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**Talking about Bereavement Podcast Series – Transcript of ‘Double the listening and half the talking’ Podcast**

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**Speaker**: Alison Allan, Centre Head, Maggie’s Fife (AA)

**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, Alison Allan. Alison is a nurse by professional background. She started her training in 1983 with very much a vocational approach to nurse education at that time. She worked full time while attaining her BSc in Nursing Studies and then an MSc in Palliative Care. Now with 40 years experience behind her, including palliative care at St Columba's Hospice, Marie Curie and CHAS, she spent the last eight years at Maggie's in Fife as the Centre Head. She tells me she's looking towards retirement and leaving behind a very different healthcare landscape. Alison, lovely to have you with me. And we kinda know each other because I come into Maggie's and it's really nice to, it's really lovely to have you here on this podcast. Now having 40 years experience behind you that, that's a very brief introduction I've given to you and so I wonder if you could expand a bit on that introduction, tell us a bit more about yourself, how you've got to where you are in terms of your life and your work.

**AA:** Thanks, Lynne. It's lovely to have the opportunity to speak to you for this podcast. Bereavements something that's quite close to my heart. I never had a plan coming into nursing. In fact, I probably wanted to really be a teacher and decided that actually nursing was a bit more my thing, with a bit more variety in it, which I realised is very naive at the time. And I, I started when I qualified, I worked in Eastern General Hospital, which is now no longer. And, and I went to St Columba’s Hospice on escort as you did in these days in 1988, where I was taking a patient who was facing end of their life into St Columba’s Hospice and was really impressed at that time with the welcome we got and the preparation they had in place for, for this person for their admission. And I was there for the best part of 25 years…

**LI:** Oh right.

**AA**: …and hadn't intended to stay that long but did lots of different things. I started off in the inpatient unit and that was just at the time when specialist palliative care became a speciality. Dr Doyle was still there at the time and he certainly had, had been instrumental in setting up St Columba’s Hospice and had, had great input with Cecily Saunders and I did lots of things in St Columba’s. So I worked in the inpatient unit initially and then I became Day Hospice Manager and Complementary Therapies Manager. And then my career took a little bit of an odd turn in that I project managed their new build when they built the new St Columba’s Hospice. And I got an opportunity after that to join CHAS and do something similar for them. And it was really interesting to look at children's palliative care in comparison to adults palliative care. I think there was a different approach in terms of making memories with children in a different way than we do with adults. And after that contract came to an end, I went and worked in the community palliative care team for Marie Curie and loved being back with patients again. I really enjoyed that aspect of it and unexpectedly an opportunity came up at Maggie's and I joined the Maggie's Fife team about eight years ago and actually realised I have very much more in depth conversations with our centre visitors than perhaps I ever did in palliative care. Perhaps because there was an assumption that people knew what they were coming to when they come into hospice care, whereas it's much more exploratory role in Maggie's in, in people's understanding and expectation of where they're at with things.

**LI:** Yeah, I was thinking as you were speaking there, there was two things. One was, you know, that's quite a kind of eclectic career. And interestingly, you, you said you were in St Columbus for 25 years and then that kind of your career changed and you've done, you know, maybe shorter jobs since then. And, and I was thinking about the parallels with my own career. I've done something like that as well. I was in general practice for over 20 years and, and never moved really. And then have ended up with about four or five different roles in the last few years as well. It's interesting how that happens. But the other thing you were talking about was making memories with children in a way that we don't do that with adults, and I suppose I wondered why that might be. And, and, and I think I could, you know, hazard a guess at it, but, but what would be the reasons that we don't do that memory making in the same way with adults, do you think?

**AA:** I wonder whether adults aren't as able for that discussion around the death and dying conversation. We're a bit of a death denying society. So we think, you know, the future is forever. And I think when people are diagnosed with something that's not curative, I think that's much more difficult than it is in the understanding in the, in the children's hospice and I'm certainly not speaking on, on their behalf, but there's an understanding that this child's life will be shortened. I wonder, Lynne, if you know, if we all acknowledge the fact that we're all going to die and lived a more mindful life in actual fact, we would be making memories all our lives. And I think you already see that in some of the younger generation now that they do that much more so than perhaps that I was used to or my parents generation. And I think cancer is still the, you know, that has been my background, a cancer population. And certainly I understand obviously that palliative care services, specialist palliative care services are for all diseases. But you know, in the 80s it was cancer and it was still the feared disease in a different sort of way. So I think that people are hoping that something else may be or that's not quite right, do you know, I don't mean that, I think that people don't necessarily acknowledge that living well is important all your life and…

**LI:** Yeah.

**AA:** …making good choices all your life.

**LI:** Yeah. And interesting you’ve said that I've just finished reading Chris Hoy's book ‘All That Matters’. And, and that was one of the things that struck me about his book. He's kind of talking about, obviously we know that he has stage 4 prostate cancer and he's very much talking about now, you know, I mean, I think he's always lived well, but he's, he's very much focused on the moment and he talks just what you said there about the future not being guaranteed. You know, that for him I think is something that he has had a realisation around or that was my interpretation of how he's writing the book that that is, so, so living now, living in, in the moment, but, but living mindfully is really fundamentally important to him. And I think we hear much more about people trying to live a bit more in the moment and that the, you know, not guaranteeing the future. But I, I, I do wonder if that's maybe perhaps why, why it's hard for us to focus on death because we're, we're, we're future focused.

**AA:** And I think sometimes it's very painful, isn't it…

**LI:** Yeah.

**AA**: …to, to think about death. And it is something perhaps on an individual level, we put it out into the future and we put it on our own back burners until we have a bereavement or until we experience death within our own close circle of friends where it's front and centre. And it may be at that point people haven't had the opportunities for the discussions they may wish to have had that might have prepared them better for the grief process. Or that it may be that they're navigating that in a way that they, they is new to them and that they don't understand some of the things that happen to you when you're bereaved and bereft and distressed, you know, as well.

**LI:** Yeah.

**AA:** So we put it onto the back burner as one of these things that will happen in the future but never take time in the present to really address the issue.

**LI:** I wonder if it feels too scary for folks…

**AA:** Yeah.

**LI:** …to do that.

**AA:** Yeah.

**LI:** So I suppose that kind of brings us nicely onto thinking about what, you know what, what is it that you do or have done in your roles, different roles to support people who are bereaved or anticipating loss or bereavement.

**AA:** So I think most recently working in Maggie's, I think actually that is where I have seen that the more the longer-term impact of grief and bereavement on individuals and on groups. When I worked in St Columba's Hospice and at Marie Curie, I very much experienced that immediate bereavement and that immediate process of bereavement. But in actual fact, some of the support afterwards was not necessarily done by myself being the inpatient, working in the inpatient unit or working in the day services. So it was not necessarily picked up by myself. And it's been really interesting to come and work in Maggie's and see people bereaved and bereft and distressed, you know, immediately. And it's six weeks and it's three months and a year and 18 months at all these different stages. Or as you say, or in advance, they are grieving for somebody who's still alive, which often people find very overwhelming because they don't realise that that's a normal part of the, the grief process. And so, you know, I, I see people at any point in wherever they are in that process, for as long as they need to. And that could be on a one-to-one basis. So I, I wouldn't normally, you know, that first six weeks we would be normalising some of their feelings. Yes, it is overwhelming, it's distressing. And we have access to psychology, but not very many people really need psychological input at that point in time. And we have peer support for bereavement as well. And I think nobody ever really wants to join a group because when you're bereaved, you think you're the only person in the world that's experiencing that, you feel isolated and alone. However, when people feel ready, often meeting other people and that peer support in a structured bereavement course can be really helpful in moving people forward in a, in a different sort of way.

**LI:** So you, you mentioned there a course and I suppose I wondered what other, what other ways do you offer that support? Are there specific ways that you offer support to people? Like you talked about the bereavement course there. But, and I don't know if you run a course or not or that was just a turn of phrase but, but yeah, what, what other ways, what other ways do you offer that support to people?

**AA:** So we would offer a bereavement course, that'd be a seven-week course ,six…

**LI:** Okay.

AA: …or seven-week course over, you know, meeting every fortnight in order that people are able to do the work, that emotional work of kind of moving forward in terms of exploring where people are at and exploring their understanding of what they thought was happening and that psychological and emotional impact. And how do people move forward. What was the person like that had died? And you know, what are the, the bits that are the big gaps of what are the bits that they stop doing and how do they navigate moving forward, not necessarily closing the gap, but making their own lives a bit bigger again. So we offer a course if and when people are ready. Sometimes that could be, you know, my experience, I probably would say not before three, four, five months, you know, they need to sort of get used to being without the person that has died. But we would offer one to one support maybe once every two or three weeks…

**LI:** Okay.

**AA:** …and initially, and that's to see if people move on naturally, it's normalising some of that. And actually, they're actually, they're resilient enough to move forward. And for some people actually they now find they're ready for a group. And for a small percentage of people actually they, they need more psychological input in terms of their thoughts and feelings are affecting their behaviour. So we would refer them to our psychologist…

**LI:** Right.

**AA:** …initially. So we, we have a variety of ways to support.

**LI:** Yeah, yeah and, and making that, I suppose really person centred for each individual that comes to you as well, which is always kind of lovely to do. And how, how do you think maybe not just you, but how about as a, as a society, how do we ensure that we do kind of bereavement support well.

**AA:** So it's really interesting isn't it Lynne, because if we were 100 years ago, you know, our grannies or our great grannies would have had the whole community in, the neighbours would have cooked things, that things would have been different. And I think actually we need, I wonder if we developed a little bit more resilient communities. You know, we're very isolated, aren't we? I'm always fascinated, when I did my Master’s, I'm always fascinated by Allan Kellehear's work about resilient communities, resilient organisations around, you know, when death is there and, and you know, how, how we start these conversations, how we support people because dying's a very normal part of life and we seem to have hidden it away. So I think we're a wee bit less resilient on the death and dying front than we might have been, you know, you know, our grannies and our great grannies were. So I think it's just a bit different. I wonder, you know, as I'm coming to the end of my career and confident in my ability to talk about death and dying and bereavement and distress, whether all healthcare professionals feel like that. I wonder if there's a little bit of lack of confidence around, I'm scared to upset people…

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

**AA:** …I'm scared to raise the subject. And I wonder if it's something, and it's a long time since I've been, you know, since I've done my training. But I wonder, are we arming our healthcare professionals efficiently and effectively in that death and dying conversation because we don't want to take away hope.

**LI:** Yeah, yeah, absolutely.

**AA:** You know, and, and I completely get that. You know, they want to give as much hope as possible. So it's really difficult, isn't it? It is difficult to get it right because you're right, it has to be person centred.

**LI:** And I think we know, just echoing what you've just said there, I think I mean there is some evidence to support exactly what you've said, that people are worried they upset people and they also don't know what to say and they're worried they say the wrong thing. So as a consequence, often we might say nothing because we're so worried that we upset them, say the wrong thing and then don't really know what to say. And often, certainly in my work in bereavement, we would often be asked for a script to, you know, to say how to, how to deal with, with a certain circumstance. And we've, we've very much resisted the script because obviously that's not person centred. You're always worried that it doesn't come quite out the right way. And that actually we all need to find our own words and our own way of, our own way of expressing it. But, but that's something that folks really, I think, well, my impression is it's something people really struggle with.

**AA:** And I think it's something families struggle with as well. In terms of when there's somebody with a life shortening illness, they may not want to pick up that conversation. They may not feel able to, suddenly there's this elephant in the room they, that they might want to, to have a bit conversation and the person themselves doesn't want to talk about it or vice versa. It, it just depends. It's really difficult to navigate I think for people and, but I always think it's better to pick up the cues you have to, I think it's always better to do the listening, double the listening and half the talking. You know to really hear what's being said so that you can respond to that. And I think families find that difficult as well.

**LI:** Yes, yeah, yeah, yeah. And we, we you know, we've talked a lot in, in certainly in NES about the value of listening, the importance of listening, that you know, how much it makes such a difference. But we struggle to list, you know, we struggle to listen. And of course, as you will, we know this, the different types of listening, where we might, we, most of us listen to reply instead of listening to understand. And so we're already formulating our reply in our head while we're listening rather than listening…

**AA:** Yeah.

**LI:** …or while we're waiting for the person to stop speaking, we're formulating that reply.

**AA:** Yeah.

**LI:** And so that, that reduces the impact of the listening then when that happens. Do you think then, I mean we've maybe touched on this a bit, is there, are there better ways to offer bereavement care than we currently do it?

**AA:** Gosh, that's an interesting question. Are there, are there better ways to offer bereavement care? You know, I wonder if in society we expect a quick fix. We want…we don't like sitting with uncomfortable feelings and being bereft and bereaved and distressed is uncomfortable. We want it fixed, but it's not quickly fixable. I wonder, you know, it's, it is very interesting in, in some of these demystifying death, death awareness weeks, death cafe stuff, you know, I wonder whether we discuss things in advance. You, you know, with, with if everybody if, if we did some education with everybody with the well, with the hale and hearty, whether it would make a difference to that bereavement process. I think formative experience is really important, isn't it, in terms of how people have experienced that first death and when really shapes people's future in terms of how they cope with bereavement. I do, I'm kind of that at that stage of I think I learn best from other people, from watching, from learning that experiential type of, of learning. But it's difficult to do in bereavement care because it's so intense, isn't it?

**LI:** Yes, yeah.

**AA:** Yeah, but I'm not, I'm not sure what would be ideal. I think there would have to be a variety of things.

**LI:** Yeah, I was thinking that as you were saying it is it's, it's difficult to role model, you know, because we, we don't want, we don't want to, you know, what's it called do role play, you know, because it's it doesn't, it doesn't really work and it's not, doesn't feel authentic or real if we do it like that. So it is quite difficult to role model from that perspective. And obviously we're all very different so we will all do it in different ways. And I think that's really important is, is not trying to kind of exactly match how someone else does it.

**AA:** I think it's also interesting looking at other culture, isn't it, where other cultures may cope with grief and bereavement very differently. I think it's the Scottish sort of race we are, we're quite, quiet emotionally, unless it comes to, you know, in relation to death. We think there's something around emotion that is, should be suppressed or is embarrassing, you know, different sort of way. And, and I think it is having, you know, that conversation to say there are people there to help you navigate this regardless, it's just finding what's right for you. And for most people that will be friends and family and normal sadness and normal anticipation of, of different things that are coming up in terms of anniversaries or birthdays. And most people will be fine. But actually some people will need additional bereavement support and it's finding what, what should be right for that person.

**LI:** Absolutely. I suppose kind of final thing that I was thinking about and something because of my job involves wellbeing, staff wellbeing really and staff care, I suppose, how do, how do you keep well? How have you kept well in your jobs, in your roles, in your commitment to the work that you're doing?

**AA:** Well, maybe my team would say differently [inaudible]. It's interesting. And I think you have to be resilient in terms of being able to deliver what you need to deliver with a self-awareness of what, what your strengths are and, and when you need support. I think, I think working in a team where you can have an ability to say I'm not able to do this because I feel vulnerable or I'm exhausted, you know, it's an absolute luxury and I'm not saying I have an opportunity to do that but we are really lucky in Maggie’s where we have a mandatory 90 minutes a week.

**LI:** Oh right.

**AA:** Once a week, where we sit down as a staff team and discuss things that may be good, things that are worrying us - that could be centre things, centre visitors, incidents that have happened in the centre or actually on occasion it may be something that's happening at home or something that I just might be feeling myself. I found that really, really helpful once I've got my head round, allowing myself to be vulnerable. I think that's the strength of the rest of the team, to see the team, for the team to see me as vulnerable, you know, and you know, everybody has, you know, different things that they bring but we do that one, once a week, which is really helpful. I have used supervision in the past and my supervisor would say here she comes with her little silver notebook and I would take notes in it over the month to go ‘right this is what I want to discuss’ and then, so that's been really helpful. I think it's really important to have a work life balance, you know, and, and in nursing these days, honestly, I, I think that's a real challenge, isn't it, you know, but it is important to leave work at work and have some interests outside work. I love doing the garden, do you know, I like to see friends. I like to walk. I don't like to go to the gym, but I know it's good for me. But I try and make good choices when I can and when I'm feeling particularly stressed or overwhelmed or distressed, I would either talk about it with a team member or make some choices that are good for me at that time. And that might just be getting outside or, you know, having, you know, having a chat with someone, say I’m meeting friends, whatever that might be.

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

**AA:** I think it's important that it's not an optional extra that it’s integral to your whole person because that makes you a better, makes you a better professional, and it makes you more resilient to be able to deliver that bereavement support to people that are distressed and upset.

**LI:** Yeah, and what I've noticed about what you said there was, there's, there was a whole different range of things that you're doing. You're not just doing one particular thing, you're actually doing lots of different things for what suits you at certain times. And, and actually also kind of articulated that sometimes it's just about making a different choice from the one that maybe you might have been making and so really being mindful of that. And I suppose that's about back to kind of living mindfully and, and not, not always future focus, but actually thinking about what's right for me just now and what do I need to do to keep me well so that every day I can go back in and, and do this job, which does require, these jobs do require a lot of our kind of emotional and psychological selves to do them. And, and we're constantly thinking about our own kind of self-awareness and emotional intelligence and such like to, to cope with the jobs. So it's really important that we, we have different ways of kind of managing those different things.

**AA:** One of the really nice things at running a bereavement course is I'm always a bit anxious when it starts off because you know, working with a group is, is always a challenge. But these people come in, in into the group and they're often distressed and upset and emotional. And over the course of 12 or 14 weeks on the last week, undoubtedly when we reflect as a group to see where were you when you came in and where are you now, undoubtedly there is growth in that group. People are going out, they are moving forward. You know, that's a huge, you know, that's hugely rewarding in terms of that emotional work that we've put in. And it may be tiring at, at times, but you know, the reward at the end is great.

**LI:** That's really interesting, isn't it? Because I imagine people might not think they're going to grow during the, the, the, the duration of the group. So it's lovely to see that kind of reflection at the end. So as we finish off Alison, I just wonder if there's anything, any kind of final kind of thoughts or comments you'd like to make before you head off into the, the sunshine of retirement because I know that's actually quite imminent for you now.

**AA:** I think, do you know, I, I've been very lucky in, in my career and I've, I've never set out to follow a particular path, but I have met some amazing people on the way. And the things I've learned whilst I've done the formal studying, the things I've learned have been that experiential that with patients and centre visitors, which absolutely backs up the theory. It is difficult to step down from that caring role. I think particularly difficult and you know, hope that in some way with the people that we touch, I'm, I’m leaving a little bit of a legacy with them in being able to move forward.

**LI:** I'm sure you are Alison, because I’ve certainly very much enjoyed coming into the, the centre as, as you have been the centre head. I'm sure, I'm looking forward to continuing to come into it but I think it's been lovely to that, that welcome that is extended at Maggie's is always so warm and open and inviting and almost any time that we need to pop in or decide to pop in, that it is such a welcoming place to come into. And I'm really grateful for that. And I know that a lot of my colleagues and, and nurse colleagues as well, sometimes just come in because they actually need a wee space and you provide them with that wee space and a cup of tea at your kitchen table. And it's very, it's very much spiritual care that you're, you're offering there, which is, is, is very kind and generous. So I wish you well.

**AA:** Thank you, thank you, Lynne, it has been fabulous. I have a warm place in my heart for the NHS Fife.

**LI:** Thank you so much for joining me on this podcast today and enjoy your retirement.

**AA:** Thank you.

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