I've thought, oh why did I say that, what did I say that for, that was not the right thing to say or, you know, and you think why? And sometimes you just can't find the answer, you just can't, you know some you might be asked a question you just can't, you think what I'm going to say to that? And sometimes conversations are so difficult. I’ve found myself in, in, in a very extreme case, saying to someone, ‘I'm very sorry we're having this conversation’. Because I was. And I was struck by, you know, if things are so difficult, so tragic, whatever, sometimes there are no words to make it better, it’s just the being there. It's that, and the use of touch as well, although COVID put a bit of a sharp stop to that at the time. And I suppose some people are still a bit nervous about that but, but I do think that you know when you've made that connection; David Reilly talks about, the dance with someone. I don't know if you've seen his work, you know, and you may want to. It might be appropriate to touch, it might not, and you will get the feel whether it's, you know, the person will let you know if that's. I think everything should be person led, or client led, and once you start to talk to someone, you get that feel around what, what, what’s right and what might not be right, and what's appropriate or not appropriate. But definitely, it's just about being there for people, being in the room. The Chief, I’ve forgotten his name, the Chief Medical Officer talked about that once, many, many years ago, and I like that phrasing. You've read about that, and seen that, you know. Being in the room, really truly been in the room. Not got your face on a computer screen and you're not looking at the person, you know, just just the way you are around that person,

**LI**: About presence, isn't it?

**SC**: Absolutely. Just the whole, all the

**LI**: Being present

**SC**: …poor communication skills. But, but apart from that, it's around that, it's that human connection. Let that person know that you really do feel for them, you know, in their, in their difficult circumstances. But also to know that it will not always be as difficult as it might be on that day, and that's not about saying time’s a great healer, because that's not a good phrase. But it's just, about that it won't always be so difficult. That'll be, hopefully your hope, that that intense distress will be less and less, you know.

**LI**: And so I suppose, self-compassion in bereavement is about going gently, isn't it, with yourself. And and, there's something there about you've said human connection quite a bit, there's something there about that human, our humanity in that, in that moment with one another.

**SC**: Yeah. And to recognise when you're not having a good day yourself, you know, to recognise and not to push yourself and not to be too hard on yourself either. That's the, you know, and just to be honest. No, I can't do that today or I can't, you know, I can't do this or I can't go that or I can't do this for you today. I can do it tomorrow maybe, or let's plan for next week, but I can't, I just need some time today. Whether that's to be, to go to the grave or whatever it might be that you need to do. Or you know things that people have to do and like you said that people talk about grief being a process, but it's, as you say, it's not a, it’s no linear thing in it. I like the Stroebe work, oscillating. You know, when it comes and goes. And I think that, that's a really good model where, you know, things come and, you know, thing, you, you, your emotions can come and go, and you can be, you know, comes and goes. There's no linear thing there. And again, no right and wrong. And I think it's important that people understand that and know that. And that that it's okay not to be okay.

**LI**: Yeah. I think that's a good place to finish, Sandra. We started off with, it's okay to not be okay, and now we're finished with it's okay to not be okay, so that's the I think that's a, a lovely way to finish. There's been so much in there to think about. Thank you so much for taking part in this podcast. We're really grateful to you, bringing your support and experience into this space for us.

Thanks to Sandra for her reflections today. I hope that you've enjoyed these reflections on the self-compassionate space in bereavement. Our next podcast will focus on team compassionate space and bereavement with Andy Gillies. Please join us then.

The podcast was recorded in February 2023 and can be found at <https://www.sad.scot.nhs.uk/events/podcast-series/> or <https://talkingaboutbereavement.podbean.com/>

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