



Speakers:

- Caroline Pretty - Bereavement Coordinator, NHS Lothian
- Derek Brown - Lead Chaplain, NHS Highland
- Mark Evans - Spiritual Care and Bereavement Lead, NHS Fife

Mark Evans (ME): When an individual dies, it becomes like a ripple effect in a pool. There's those who are closest to the patient, but then, it also impacts the staff and those who are caring for the person, and ultimately, the wider community.

Caroline Pretty (CP): It's good to help families understand that they might need practical, as well as emotional support. And that can be all sorts of different issues some of which can feel a bit embarrassing sometimes if it's to do with money or not being sure how to go about doing things after someone has died.

ME: We are not mere practitioners that come with skills and interventions. We are human beings who come with our own hopes, our own dreams, our own sadness's, and our own fears.

Derek Brown (DB): Our care of the individual doesn't stop at the point of death because life goes on, therefore, our care must go on too.

DB: I think it's important to focus on everyone who's involved in the death of someone, mainly because we have to attend to the needs of the family, but also, not neglecting our own needs as professionals. We may have had a very different relationship with the individual who's died. It could be over a long time, over many months, perhaps even years, or it may have been very intense and short-term at the end of life in a trauma situation perhaps. But nevertheless, we have feelings and emotions that need expression somehow.

ME: Don't be scared or afraid of what you feel. You came into this job because you wanted to care. And if you're going to care, you have to give part of yourself. And when a death occurs, that part of yourself will be hurt. Therefore, it's really important that you acknowledge that, and you give yourself permission to grieve the loss. We also have to give our colleagues permission as a team. And by doing that, we are able to talk about the person's life. We are able to talk about our own emotions, our own doing that, you can then build your resilience to carry on caring.

CP: Those of us who work in caring roles- have come into these professions because we want to look after people, literally because we care. And I think it's absolutely natural to show our care and concern for people. And what I've also found is that families value that. They appreciate our genuine feelings, that we're alongside them in their moment of loss and that we can relate and empathize with what they're going through.

DB: I think it's important that we, as far as we are able, can display a degree of empathy to those who are grieving. And it's not a sign of weakness or not able to cope if we're showing our emotions within reason, we still need to do our jobs, of course. But I distinctly remember that being brought home to me many years ago in intensive care, sitting with a family whose loved one had just died. And the nurse who was doing what she was needing to do at

that point, stopped to just wipe away a tear from her eye. And when she left the room, the family just explained to me how much that meant to them, that here was someone who cared for the person who died, and by extension, cared for them as the family.

DB: No matter what the circumstances are of the death of someone, it's important that we don't pathologize it, i.e., make it another condition to be dealt with. We have to be aware perhaps of our triggers as professionals caring for someone who's the same age as us, or our own child, or something. And recognising that, acknowledging these things as real, and not making that too difficult for ourselves or for those that we care for. In the immediacy of a moment where there's things that need to be done, adrenaline rushing, and all the busyness of attending to perhaps a crisis situation, it's easy to focus on the tasks.

And perhaps on reflection, we realise that "Oh, I wonder if I did everything the way it should have been?" or "Was that really the best I could do?" or "That situation was actually horrendous. I'm just finding it difficult to comprehend what happened there, to come to terms with that, not to leave those feelings inside that can sit there, and cause problems later."

ME: So, take time, take moments out, take a break just to accept and to acknowledge what you feel, and how that person's life has impacted on your life, both professionally and personally.

One of the things we've noticed during COVID is the impact it's had on those staff who have had to work in new or different areas. There's a very basic thing that if you move areas, the people you work with, your support structure is not there. But there's also the more obvious, that you might be working in an area that you're not used to, you're working in a team that you don't know, that you're dealing with new experiences and new events which you might not have been prepared for. All this impacts us, and usually, negatively. We have also seen high levels of deaths which some people may not have seen in the areas they normally work in. It can often leave us feeling a whole mix of emotions. Guilt that we might not feel good enough. Pain at the amount of deaths we see. Sadness under the circumstances that we work, so we are not able to have visitors or relatives at the bedside. And that makes us question our work, both personally and professionally. So, it's really important we support these staff.

CP: It's a real privilege to work with people around the time of death and in bereavement, but it's also important to understand that grief goes on beyond that point, and our care needs to continue as well.

DB: Care of an individual after they've died is just as vital, just as important, and just needs that attention to detail in the same way as the care of someone who is still living. And there's many ways that we can do that. Just giving people time to get used to the idea of someone having died, being able to stay in the room for a while, attending to any cultural needs. It's vital that we think of what will help families in a situation where someone has died. And there may be rites of passage, for example, that are necessary for certain individuals. And sometimes we get a bit anxious about that and think, "Oh gosh, I don't want to do the wrong thing. "But we can never do the wrong thing if we ask the family, "How can we help you do this? What are the things that you would like us to do?"

It's quite difficult for people to think, "What is it I'm going to say to these people who are newly bereaved? "Every family's different. So even if you've done it a number of times before, this is a new situation you're going into. But perhaps acknowledging the loss. "I'm really sorry that John has died. "If you mean it, it comes across in that way. And perhaps even talking about the person if you haven't known much about them. "Tell me about John. What did he like?" "Would you have had his hair parted on this side or the other side? "As you're doing things after death. What do I not say? Well, you wouldn't say: "I know how you feel. "None of us can ever know what someone else feels unless they share that with us. We don't want to share our experiences either. They don't want to hear about them. Unless of course, we're asked a direct question about it.

CP: I think it's absolutely normal to find it difficult or uncomfortable to talk about bereavement, but it's really important that we try to be as clear, and straightforward, and honest as possible. I recommend using words like death, dying, and died, because otherwise, we can use euphemisms or terms that maybe aren't clear or helpful for families.

DB: Nor can we come out with perhaps what people would say were platitudes, "like time's a great healer", things like that, which, well, what does that mean? Time in itself, doesn't heal anything, but time with the appropriate support, and acknowledgements, and resources can actually make a difference.

Other things that we can do are more practical perhaps, like simply completing the medical certificate of death in a timely fashion. Handing over the belongings of that individual respectfully, in something that's not a plastic bag. So, there's lots of little things that we can do. Those little things make a huge difference.

CP: It's really important that we help people to understand that they may well need practical, as well as emotional help after a bereavement. It's totally normal and natural to ask for that support from family and friends. And it can really help people to cope. And most people cope without specialist counselling and support services if they've got a good support network around them. Sometimes the type of things that people might be worried about can feel a bit taboo or a bit stigmatising. Often it starts with funeral arrangements. People might not have organised a funeral before, be unsure how to go about it, what the options are. And they might be worried about the cost of a funeral, which can be considerable. If a person's been a carer for a long time, they might have particular practical concerns, whether that's about their financial situation, if they've been in receipt of benefits which are going to stop. Or if they've been out of the job market for a long time, they might have concerns about employability, finding work, and financial issues that come along with that.

I think it's helpful to give people who've been bereaved information and resources to give them an idea of some of the sources of support that could be available for them along their bereavement journey. That might include emotional support, but also services, like money advice, welfare rights, housing support, or organisations who can help with practical tasks. That gives people almost a kind of toolkit for living with bereavement.

ME: Sometimes when a patient or a service user dies, we can be good at caring for the patient or the deceased of the family. We are mindful of the needs of staff. But it's not unknown for us to overlook the needs other residents or other patients, patients and residents who will have known the deceased, who may have experienced? Or heard the death, and who will be impacted and grieving themselves. As such, it's important that staff are honest about where they are and what's happened. Particularly in a hospital setting, curtains are not soundproof, and they don't stop other patients hearing or seeing what's happening. After a death, it's important that we acknowledge what's happened. And sometimes, acknowledge the impact that will have on the team. So, for example, it may be if there's been a death on a ward and an arrest, but afterwards, we approach other patients and explain what's happened, explain the patient's died, but also, explain that the staff might be working a bit slower or might be a bit more upset. And for the patient to have some patience with us.

DB: Be yourself in these situations. Bring your care, your compassion, your human empathy. That's what people need. By being attentive to the needs of the family, by recognising your own needs, and by dealing with all this, you can create something that's very special for the family, a legacy if you like, that they will remember long afterwards about the care and compassion that you showed in a time of great need for them.

ME: Each individual death has an impact, not only on the immediate family, but on the staff and the wider community. We must acknowledge that. And we must recognise how that death impacts on us, both personally and professionally, so that we are well, and in a good place to move onto care for the next person.

CP: So, it's a real privilege to be involved in supporting people around about the time of death and bereavement, but the ripples of grief continue out into families and communities. And we all have a role to play in supporting those we care for, those in our families, our friends, and our communities in grief. There's always something that we can do to help, whether it's emotional or practical support.

Grief is something that doesn't just end for people. It continues and we live with it, sometimes our whole lives. So, our care needs to continue as well.

The film was produced in August 2022 and can be found at www.sad.scot.nhs.uk or <https://vimeo.com/736794504>.

For more information visit www.sad.scot.nhs.uk or contact supportarounddeath@nes.scot.nhs.uk

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