**NHS Education for Scotland**

**Talking about Bereavement Podcast Series – Transcript of ‘Honesty, listening and loss: Holistic reflections of an MND Clinical Nurse Specialist’ Podcast**

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**LI:** Hello and welcome to the Talking about Bereavement podcast, which is brought to you by the Bereavement Education Programme in NHS Education for Scotland. I'm Lynne Innes, I'm one of the educators in the team and in these podcasts, I'm going to be talking about bereavement with our guests who will be sharing and reflecting some of the work and the 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, Louise Gardiner. Louise is a motor neuron disease clinical nurse specialist for NHS Fife. Louise qualified in 2013 and has had a nursing career background in specialist, specialist palliative care. She started as a newly qualified nurse in the inpatient hospice unit at Queen Margaret Hospital in Dunfermline, where she was promoted to charge nurse of the inpatient hospice and day hospice in Kirkcaldy. In 2020 the opportunity to become the first NHS Fife MND CNS was offered to her, and she has developed a new MND nurse led service over the past four years delivering care and support to MND patients in Fife. She was delighted to have been a successful recipient of the Gordon Aikman Scholarship which has enabled her the opportunity to develop an MND specific future care plan. Hi Louise, thanks so much for joining me today to talk about your work and bereavement.

**LG:** Good morning. Thank you for having me, Lynne.

**LI:** No, it's great to find out a bit more about what you do. And obviously Louise and I do know each other a bit through, through our work together in Fife, but actually we probably haven't sat down and spoken about specific MND work so and, and, and that how that relates to bereavement. So, I wonder Louise, if you would like to expand a wee 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 work. But also, I'm really interested to hear a bit more about your specific future care plan, because I know that's been something you've been working on over the last couple of years.

**LG:** Yeah so, so yeah, I've had a kind of nursing career in specialist palliative care since being newly qualified. So, I think it kind of sparked in me as a, as a student nurse when I got a placement in the hospice. And that's when I kind of realised that's where I wanted to be and the type of nursing that I wanted to do. So, I was lucky enough to, to start as a newly qualified within the inpatient hospice unit. And I've kind of just stayed within palliative care my whole career so far. And that's kind of been where my kind of passion lies as well. So I’ve obviously now motor neuron disease clinical nurse specialist and kind of started this service in Fife and has been able, I've been able to kind of build it up over the past four years, which has been, which has been a task in itself, but, but quite exciting as well to be able to put your own spin on how the service should be delivered and things like that. So, it's, it's been, it's been a very busy four years. But really rewarding 4 years also. The Aikman scholarship, the Gordon Aikman scholarship that I was, I was lucky enough to, to, to actually be one of the recipients for that. Gordon Aikman, I don't know if you, you know much about, about who, who he is. He was a gentleman. He was, he was originally from Fife but looked after by the Lothian team and he had motor neuron disease who worked within the government. So, he had done a lot of kind of work around trying to improve care for MND patients in Scotland. And as part of that kind of work that he did, they were able to get more MND nurses in Scotland to look after these patients being diagnosed. Sadly, when Gordon died, they, they had decided to put together a scholarship kind of in his memory and his legacy and allow the opportunity for people to kind of focus work on improving the lives of those with MND. So, this is like kind of joint partnership from the Scottish Government and the, the kind of charities, the MND charities and things as well. So, I was lucky enough to, to be the recipient of this scholarship and I was able to focus on the, the need for a kind of MND specific future care plan. So, we, we all kind of know it as like ACP, so Anticipatory Care Planning or Advanced Care Planning, that's recently changed terminology to Future Care Planning. And what I found when I came into this job was that MND is so complex, massively complex. There's loads to think about with these people. There's a lot of changes, there's a lot of decisions, there's a lot of wishes that we need to explore for these people. But what I found was that the actual ACP documents that were available to use, they, they just weren't quite hitting the spot for kind of, you know, focusing on the, the complexity of the disease. And I think a lot was getting missed, maybe not missed, but maybe just not explored as in depth as it possibly could be with these, these patients as well. I've got a huge passion around exploring people's wishes terminally ill patients. What do they want? What's important to them? I think, you know, as you know, nurses that work within palliative care, we, we know what, what should be done. We know what we can do, and we know what we can offer to people and their families. But sometimes we're not amazing at actually finding out what do they want. They might not want what, what we think they should have, and they might have a different perception of what's most important to them. So, I really wanted to try and capture that and what's important to them as their disease progresses. So, I've now developed an MND specific future care plan, which we have kind of working through still at the moment. It's a huge piece of work trying to get round all the patients, but I think we've got over half the caseload who now have an Aikman Future Care Plan in place. So, this kind of details, you know what's most important to them, it details their, the team involved, there's loads of people involved with MND patients, they've got speech and language, they've got dietitian, they've got an OT, they might have physio, they've got myself, a consultant, district nurses, home ventilation, like the list goes on and on. So, it kind of details who's, who's, they're allocated kind of support and then it goes through what their wishes are in terms of, you know, do, do what do they want if they had to go into hospital, what's important to them? You know, if there was a reversible cause of deterioration, what is most important for them at that point? Do they want to go into hospital? Do they want to consider support at home, from hospital at home? You know, how, how much are we going to escalate their care? What's appropriate for that person, but also what's their wishes? A lot of MND patients, I’ve yet to come across one actually who says that they want to go into hospital. Majority of them want to be at home with their family. So, it's about, you know, giving them the right knowledge, like, you know, the right information, the right advice about the teams around them that, that can, can help them stay at home, but also about being realistic about what we can offer as well. You know, we don't have 24-hour care for people in the community. So, it's just about being realistic with that, with the family. And, you know, if, if that wasn't an option or if, you know, symptoms became uncontrolled then what are your wishes in that scenario? You know, what do you want us to do? And then it talks through kind of interventions in terms of, of gastrostomy feeding tubes and non-invasive ventilation and what's important to them. Do they want these interventions? Do they not, are they appropriate or are they not? And this is all documented within the, the document as well. And then we speak about power of attorney, about a will, is that in place? Where's their preferred place of care, preferred place of death. And again, we speak about a lot of MND patients, well they all get the opportunity to donate their brain and spinal cord tissue after death. So, you know, they can't donate their organs. So sometimes this is a way that people can donate, but, but not in, in the same way as, as other diseases can. And it allows them to, to kind of donate and we do further research into the, the brain and spinal cord tissue to, into motor neuron disease as well. So, this is all captured within the one document. So, it's, it sounds a lot. It's not, it's not quite as intense as I've probably made it sound. And the questions, we did a lot of work on the questions. So, I worked alongside I got volunteers from all of the multidisciplinary team around me to kind of little groups of speech and language, little groups of dietitians, little groups of community OT’s, I had specialist palliative care involved. And we did a lot of work around the questioning within the document because that is patient held. So, it's very much a focus on you know what, what matters to you, and it's written from their perspective as well. So, it was a much bigger piece of work than I think I first anticipated when I, when I thought, you know, this'll, this'll be easy enough to just put together a, a future care plan. It, it wasn't. And probably because I wanted it to come from a multidisciplinary approach. I didn't want it to just be me and my ideas because I really need everyone else to buy into it as well. So it was, it was a lot of work, but it's definitely paying off now. So, it's quite exciting in, in Fife and there are talks in the next couple of weeks with other health boards as well about whether they will be able to kind of adopt this care plan in their own health board area as well. So, yeah, we'll see what happens over the next wee while I guess.

**LI:** Wow Louise, that's like amazing. I'm kind of feeling like there's so much in there that you've, you've achieved from that. I suppose the thing that keeps coming back to me is this is entirely person-centred. This is person-centred care at its, at its very best. And also, so you were hearing the voices of the patients that you, that you support, but also from the multidisciplinary team. So, there’s a real team can a whole system approach here to making this care plan something that works for the people in, that you care for in your service. I mean, it's, it's amazing. I think I feel like we should be shouting from the rooftops about this because it's like, it's just like so amazing. And the fact that other boards are now thinking about picking it up and, and that this is your work, and this is what you've developed. And I know, and going back to I, I mean, I knew of Gordon Aikman. I didn't know him, but I knew of him. I remember he did a lot of kind of publicity and he, he was, you know, he, he spoke a lot about MND and his hopes for the future. And I think I was thinking, what would Gordon think of this, you know, if he was able to see this in action and, and this kind of making, making life better for the people and their families who are going through MND. Because we know that, that it's a really, I suppose, horrific thing for people to go through and, and that you've made this really person-centred. And when you said what matters to me there at the end, I felt like cheering because that's just like, you know, phenomenal really. So, that's amazing.

**LG:** Yeah.

**LI:** I'm, I'm really excited about the fact that you've done this. Yeah, its, yeah, phenomenal. I suppose…

**LG:** I think it was important…

**LI:** Yeah.

**LG:** …for, for me to, to make sure that, you know, it was named after him also.

**LI:** Yeah, yeah.

**LG:** So, you know, that, that, that legacy lives on. I mean, I never, I never got to meet Gordon himself, but I think because like, you know, he was a Fife man as well.

**LI:** Yeah, yeah.

**LG:** And then the, the scholarship came from, from all his hard work that it was important for me to make sure that, it, it's called the Aikman Future Care Plan as well, just to kind of live on, on that as well so.

**LI:** I suppose that kind of leads us on to talk about bereavement. And I know that you support people obviously who are bereaved, you're supporting families who are bereaved. But, but also, I'm wondering about anticipatory loss or anticipatory grief and bereavement, because I imagine that's something that you're, you're responding to as well. And what, what, what, what, what do you do to support people who are bereaved or anticipating loss and bereavement?

**LG:** Yeah so, I think anticipatory grief is something that we deal with every single day in these roles and, you know, patients with MND, they lose a lot. They lose a lot of who they are about, you know, what, what they were able to do and what they're no longer able to do. So, you know, they lose the ability to scratch their own nose. They lose the ability to, to walk to the toilet, they lose the ability to, to speak to their family. They can lose the ability to, to swallow their, you know, a piece of cake that they enjoy eating. They can lose the ability to, to breathe without some support for that breathing. So that's a constant loss throughout, throughout the disease. And I think, you know, we're, we're involved as MND nurses from, from the date of diagnosis to, to death. And, and we see that loss throughout the entire trajectory of, of their disease. And they, and they lose so much. And, and it's really difficult to, to try and keep them upbeat at times as well, because it is just a constant loss after loss, constant progression of the disease. But I think the families also, and I think, you know, it's a huge carer burden on, on, on families who look after a loved one who's, who's, who has MND. And I think it's an area that we're, we can probably improve in. And I think that, you know, we don't always acknowledge the, the, the huge input the family puts in to, to keep these people at home and cared for so well at home as well. And they pick up a lot of the pieces at home as well. So, I think their, their grief is also, you know, they're, they're losing that person they knew, you know, they're losing. You know, it could be, you know, a daughter who her, her dad did everything. She phoned him for everything. He was good at DIY. He was, he was, he was the person she always phoned. And he's now no longer able to do that. And there's this just this constant loss around everybody that this disease impacts. It doesn't just impact that person who has the diagnosis, it impacts every single person around them. And then I think, you know, it also impacts me. You know, it's a constant, it, it's another area that I think we, we can also improve in. I think, you know, it’s, it's a constant grief. You know, I'm constantly going round that grief circle with every single patient. And you know, I'm not alone. I've got friends who are, are cancer CNSs, and they do quite similar jobs to myself and it's constant loss around them. And you know, you build up, you build up these relationships and I'm very lucky in my role, I guess where, you know, because we're involved from diagnosis to death and we're the first point of contact for MND patients, we get to know our patients and families really, really well and, and they get to know us really well as well. And I think that sometimes that anticipatory grief is often maybe overlooked a little bit in terms of the family and the carer, but also in terms of, of the, the nurses or even the other members of the multidisciplinary team around these patients with MND. We, we are kind of, yeah, we're all, we're all going through that cycle of grief, I think. And I feel like for, you know, the past 10 years, I've probably never got off that cycle of grief. It just goes round and round and round and working with terminally ill patients and that constant loss of people that, that, you know, I really like and I get to know really well. And, and you can't help, you know, there are professional boundaries, of course there are, but you can't help but be human. You can't help but, you know, enjoy the company of patients that you meet and their families and enjoy spending that time with them and getting to know them as well. So there, there is all that kind of overlooked grief. We focus a lot on, on the person who has the diagnosis. And I think we're really good at that. I think we're really good at supporting that person and providing all this support and referrals to X, Y and Z, whatever they, they require. We're not always great at looking at the, the circle outwith that and looking at the family and then looking at the people around about supporting as well. You know, I had a conversation with, this always sticks in my mind, it was years ago now when I worked in the, the hospice and I had a conversation, I'd had a really hard shift. I was the charge nurse, there was a few kind of managerial issues going on, but we also had a lot of death and a couple of patients that I had come quite close to in the hospice as well. And I just kind of hit, you know when you just hit that point and I was like, I need, I need space. I need to get out of here for a bit. So, I took a wee walk round the hospice garden and the chaplain at the time had came out and, and I knew her really well. And she sat me down on the bench and she was like, she was like, how are you and stuff and I was like, I'm not good and of course, I started crying and I was like, oh, I was like, I just feel really overwhelmed and I was like, I'm normally quite good at holding my emotions in. And then I always remember her saying to me. So, she was like, you know, you're constantly holding people. So, you're holding patients, you're holding their family, you're holding all your members of staff within the hospice. She was like, you're always holding everyone. Then you go home and you're holding your own family and you're holding your children and you're and she's like, who's holding you? And I was like, no one. Who is holding me because I am. And you know, when she made me kind of visualise that I was like, I am holding all these people and all their emotions and all their upsets and all their worries. And I was like, no wonder that I'm sitting here crying on a bench in the hospice garden right now because actually who, who was holding me at that point? And I just always remember it. It's one of these things that, you know, it was years ago, but I just always remember that as well.

**LI:** So that's a, that's a lovely story. And as a chaplain, it wasn't me, but as a chaplain, I’m, I felt, I felt really, you know, pleased that this is, this is something you remember that, that, that, that, that that chaplain said to you. And I suppose one of the questions that was running through my head was so where, who is holding you? And, and you know, where do you get, where do you get your support to, to, to hold you? And has that changed from that day sitting in the hospice garden?

**LG:** Yeah, I think I'm very good at giving advice to people. So, I think, you know, I'm, I'm really, really good at giving advice. I remember I worked really closely with a, an OT who worked in the hospice. And I always remember we had a, a really tricky couple of days, really hard couple of days where quite a few patients had, had had quite traumatic deaths within the hospice and we were all just feeling quite emotionally depleted, unstable potentially at that point. And I remember her saying that she was really, really struggling and, and she'd been having quite a hard time over the past week at work. And, and I felt the same. And I remember saying to her like, you know, you can't pour from an empty cup. And she always remembers me saying that to her. And but it's funny because I'm, I'm so good that giving this advice and I'm like, focus on you, you know, fill your cup back up before you give any to…

**LI:** Yeah.

**LG:** …anyone else. And then I'm like, I don't, I'm not great at actually taking that advice on myself. So, I'm very, very good at giving it to other people. But yeah, maybe not, not the best at actually listening to my own advice. I think over the years I have got much better. I think, you know, things, you know, we see on a daily basis in these types of jobs, we see on a daily basis how, how important life is and how quickly things can change for people. And I think for me, seeing that every single day and being exposed to that every single day, I just make sure that I make the most of my time outwith work and I try to find that balance as much as I can. Again, I'm not the best at that either, trying to find that kind of work life balance. But I am getting better and I'm chipping away at it. I think just spending time with the kids and, and not missing the milestones and the, the big things and the school events and making sure that I'm, I’m there when I can be there and focusing and prioritising on that is important for me as well. And then just speaking about it, you know I did this job initially on my own and you know, I'd be lying if I said it, it wasn't horrendous at times. It was and I'm guilty of driving from house to house with tears rolling down my face and nobody to talk to and nobody to bounce off and just holding that within myself. And then putting on, you know, wiping the tears away and putting on this, this fresh face for the next family and the next patient you're about to meet in their home and trying to not kind of show them that you've been upset in the car on the way there. That's changed with now having that, you know, I've got a colleague, so I now don't, don't work on my own. So, it's now good that I can bounce these feelings off with her and we can discuss and reflect and say, you know, I was thinking this, or this patient just didn't seem, seem the same today to me. And you know, we can bounce it off each other. And I think that definitely helps being able to, to speak about, about it with someone and not kind of hold all that in. It's like forever learning I guess it's forever just chipping away at trying to, to have these kind of boundaries in place. When you work in jobs like this, you can't help but want the best for people because you know that time's short and…

**LI:** Yeah.

**LG:** …you hold a lot of responsibility, and you do hold a lot of responsibility on your shoulders. And I think that, you know, it's hard sometimes to get that balance and focus on, on filling your own cup up instead of filling everyone else's as well. So, it's a constant battle, in all honesty. And I don't know if there's a, a right, a right answer for it apart from just talking it out when you can. And obviously we do VBRP as well, which is always really helpful. It's helpful to do it with the group of nurses that I do who all do similar roles, work with different diseases, but we all hold the same kind of responsibility and the same kind of themes that, that we work through with loss and, and death and you know grief and things like that. And it, it kind of makes me feel a bit sane, more sane when I know that I'm not the only person experiencing some of the feelings that, that we do experience in these jobs as well, so.

**LI:** So, it's, so it's so important to, to be, and I suppose in my role, particularly outwith my educator role, I’m a chaplain with responsibility for staff care. And so, I suppose I kind of focus on how do we, how do we remember that the people who are, who are caring for people need cared for too, and how and how do we prioritise that as a, as a kind of service as a, as a nation? You know, it's bigger than just kind of being here in Fife. It's bigger than Scotland. It's actually, it's a kind of global, how do we care for, how do we care for the carers? How do we make sure that they're, that they are held, that they are supported, that the burden of what they're hearing and listening to and responding to and you know, my, my heart's breaking for you talking about driving from person to person and the tears rolling down your eyes. And then you have to get out of the car and, and pretend that that wasn't the case. And I was thinking about how we, we know people are, you know, people don't pretend to be depressed, people pretend to be ok. And, and here you were driving between people and because you're a professional and, you know, you've got to kind of put your professional kind of face on. You managed to do that, get yourself together, get out of the car, go into the next house and, and start that all over again. But actually, we haven't, I think we have an obligation. We have a responsibility to care for, for the people that are caring and, and that that's something that's, as you know, very kind of dear to my heart as to how, how we do that better. I was thinking about going back to what you were talking about with patients, you were talking about the burden of care on, on the families to care for the person that's, that's, that has MND, and I was wondering about what about the people that don't have family to help care for them. What, what kind of support, because you said there isn't 24 hours care support and people don't want to come into hospital. So, what do you do in those circumstances?

**LG:** It's probably more rare…

**LI:** Right ok.

**LG:** …that there's not any, any family around, although it has happened in the past. There has been a few patients that I've had that have had this diagnosis of MND and, and they've not had a lot of support around them. And I've thought, gosh, what are we going to do when they can no longer go to the bathroom on their own? When they can no longer go out their house on their own, when they can no longer, you know, move that cup up to their mouth or move that, that fork up to their mouth to feed themselves. And what are we going to do in this scenario? And obviously, you know, I think at that point it's just about being really honest. I don't beat about the bush, it’s not, it’s just not who I am. I don't tiptoe around any difficult discussions with, with people. I just, I'm very transparent. I'm very, you know, honest about what, what I envision this to be like for this person. And obviously all MND patients are different. Every single patient on my caseload is different. But what we do know is at times there's going to be difficulties and they're going to need a lot of support, whether that's with eating and drinking, whether that's with breathing, whether that's with, you know, loss of upper limb or loss of lower limb there, there's going to need to be some form of support and probably quite a lot of complex support that they require at some point within their disease. And I think, you know, when patients say to me, you know, I want, I want to be at home that's my preferred place of care, I also want to die at home. And, and you know, who am I to say no, you're not allowed to do that. And, and we will do everything to, to, you know, try to allow people's wishes to be upheld if that's what they wish to be at home. And we're actually very, very good at it keeping MND patients at home for end-of-life care and things as well. But I think a lot of that comes from just being really, really honest. So, I will often say to people, you know, this, this is going to be hard. This is going to be challenging. I'm worried about your ability to look after yourself within your own home or, or whatever it may be. And I think it's just about, yeah, kind of back to basics about listening and actively actually listening to what the patient wants and what their views are. And, and, and then being honest about how we can support from the NHS or from Fife Council or just from the wider team around right what can we offer you and what are our limitations? You know, we can't provide a 24-hour care package. It's not a thing that we're able to do, but you'll have four times a day package of care. You know, we do get support from Marie Curie and things overnight at times as well, but nothing like that is guaranteed. So, it's just about being honest about there will be times where you know you will be on your own or your family will be picking up those pieces between the visits or overnight and just kind of being consistent and, and realistic I think is the biggest thing for me, you know, it's a hard disease. I'm not going to hide that from anyone that's diagnosed with it. They're going to live that. So, whether I tell a lie or don't tell, you know, the full truth of how difficult things will be, they are going to face that at some point. So, I think it's just been really upfront with them and honest and, and being realistic about what we can offer, what we can't offer and then putting in those kind of boundaries. And I guess, you know, if patients still want to stay at home. I did have one lady who wanted to stay at home. She didn't have any support really around her. She sadly kind of lost her lower limb function, upper limb function, our speech and swallow and she was in a wheelchair. And there was a lot of times where social work were thinking, you know, she needs to probably go into to somewhere for 24-hour care, but she was adamant she was not going in. And the district nurses that I worked with, with this lady were absolutely incredible. Honestly, those, those nurses were just brilliant. We did a lot of joint visits. We did a lot of like, you know, how, let's think outside the box, how can we make this happen but make it happen safely as well. And a lot of that was just actually having these honest conversations and saying, you know, I am worried that overnight if you're sick, how, how you can't move. So how are you going to be able to call for help or get yourself onto your side? But she accepted the risks. And I think a lot can be said for that as well. You know, as nurses, it's our role to, to educate and, you know, educate them about the disease, about what might happen, about what our worries are and, and what support we feel that they, they might, you know, benefit from. But ultimately, if they've been given all the right information and they still choose to do something, that might not be what we really want them to do. As long as they're accepting of that risk, it's their life, it’s their wishes, and then it's our job to support that as, as well as we can. But understanding that they're accepting of these risks as well, that's a hard thing to take on. And it's a hard thing if you're the nurse who's saying, yes, you can stay at home. Yes, there's huge risks, There's all of these risks around, but you're accepting of these risks, and you're kind of, you almost feel like you're putting it onto your shoulders. You know, you're the one that's saying let's keep you at home, but this might not go very well…

**LI:** Yeah.

**LG:** …as well. So, yeah, it, it, it's tough. I think I've maybe sidetracked a little bit there as well.

**LI:** That's ok.

**LG:** But yeah, I think it, I think it is. It's just about being, being honest and listening and, and being consistent with your approach to care and being realistic about what we can offer. You know, we can't offer a whole singing and dancing package of care for people out in the community, but we can make them known what is available to them.

**LI:** Yeah, yeah. I don't, I don't think that was sidetracked because I actually asked you what you, how you supported people who maybe didn't have family…

**LG:** Oh yeah.

**LI:** …and actually then you can, you've spoken about the risks of pertaining around that. So that's very specific to them. But also, what you then spoke about was how person centred that can still be, even though there's a probably a bit of burden for you, a bit of responsibility for you that you may not really want and, and you've taken on the risks. And even though you've taken it on with your district nurse colleagues and they sounded phenomenal in terms of the support that they were, they were given that this lady as well, that actually that, that nevertheless remains that, that that burden and, and how we, how we manage the burden…

**LG:** Yep.

**LI:** …of responsibility.

**LG:** I think for the patient herself as well, like she always fed back to say, like, I'm just thankful that you're always so honest.

**LI:** Right.

**LG:** She's like, you don't always say what I want to hear, but you're always honest with me. And like that kind of stuck with me as well because I just thought, you know, it's not what she wants to hear. She wants me to say, yes, everything will be fine and, and great. And she didn't want to hear what I went through and my, and my worries about her being at home on her own. But, but ultimately, like, she appreciated the honesty that, that, that we gave her as a, as a wider team. And, you know, district nurses were great in supporting me with, with these visits and things as well. And to the point where, you know, this lady wrote her eulogy for her funeral.

**LI:** Oh right.

**LG:** I think I might have mentioned this to you before.

**LI:** I think you maybe have in the past before.

**LG:** Yeah. So, I actually helped her write her own eulogy for her funeral. And, and we worked through it for, for a wee while back and forward together. And then she sent it to me and asked if I would speak at her funeral and, and, and say, say the eulogy, you know, read the eulogy out which, which I did. And again, it's one of these things I don't think I'll ever forget because I think she trusted me so much with that information and that vulnerability and about, you know, about, yeah, like I, I, I was just her nurse. I was just her specialist nurse, like, but she, she, she gave that responsibility to me. And, and I obviously feel hugely privileged that she did do that. And even when reading out her funeral, you know, you can hear her cheekiness and her stubbornness because she was stubborn. And you can hear it through what she was saying, through the words I was reading. And it was just, and the district nurses were sitting in the front row that, that looked after her as well. They come to her funeral. And we were all just kind of happy tears. But, but, you know, laughing at, you know, thinking about all these memories. She was an incredible lady, but a very stubborn one at that. And, and very much tested, tested our boundaries and, and, and made us have to think outside the box a lot. But yeah, incredible. Nice, nice memory.

**LI:** I'm going to come back at you and just say, I wonder if there's any just. Any just, I'm just a clinical nurse specialist. I'm just her nurse. I wonder if that, that is such a thing. I'm going to say I don't think it is.

**LG:** Yeah.

**LI:** I think what you did was pretty special.

**LG:** I guess we, I guess we just view ourselves as like a tiny, well I certainly do is that I'm just a small part of their story. And it's not my story…

**LI:** Yeah.

**LG:** …it's their story.

**LI:** Yeah, yeah.

**LG:** And, and I'm just a, a small part that, that pops in and out of that, that story. And, but I guess you know, the, the way what's like that quote that you, you always read everywhere, it’s like it's not, it's not about what you say, it's, it's how you made them feel or something like that.

**LI:** Yeah, yeah. Maya Angelou.

**LG:** And yeah, and I guess like that, that, that pops up everywhere, doesn't it? All over social media all the time. And I guess that's true, isn't it? Because…

**LI:** Yeah absolutely.

**LG:** …you know, might not remember what I've said or, or what I've, I've, I've done, but they will remember the way that I made them feel at that point. So…

**LI:** Yeah.

**LG:** …you know, you can't measure a lot of the work that we do in these roles. All this…

**LI:** Yeah, that's right.

**LG:** …spiritual because we do, we do a lot of spiritual care.

**LI:** Yeah, you do.

**LG:** And, and you know, a lot of emotional support and a lot of kind of counselling skills and things like that in this, this job and, but we can't measure it, or we don't measure it. But I guess it can be measured on the feedback that you get and that lasting impression that you give to families.

**LI:** I think measured by the fact that in this case that she asked you to, to read out her eulogy at her funeral.

**LG:** Yeah.

**LI:** You know that that's that kind of qualitative measurement of, of how much she trusted you. And I know you're saying there as a small part in her story, but in that, in that time, you were a probably a big part in her life, you know, over the period of time that you looked after her and, and phenomenally so in that she asked you to do that. You know, that was you were somebody she trusted.

**LG:** Yeah.

**LI:** You, you made, you made her feel like she mattered that she was important. That her voice mattered. Even when she couldn't use her voice potentially, you know, you made her feel like that, that that she was important. She gave you her voice at the end of her life, didn't she? To, to read out her eulogy.

**LG**: God, yeah. God, you're making me feel emotional now. If you look at that, that bigger picture, don't you?

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

**LG:** Yeah.

**LG:** It's quite, it's quite amazing…

**LI:** So…

**LG:** …actually.

**LI:** Kind of as we get towards the end of the podcast at this point, I'm usually kind of saying thinking about, ok, how do we, how could you do this even better than you're currently doing it? But I'm not sure, I'm not sure you can do this even better. I feel like you're doing this so well that I'm not sure what you could add, you could add that's better. But we always try and say that there's always something better we can do.

**LG:** I probably have my own ideas about what I would like to do for the service. And obviously, you know, it's, it's four years, but a lot of that was within COVID times. So, I feel like there's still a lot of things that I'll want to do for the service, and I want to develop for, for the MND nurse led service in Fife and how do we do that? And I think a huge thing for me is I'd love to bring people together face to face and bring these patients in Fife, you know, together for some kind of like drop-in support with their loved ones where there's no, there's no agenda, there's no, they don't need to come. They can come if they want to come. They don't need to come. They can stay for an hour, they can stay for 5 minutes, but just so they can come and meet other people who are also going through a lot of similarities and a lot of the same issues and just give, you know, their loved ones a chance to meet other people and, and try to facilitate that. And it's something that I'd love to try and achieve and it is on, on my list. It's just trying to get to it on the list.

**LI:** Yeah.

**LG:** It's the hard part, but I'd love to be able to do that. And I think that would potentially, you know, show the carers that, that, you know, we do appreciate everything that they're doing and we do value their massive, massive input, I mean, without, without the family at home, these patients would all sadly be within 24 hour care facilities and that would cost so much money to, to, to house all of these patients. And, you know, just, just to make them feel that they're not alone, I guess, and that we, we all appreciate what they're doing. And, and although they might feel a wee bit alone at times, like we, we, we do value them I guess as well.

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

**LG:** And we value where they're at in their grief and, and how much they'll, they're losing as well with their loved one, you know, deteriorating and things like that as well. So, I'd love, I'd love to do that. It's definitely a big thing that I would love to set up some kind of drop in kind of support thing. I'm not really sure how it looks yet, but…

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

**LG:** …it's in my head. I just need to get it…

**LI:** Yeah.

**LG:** …get it out and, and do something about it, I guess. But I guess that would, you know, tick the box of, of giving a wee bit more out for the carers…

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

**LG: …**as well.

**LI:** That sounds very generous and kind as well to, to want to do that. So, I think we've probably come to the end of the podcast and just want to say thank you so much for sharing what you've shared really honestly, very vulnerably as well. And I feel, I feel a bit emotional as well, but also really inspired by what you're doing.

**LG:** Thank you.

**LI:** So, thank you so much, Louise.

**LG:** Thank you so much for having me. You know, I feel a bit emotional also. It's weird when you start to talk, talk through it, isn't it? But yeah, no, I appreciate, I appreciate you asking me to come on the podcast. Thank you so much.

**LI:** Thank you.

The podcast was recorded in October 2024 and can be found at <https://www.sad.scot.nhs.uk/podcast/> or <https://open.spotify.com/show/11AORpjHqbsYwgg1DJUtLk?si=687dba351d1f45d4>

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