**NHS Education for Scotland**

**Transcript of ‘Rituals, Memories and Preparing for Death: Exploring Good Practice and Barriers’**

**NES Bereavement Conference 2021 session recording**

**Speaker**: Mark Evans, Head of Spiritual Care and Bereavement Lead, NHS Fife

**Chair**: Andrew Gillies, Lead for Bereavement Services, NHS Ayrshire & Arran

Andrew Gillies (AG): Welcome, everyone, to this session on ‘Rituals, memories and preparing for death: exploring good practice and barriers’. My name's Andy Gillies and I'm facilitating the session for Mark, who's going to deliver the content on it. Just before I formally introduce Mark, I wonder, on a day like today, when there are so many inspiring stories that, that have a huge impact on us, and when there are also some wounding stories, how it is that we are grounded enough that we can flip from session to session and that we can actually leave today carrying something forward that we need, something forward that's hopeful, and something that makes the world better in some way. So, I wonder what it is that, that you would do, what you would call your centre before the session begins. My invite to you is to just take three breaths and with each breath that you take, let them be a slow breath, imagine that you are returning closer to your centre, to your here, and that you are ready and able to hear what Mark has to say and share, and you are ready to hear yourself. So, on your first breath, just breathe in. Returning to your centre to hear this work.

Mark is, there's various things in Mark's bio that you'll see, but Mark not only exists as a, a Lead Chaplain for a acute health board, but he is also the Chair of the National Professional Leadership Group for Spiritual Care in Scotland, an honorary lecturer at St Andrews University, on the topic of bereavement, contributed to various national programmes, events and documentation. And the list goes on, but Mark is also a hugely cheeky and, and fun man with a big heart. And I think the greatest accolade that I can give Mark as he facilitates and takes us through this session is that I know there were someone who deeply mattered to me in need of a ritual, in need of support around memories, or to prepare for death, it would be no concern of mine to have Mark come along. It would be an honour and a privilege. So, here's Mark's session on ‘Rituals, memories and preparing for death: Exploring good practice and barriers’.

Mark Evans (ME): Thanks, Andy. So, I'm not sure how I got into bereavement and grief in a professional capacity. But I suppose, one of the, the main triggers for me was when my granny, who brought me up, died. And I was just, I noticed very much about how that was handled by the nursing staff and the medical staff. And I just wondered if we could do it better and it’s really became almost a passion for me. One of the lines I often use is from Lord of the Rings when I'm doing teaching with the students. Gandalf the wizard says at a parting, "I will not say: do not weep; for not all tears are an evil." It was Saint Augustine who first wrote some centuries ago following the death of a friend that his pain flowed as tears from his eyes. And those tears made a pillow on which his heart rested. And I think there's something very powerful about the tears we bring and the tears we share at the time of a death.

We all know there's many models and different explanations about what's going on around death and the grief process. I'm sure, like many of the people in the conference today, when I done my training 30 years ago, we used Kubler-Ross and we almost used it as a checklist. But, of course, 30-odd years later, we now know that there is no such thing as a set pattern, but rather grief and the journey of grief is unique to each and every one of us. But one of the things I still find helpful is Worden's Four Tasks of Mourning. The need for us to accept the reality of the loss. The need for us to process the pain of the grief. The need to adjust to the world without the deceased. And the need to find an enduring connection with the deceased. And I would suggest that, through appropriate ritual and rites and listening and honouring people's stories, we can help them work through these tasks.

So, why do we grieve? The main reason we grieve is, it helps us try to make sense of the new world. It helps us make sense when the person we loved is no longer there. But perhaps more importantly, a world which no longer makes sense to us. And we have all heard that with parents whose children have died, and they will tell you it is abnormal, it is the wrong order, it goes against nature for a child to die without their parent. We also see it in couples who have been together for decades. Where one doesn't know how to shop or even cook or do the washing for one, so does still shops and cooks for two.

But grief eats away. One of the things I learnt when my Gran died was that I used to tell people "time heals". And I realise now that that's a lie. Time allows us to cope with it, it doesn't heal it. And every anniversary, every Christmas, every significant event, it's like somebody picks the scab and it's as red and raw underneath as the day it first happened. However, we can help people make sense of the new world and the new order in which they live in. And it's important that we do.

One of the unenviable jobs I have is I am often asked by our patient complaints team to be the reviewer for complaints around care at end of life. And one of the things I've become very aware of is that when we get it wrong, the consequences of that are far-reaching. It stops the bereaved people engaging with us. If they are having treatment or if they are ill, it can adversely affect the treatment or recovery. And it generally affects their wellbeing. Where rather in grief, we find they are suffering from anger and bitterness. And that then affects the people around them as well. However, when we get it right, where we show empathy and what I would suggest is good person-centred care, those who are bereaved and experiencing grief can be supported. They can be supported in their new world to find a new order and to re-establish meaning, purpose and hope.

A few years ago, I was doing a home visit for one of our patients from the hospice and his daughter had just found out she was pregnant and been to her first neonatal class, and he said to me, "Look at all the books there. She gets a book on everything, telling her everything she can expect, everything she has to do, and everything she has to prepare over the next nine months. I'm dying, I get nowt." And I said to him, "Well what do you want? Do you want a handbook?" And he went, "Yeah, cos no-one gives you a Haynes Manual." When we work in healthcare, death and the dying process can almost become second nature to us. I remember, as a student nurse, hearing my first patient Cheyne Stoke and remember how scary and frightening it must be. Now I hear on a regular basis and I don't even bat an eyelid. But I'm used to it. And many of our families and carers, sitting with someone dying, they only do once, so it's important we get it right. Yet, we do live in a society where death remains one of the last great taboos and the process surrounding it is often shrouded in myth and mystery, so people assume death will be painful... People think it's scary... And yet, for most of the deaths I'm involved in, they are peaceful, and quiet, and in some way uneventful. Where the death of a patient is a regular occurrence for us... for those who loved them, it is a unique event and, hopefully, only once, experienced once in life. Yet, those who care for those who are dying are often unprepared. And I would suggest that one of the things we have to do at the very beginning is prepare people for what happens at death, and that we prepare people properly.

This is just a wee... poll that was done in California. 80% of people say that if they were seriously ill,

they would want the doctor to talk to them about end-of-life care. And yet only 7% reported that they had an end-of-life conversation with their doctor. 90% of people say that talking with loved ones about end-of-life is important, but only 27% of them have actually done so. I have been with my husband for 32 years and the first time we spoke about his death and what he wanted for his funeral was at the start of Covid because he had to go into shielding. And in some ways I thought it was quite sad that it took a worldwide pandemic for us to sit and have open and honest conversations about what we wanted around the time of death. But people are still, I suspect, scared and unsure and uncertain about talking about it. So, things like bereavement cafes, grief cafes, death cafes, they allow people permission and the space and the time to have those honest conversations. But, as healthcare professionals, we also have a responsibility and a duty to encourage and support people in these conversations.

If you have never seen this book, I strongly recommend it. It is produced by Marie Curie, you can download it for free from their website or you can buy printed copies. And it is almost a Haynes Manual about what happens... in the last few days and hours of life. So, things like is there an anticipatory care plan? Telling the family about changes to diet, to bowels, to bladder. How many of us have seen family trying to put soup into to the dying patient because they need to keep their energy up? When a patient has terminal confusion or restlessness or agitation, it can be scary. The patient whose hands are cold, so the family puts on extra covers and makes the patient uncomfortable. Increased sleeping. Bedside vigils, also an interesting one, where people camp out, and I often say to people, "Remember, it's not your choice if you are here when Mum dies, that's Mum's choice. And to protect you and because she loves you, she might decide to go when you're not in the room, when you're away for a fag or a coffee or your bacon roll." And that simple conversation stops a lot of guilt later on down the line when people say, "I wasn't there."

The other interesting thing is the process after death. What do we actually physically have to do once our loved one dies? I have lost count of how many times I've been asked, "How do you order a coffin?

Where would I get a wreath? How do I register the death?" Families will assume, as healthcare professionals, we know the answers to these questions. Therefore there is also a responsibility that we are prepared so that we know what the processes are in our local area after a death. But those processes have been changed as a result of Covid.

One of the most moving things that I have seen through Covid was a play up at Pitlochry called Requiem for Covid. And it was an interactive play where those who were present were encouraged to pick up a stone. The play described grief as a journey carrying the stone and the audience were invited to take the stone away with them and that they could put the stone down at any time if they so wished. In the same way they could lay their grief down. A simple but profound act. A simple but profound ritual. Which brought healing and peace to many in the audience. Since the very dawn of time and the pyramids and Stonehenge, humanity have looked to religion and faith to try and answer some of the deep questions about what it means to be human. About laughter and tears, about life and death, health and illness. And many of our organised religions are rooted within particular traditions and will have specific rites or rituals which will be expected around the time of death. And such rites and such rituals, for some, helps them interpret and make sense of their experiences. But just because somebody claims to have a specific religious belief doesn't mean they will follow all the doctrines or practices of that religion.

This is a painting from a mediaeval prayer book showing the last rites. As a duty chaplain, it was something I was frequently phoned for in the middle of the night by A&E or Switchboard asking to see or asking to arrange a priest to come in and part of me used to want to say yeah, but the problem is the Roman Catholic Church hasn't done the last rites for years, if not decades, at least since Vatican II. We could arrange sacrament of the sick. So, what people think they need and what people think they want and what is available is not always the same. However, such religious or spiritual rites can have a huge influence on how people recover and deal with their grief. A good example of that, I suspect, is for those women who have had a pregnancy loss. We supposedly live in an increasingly secular society, but duty chaplains will always offer a civil or non-religious naming ceremony or a religious blessing and about 80% of parents choose to go for a religious blessing. Is it folklore, is it superstition? I don't know. Is it faith, is it belief? I still don't know. But what I do know is it does bring comfort. The last acts of care is something which has also been shrouded in mystery. But we would encourage nursing staff and care staff to support families through the last act of care. It always seems strange to me that when a baby or a child dies, we get the parents, or support the parents to wash and dress the child. But when an adult dies, we hide them away. And I think there’s, there's something really important about saying, "Your mum always had the most amazing haircut or your mum always had her hair in an amazing way. I'm rubbish at doing hair. Is there any chance you could come in and help me do your mum's hair? Or do your mum's nails?" And people really can benefit from that.

We know through Covid that the lack of a funeral, the lack of attendance at a funeral did impact people. But we also know act of remembrances can help. And one thing that we often forget is established routines. I was speaking to a patient's husband, she died after a long stay in a care for the elderly ward from dementia, and I said to him, "It must be a big part of your life that's gone now Jessie's not here." And he said, "Actually, the biggest loss is not coming up to the hospital every day for my soup and sandwich." Routine is important to people. And sometimes ritual can allow us to lay down or put down old routines, old patterns, and pick up new ones. We cannot talk about ritual and rite without talking about the effect that COVID-19 has had. COVID-19 has changed the way that we as a society and as individuals have marked grief and celebrated life. Traditional bereavement rituals and rites have changed and many people were unable to do or celebrate or grieve in the way in which they used to do.

Memories are wonderful. They warm you up from the inside, but they can also tear you apart. During Covid, I was in intensive care, working in the Covid ward and there was a young gentleman in his 20s who was on end-of-life care, and his mum came in and sat on the bedside and started singing Ally Bally Bee. During the singing of the nursery rhyme, I could feel the tears run down my cheeks. But I noticed that I wasn't crying for the young boy in the bed beside me, I was crying for my granny who died 30 years ago, who used to say to us when things were bad, when things were difficult, "Come on, cooriein,it's going to be OK." And would sing us Ally Bally Bee. So, things come back, memories come back and they bring us comfort, but they can also bring tears. And, again, in going full circle, as Gandalf said, not all tears are evil.

Cicely Saunders is one of my heroes. The founder of the modern palliative care movement. And in one of her books she wrote, "How people die remains in the memory of those who live on." These are just some of the things which we were using through Covid. The Heart in the Hand project, if you can see it, it's, it’s a keyring with a heart on it and the heart pops out and the family can put the, the heart into the hands of their loved one... and then they keep the keyring to themselves. The knitted heart, we had these donated during Covid from local community groups and church groups. Two hearts made from one bit of wool and you would cut the, the, the wool that held them together and you could give one heart to the family and one heart was given to the patient. The bottom right-hand corner, the bottom right-hand picture is the Sands memory boxes, which our maternity and paediatric wards use. But more and more we are starting to see these being used in adult wards and I know that intensive care in Fife have started exploring their use. And then the top one is a wee letter from ITU nurses. And if, if you can't read it, I'll read it out to you. It simply says, "The nurses wanted you to know that your relative was not alone when they died. We sat with them and held their hands. This box contains a wooden heart with their fingerprint, a lock of their hair tied in a ribbon. We are sorry for your loss." And then the nurses who looked after that patient simply sign it and it's put into a small wooden box and passed on to the family.

These are some of the commercial memories you can buy. The teddy bear made from pyjamas and shirts. The cushion made from Dad's shirt. Or the bag for life made from Grandad's ties. They are not cheap, but some people find them really precious, particularly the teddy bears. And they are a real special keepsake.

Viktor Frankl was an Austrian psychologist. And he was also a Jew. And Viktor was sent to the concentration camps with all his family and only him and one other member of his family survived. And after he was released and started back into some sort of normality, he tried to make sense of the pain and the suffering he had went through and wrote a book called The Meaning of Suffering. And one of the lines from that states, "Fear makes come true that which one is afraid of." And I think that's one of our biggest barriers in providing good bereavement care. We are afraid of death. And we are afraid of the reactions of those around us, and those we care for. The first thing we have to accept and be aware of is that thinking and talking about loss, death, dying and bereavement is uncomfortable. So, there is uncertainty and we can often be uncomfortable around death and with death. Often we have poor awareness of our own beliefs around death. When teaching the medical students who are predominantly in their early 20s, I will often ask the question, "What do you think happens when you die?" And the students are really thrown by that. But if we have never asked the questions of ourselves, how can we support others who are asking the same questions?

Good bereavement care and making up memory boxes takes time. And we are seeing increased pressures on our workforce, increased workloads, a lack of time and a lack of resources. And that does impact, I believe, some of the ways we care for people. So, one of the things we’d done in Fife very early on when we were doing our new bereavement policy was we stopped wards giving back next of kin's belongings in rubbish bags or plastic bags. And we use endowments to buy specially-made bags. Where clothes and possessions were wrapped as precious objects, placed in the bag and given back to the family. How do we use language which is shared? As we live in an increasingly post-modern society, that shared language vanishes. This transference and countertransference. Whose needs are really being met here and whose grief is really being displayed? We also have an overreliance still on a biomedical or a biosocial model of care. And there is often a confusion of role. Whose job is it to provide bereavement care? Whose job is it to sit and hold the hands of those whose hearts are breaking? And who has the time and the training and the experience to do that? Questions.

AG: Thank you, Mark. You'll notice that there's lots of comments in the chat, one, one of the common comments around there, was something, was something about the significance of those objects that people were able to give to families or objects along with words. And, you spoke about that idea of in the past, there may have been stones, just things of the ground, what's available to you, and those can be symbolic objects that allow memories and ritual to happen. I wonder what advice you would give people in this, on this chat who are telling you how fantastic the presentation was. What advice you would give them about helping facilitate those sort of memory making objects or how they might do it in their places of work?

ME: So, you can go and buy the really expensive, you know, you can go into Winston's Wish or, or, or commercial sites and by some of these really expensive... memory books. Or memory bags or memory boxes, whatever you want to do, but actually, you, you can really do really simple things. So, if you take, for example, we had a gentleman and his wife had died some years ago and he wore her crucifix. And the family, the, the patient died, and the family went away and came back and said, "We're really sorry, we just realised Dad's still wearing Mum's cross. This is going to sound horrible. We want it back. We don't want him to go down to the mortuary in case it gets lost." And I knew from a previous conversation that their mum's favourite flower was a rose, yellow roses, so this was in the days when you were allowed flowers in the wards, so I went to another patient who had roses and said... "Would you mind if I pinch one of your yellow roses?" He went, "No, no, no, no." So, what we done was we went in with the family and I simply said to the gentleman, the deceased gentleman, "Hi, Bill, your daughters want Jessie's cross back so I'm going to do you a swap. I will leave you this yellow rose if I can take the cross." And that rose stayed with him until just before the coffin was closed. And that was about seven or eight years ago and I know that the three daughters still have petals from that yellow rose in the house. So, there's something that's really simple, but it has a big impact on, on the family.

AG: And there's something there, Mark, that really stands out to me, and I think there was a theme through this, and not only the chat, but throughout the day, about the power of truly listening and truly having a relationship with people. Then you can identify what someone might actually need or want.

ME: Yeah.

AG: And also, what I'm hearing is the huge value of creativity. I'm just looking through these other questions, there's so many comments to say how deeply appreciated it was and people have shared beautiful stories of, of rituals and memory making activities around about people they love dying. There was, there was another comment around about the, the shock, at the gap in people wanting to talk about death and the people, as... so, there's the three domains, isn't there? There’s the people who are dying, there’s the families and then there's the staff. And so, if you are taking the domain of the people who are dying, I want to talk about it, 90%, 80%, 7% actually have that happen. I wonder if you've got any advice about what we could do as, as people here to influence the culture where those conversations happen more readily and that, that need is met?

ME: So, I, I suppose one of the first things to do, one of the things I would always do first is actually find out where the person's at. How much do they understand, how much do they know? In, in my experience, particularly within palliative care, is patients will know they're dying long before the staff do. You know, so one of the most frequent questions we, we will get is, "How long have I got?” “How long has my mum got?" And, and I know, within our unit, we, we really try not to answer that, but say to the family or say to the patient, "When you see things getting worse by the, the week or deteriorating by the week, it's weeks, if you're deteriorating by the day, it's days." So, once the patient knows, you can then give them that option to talk about it. But often in the last few days, it's too late. Because they're tired, they're sleepy, they'll maybe be on more opioids. So actually we have to start those conversations a way, way back. And one of the things that Shaping Bereavement Care set out, which was the government's framework for bereavement care with the NHS, which I think, if I remember rightly, was 2008, so it wasn't yesterday. But what they said was bereavement care traditionally started when the patient died. Actually, we have to start palliative care, we have to start bereavement care at the same time as palliative care. Because the patient will be going through a grief process as well. So, so we have to start that very early on. And, and I have to say, one of the, the, the you know, most... medical students and nursing students will often say to me, "What's your most common phrase when dealing in this area?" And I say my most common phrase is one of two – and it's either, 'that sounds really shite' or 'that just must be crap'. And actually, just by saying that, in 99% of the case, the family will come back or the patient will come back and say, "Yes, because..." or "No, actually, I've made my peace." And that just opens that up. You know, and, and, and, and you can then go down the route of saying, "I noticed, you know, you're very upset when your family leaves. I wonder what is it that's upsetting you. Is it because they're leaving you and you're scared to be alone? Or I wonder is it because they've left and you've not had the chance to say things?" But unless we're willing to enter that space and enter into that pain to have those open conversations... we won't know what matters to the patient.

AG: So, and again... not to try and disentangle key points in this, but here and again there's something about truly noticing a person and noticing their situation. And not only noticing it when it's last minute, so there's something there about that and, and I wonder whether you, by you doing that, osmotically, people around might say, "Wow, that's something I could do", but also, the kind of being willing to be curious with people and not assume that it's because of this, or it’s because of that, putting it out as a 'wondering'. And also, here... just also I just want to… I hope you've read the, the chat, Mark, and you can see that, but there are so many hugely affirming, you may well cry when you read the, read the comments.

ME: Okay. I won't read it just now then.

AG: No. So, there's the being curious enough to not come in with your solutions, there's the being willing to turn up and show up there, but also when I heard you talking about, when I’d heard your language, you know, as somebody who never swears, hearing your language of what you say to people at end of life, there's something there about being yourself, you know? And that it, and, and how that genuine self is, is not just enough, it's the best thing you can give someone. So I really love that. One of the comments in there was something about a values-based approach and I wondered, I wonder if that's around about the, the curious, compassionate, kind of, reflective language. Is that something that you've, kind of, incorporated, not just in bereavement practice, for people who are dying, but for their families and for staff too?

ME: Yeah, I mean... For those who haven't done it, you know, the, the three levels of seeing can be hugely powerful around death and dying. And I know I would often tweak it because what I would normally do is I would do the noticing and wondering and leave the person I was working with to do the realisation. But sometimes round, particularly death and dying, because people are in that state of shock, I have to do the realisation for them as well. But they’re, they’re often, they'll be more than able to say to you, "No, that's not the case" or, "Yeah, that's true”, or “Yeah that, that makes sense." And, but it's so non-threatening. You know, and, and when somebody's in the adrenal state or is, is in shock, then... it, it's really hard for them to try and [inaudible] where their head's at. You know, and, and I'll come back to this idea that following a death, normality is shattered. So the normal things no longer make sense.

AG: Yeah.

ME: And, and sometimes you just have to say, you know... you know, so "Why did God allow this?" "I don't know." You know, "Why has this happened?" "I don't know." Because all I can do is stand there and, and be with the person. And, and it's interesting, because what... very few bereaved people ever remember what you say. What they remember is that you were there.

AG: Absolutely. And there was something, Mark, I just want to put this out at the level of noticing. I notice the tone of voice that you used during the presentation was a gentle tone. Most of what we communicate isn't the words, is it? It's how we say it. And, and I noticed that even as I was listening to it, that sense of comfort, calm, as you were talking about deeply powerful things. And there's some comments in there where people are talking about hugely personal circumstances where the gift of not being told, "Oh, don't worry, your loved one's in a better place." And just offhandedly, offhandedly remarking on it. There's something I was going to ask you around about this, because there's so many people here from the NHS, from health and social care, from third sector… all connected to care in some way. When you're noticing and wondering with people [inaudible], I wonder how many, or I wonder how many realisations you take away for, for yourself as you take part in these rituals and you help people have those memories. I wonder what sort of realisations you take away?

ME: I, I think one, for me one of the big realisation is how small we are. You know, it, it's interesting, that old joke about if you go to, to... to a graveyard, you know, the two dates, the date you're born, the date you die, and everything else in between is a tiny wee line. So actually, you know, in the bigger picture of the universe, we are very small. And what we do at the time of a death is very small. But it goes back to that, if we get it wrong, it is huge for the families concerned. So one of the things I often take away is one, how privileged I am. And two, I will often go... For those who know me, you'll know I've got a huge imposter syndrome and I also [inaudible] take away the "I got away with it again without being found out." Because sometimes you are just winging it because you're going in there not knowing what the family want and what the, the patient wants and what's going to work and what's not going to work.

AG: I'm noticing in the chat, Mark, that there's affirmation for that, for bad language at the end of life. But there's something about, you know, something about there, about your… how you've presented this to us, and what people have commented on is that the biggest barrier is not caring and not trying your best and not showing up, you know. And so, I'm wondering about... I'm wondering about, actually, there's another couple of comments that came in around about that showing up and how it might be easier for... how it might be easier for children to put things into memories and into ritual and the gap between child and adult. And there's only two minutes left, but I wonder if you'd say anything about, rather than a discussion about why that may be the case, how might we normalise stuff for adults?

ME: So, the, yeah, so the, the Heart in their Hand started as a children's project. It started for teenagers to give something to dying patients. Or dying parents, sorry. But the other thing I would say is things like Winston's Wish, it's amazing some of the resources they have. So, they do these little gift boxes, but you could easily make it yourself if, if the patient's, you know, if you've got time to work with the patient. And it's got things like, "Your first word was..." "You, you, you were five when you had your first tooth." “You were…” So the sentences are all written out, the patient just has to add the word and then they're put into a wee gift box, they're put into a wee fancy... And wee things like that, they started for, for children and teenagers, the same with the memory boxes, for the… so we have got so much to learn from how maternity and paediatrics deal with dying and death. But I think that comes because children don't have the same fear of it as we have.

AG: Yeah. Do you know, it's interesting, Mark, because how you describe that is, in these… whatever these rituals or, or memory making activities are, acknowledge what happens in that dash between…

ME: Yeah.

AG: …those two numbers. I'm conscious with about one minute left whether we might, together as a community who've heard Mark and have heard each other through the chat, just take another three breaths to ground ourself from what we've heard and get ready to go into what's next. Will we do that together? So we just take a breath in... and I notice I'm placing my hand on my heart, as though that's my centre, but it's really down in my tummy, it’s my gut. Thank you so much, Mark. Thank you for all that engagement in the chat and I hope that, as we move on through the rest of the day, we find ways to stay centred, stay connected. Thanks for your tone of voice, your wisdom and your, and your fun, Mark.

ME: No problem. Take care. Enjoy the rest of your day.

The film was produced in November 2021 and can be found at [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk/) or <https://vimeo.com/687086482>

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