**NHS Education for Scotland**

**Talking about Bereavement Podcast Series – Transcript of ‘Supporting families through a bereavement in pregnancy: A bereavement support midwife’s perspective’ Podcast**

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**Speaker**: Marcia Dean, Bereavement Support Midwife, NHS Grampian (MD)

**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 have been involved in as they talk about their experience of bereavement.

Hi and welcome to this episode of the podcast. I'm delighted to introduce my guest today as Marcia Dean. Marcia is a bereavement support midwife in NHS Grampian based at Dr Grays in Elgin. She moved from Edinburgh in 2000 to the Northeast of Scotland to take up a position on the maternity ward at Dr Grays in Elgin and over the years she has worked in all areas of maternity, caring for women and their families during the antenatal period, intrapartum and postnatally. Recently she's taken on the role of bereavement support midwife. She is passionate about ensuring staff have the skills and confidence to provide good bereavement care and that every family going through a loss have the support that they need. Welcome Marcia and thank you so much for joining us today.

**MD:** Thank you for having me. It’s a pleasure.

**LI:** I wonder I've given a brief introduction of, of what you, what you currently do and I wonder if you would like to just expand on that a bit more and tell us a bit more about yourself and how you've got to where you are in terms of your life and work.

**MD:** Sure, I remember even as a student being really interested and finding bereavement something that I enjoyed, which sounds a, a really strange thing to say, but I got a lot of, sort of reward from giving good bereavement care. So, in the last few years a position came up where I was asked to help embed the, be part of the pilot for the National Bereavement Care Pathways in Grampian, which was just 7 hours a week. Looking at the pathways and how we could embed those into everyone's care and into staff's knowledge on bereavement, which I really enjoyed. And it's sort of grown arms and legs. And through that I now find myself in having three days a week as the bereavement support midwife at Dr Grays, which is an absolute new position. It's never, never had it here in Dr Grays. We had a bereavement midwife that oversaw Grampian, but this is new to this hospital. So, it's, it's a challenge. There's lots of things to put in place and to make sure that we are providing, but it's really exciting. And so basically it's looking at if the, you know, the pathways, there's five pathways looking at each aspect of pregnancy loss from miscarriage, ectopic and molar pregnancy, termination for foetal abnormalities, stillbirth, your unexpected neonatal death and neonatal deaths. And throughout those pathways, there's nine standards that sort of oversee them all.

**LI:** Ok.

**MD:** And it's just making sure that all those standards are met within our care and within the hospital. Given it's sort of a parent led where they're given the information, they're given the options and they can make the choices that's best for, for them at the time. So, it's, it's quite exciting, challenging and scary.

**LI:** Yeah.

**MD:** So yeah.

**LI:** And is and is, is that are you supporting families through making these decisions as well?

**MD:** So, part of my role is being that support for families. They'll, they'll get the, the clinical care and the emotional care on the ward when they come in and a miscarriage is diagnosed or a stillbirth. So, they get that care. My role is that's aftercare because as we all know, a bereavement in childcare is in pregnancy is so different to any other bereavement. We don't plan for these. We, we are very aware that our parents may die or you know, but we never ever think going into a pregnancy we'll have to organise a funeral for our baby.

**LI:** Yeah.

**MD:** So, it's given that support to families, giving them the options, letting them know that they can, they have choices they don't have to do. It's not, this is what we say you need to do, you need to have this, you need to have that. It's not these are all the options, what's right for you, ‘cause what's right for one family will be quite different for another. So, my role is to make sure that they've got that opportunity of making memories, and we always say through memories. That's photographs, hand and footprints, bathing their baby if that's something they want to do, taking their baby home, if they want to take their baby home, making sure that we can give them the support to do that and then giving them the support from other agencies, you know, making sure they know that they can get in touch with Sands, Tommy's, Held in our hearts, The Miscarriage Association. There's lots of support out there, but when you're in that situation, it can be quite difficult to make that move and, and find that support. So, my role again is just helping them link in with third sector organisations to carry on that journey. And I, I stay in touch with them for as long as they need me. And then I, they often get back in touch. A lot of my, my role is in a next pregnancy because this bereavement never really ends.

**LI:** Yeah.

**MD:** And we need to make sure that we're there for them in that next pregnancy because that's a really difficult time. So, and that's probably the, the nice side of my job, the where there's another pregnancy and helping them through that to them seeing a hopefully successful end, which it doesn't always happen. You know, there are women that have several miscarriages. So, supporting them through that. So yeah, it's, there's a lot to it. It's not just that initial bereavement.

**LI:** Yeah, it does sound like there's a lot to it I suppose. It's a very supportive role, isn't it? I mean, that's, that's in essence what you're doing. I suppose it's got me wondering what, what support do you get as you carry out this role?

**MD:** Yeah, I think we, we, there's a team of three of us within Grampian and we do all support each other. Definitely. We also have within midwifery, we have clinical supervision and that is a good sort of support for us. And also, the psychological teams, they have a, a meeting with us once a month…

**LI:** Ok.

**MD:** …where we can tap in with them and say, I'm struggling with this. I'm not sure where I, I fit in, and they will help us with that emotional support. But also, Sands, they have for staff, they have a helpline that we can contact and that's for all staff. The Miscarriage Association have help lines. A lot of the third sector also support staff, which is really…

**LI:** Yeah.

**MD:** …really invaluable to be able to, especially if you want to talk to someone that maybe doesn't know you or doesn't know the area you work in, you want that. Sort of, you’re not wanting…

**LI:** Anonymity.

**MD:** Yeah, yeah.

**LI:** Yeah, yeah.

**MD:** …you want to sort of remain anonymous, but you want to speak to somebody about it.

**LI:** Yeah, yeah.

**MD:** So, there's, there's definitely a lot of support out there for staff caring for bereavement in pregnancy.

**LI:** That's quite reassuring, isn't it…

**MD:** It is.

**LI:** …that, that is that level of support for you because I imagine your job is, is quite heavy and, and, and…

**MD:** It is.

**LI:** …from day-to-day and.

**MD:** Yeah, but I think I'm quite an optimistic person…

**LI:** Ok.

**MD:** …and I have quite, I don't know. I, I, I always think there's, I'm always amazed at the strength of the, the families that go through a loss. They all are, are so strong, so brave. And their sort of strength that gives me a lot of sort of it, it helps support me, when I see how strong they can be anything, well, I can, I can. And so that makes it easier as well. So, yeah.

**LI:** I suppose just looking at your kind of, you know, your journey to, to, to come into this role, I'm wondering, and this was a new role, I think if that's right, if that's what you said…

**MD:** Yeah.

**LI:** …what, what kind of, you said you'd been interested in bereavement even as a student even you'd kind of thought about bereavement. What was the kind of catalyst to move into this role for you?

**MD:** I think I always felt we could do more. We could, I don't know, support families better and for longer even, you know, if, I just recently I met with a family who had had a loss 10 years ago, who had good support and clinical care, but once they left the hospital felt very abandoned and there was nothing. And I think we do that better now. We support these families in their journey moving forward. So, I always thought we could make that journey easier for them, we could support them more. Bereavement, it doesn't happen to everyone in pregnancy. So, it's kind of down at the bottom of everybody's agenda. You know, we spend a lot of money in lovely birthing rooms and on antenatal education and things, but bereavement gets kind of left to the end. So I was, when the bereavement care pathways came out and made it mandatory for a hospital to have a suitable room to care for these families that was away from the, the busy ward and was just for bereavement. To me that was like why, why have we waited so long to do that?

**LI:** Yeah.

**MD:** This is something we've always should have had and we should be able to provide for every family. And a lot of the things that we do provide are they're through Sands and Tommy's and all these other agencies that provide us with memory boxes and provide us with cool cots and things like that. And it always made me feel a bit, well, why, why don't we provide these things? Why have we not got that? So, I just feel it's such an important time in a family's life and long lasting, you know, this, the pain they suffered never goes away. They learn to live with it. And I've had family myself in the past. I had an auntie who had a loss which would have been over 50 years ago. She never saw her baby. She never got pictures of her baby or anything, there was, her baby was taken away and I just think we've come so far, but we could just do even so much more. It's just so important that these families get to remember their baby and have time with their baby in a safe and area where they, they feel safe and held.

**LI:** Yeah, yeah.

**MD:** I think that's, I think my, my role is just to hold these families until they're able to just go out on their own because it is just such a devastating thing to go through. Yeah.

**LI:** And that's a lovely, a lovely thing to, to say actually, that your role is to hold these families until they're ready to, to go on their own. And it feels very compassionate and caring and, and actually back to the roots of why, why we came into this…

**MD:** Yeah.

**LI:** …these roles in the first place, doesn't it? It’s that yeah.

**MD:** I think as, as nurses and midwives, you want to fix things and we can't fix this.

**LI:** No, no.

**MD:** You know, we always want to make everything better and, and we can't. But we can improve and make it easier for these families, you know, and just be there for them and for the staff as well. You know, I for, coming into this role, we've, we've now got structured training for staff that we make sure that they can attend. And, and that's really important because I don't think you can provide the care, if you're not confident in providing that care and confident of what you're saying that comes across, the families pick up on that and then they don't feel that they're getting the right care. So, we have to make sure that our staff are confident and competent in what they're doing. And if they feel happy, that just has such a knock-on effect. You know the…

**LI:** Yeah, absolutely…

**MD:** …the families get that. Oh, she knew what she was doing, she was, she was caring, and she knew and I was, I felt happy leaving my baby in their care because inevitably these families leave without their baby.

**LI:** Yeah, yeah.

**MD:** And that's, you know, that they feel that whoever's left with their baby's going to look after it until it's moved to the next is so important. So, yeah.

**LI:** And, and so does the training that you give to the staff, is that something you do or is that national training or what does that look like?

**MD:** We have Sands training twice a year. Where a trainer from Sands comes through. We hold a full day in Elgin and Aberdeen have a half, two half days and all staff are invited. It's not just midwives, healthcare support workers, doctors, definitely doctors.

**LI:** Ok.

**MD:** We always want doctors. We have some psychologists that have joined us before, counsellors, family nurse practitioners, health visitors, they all join us and it's a full day looking at sort of communication, memory making and next pregnancy. And we usually hear from a, a parent's, a parent's voice and that's always probably the, the best bit of the day and the, the bit that everyone walks away remembering, you know, how a parent felt when they were going through a loss. So, we do that. We also have in house training. We've recently started through the, the pathways. We decided the pathways are so massive. There's so many of them. How do we share that with all the staff that come across someone that's experiencing a, a loss? So, we've got champions in each area of maternity who know the pathways and how the pathways affect their area of work. So, a champion in the scanning department will be different to a champion in community. They have a different sort of perspective of what they need to share and know. So, our champions do a bit of sort of in-house tea-trolley training we call it it's sort of 10 - 15 minutes where they'll just share something very simple. So, in the scan department, making sure that everyone that's scanning ensures that families are given a scan picture…

**LI:** Ok.

**MD:** …or offered a scan picture. Even if it's very early loss and they maybe think of they're not going to want this picture to that family. It's maybe very important.

**LI:** Yeah.

**MD:** So, just making sure things like that are kept in the sort of forefront because staff change, there's a turnover. So, we need to make sure that there's always, everyone's aware. On the ward there's always changes in paperwork. And sort of the disposal of early losses, how those are, you know, what signatures we need. And so new staff coming in, they need to make sure we know that they're up to date on that. So again, the, the champion on the ward will maybe just do a wee bit of training on that. And we've got photography training coming up for some staff as well.

**LI:** Ah right, right.

**MD:** So, taking pictures of these babies.

**LI:** Yes.

**MD:** We, we use Remember My Baby who come in and take professional pictures of losses over 20 weeks, but anything earlier than that, so, sort of losses at 15 - 16 weeks, if the parents want pictures, we will take the staff take pictures and it's just how they will do that in a sensitive way. And, you know, taking pictures of hands or feet, you might not want a picture of the baby because it may not look the best, but little feet and little hands can always be made to look lovely. And that's something that the parents can treasure.

**LI:** Yeah.

**MD:** So doing training like that with staff is important as well.

**LI:** Yeah. It's quite a when you, you start to talk about it, there's quite a lot of areas that I probably hadn't really thought about myself. And so, it's like broad.

**MD:** Yeah. And parents, you know, until you're in that. So, you, you don't know, you know, why would you even know that we take pictures of a dead baby. And to some parents, they're like, oh, I don't know.

**LI:** Yeah.

**MD:** But then once you speak to them about it and they realise this is their only chance to have these pictures, you know, they're not going to get this again. They, they see, yeah, that would be a good idea. And involving the parents in the pictures as well, you know, having pictures of mum and dad holding the baby can be really…

**LI:** Yeah, yeah.

**MD:** …really helpful with, with them moving forward in the future. So, yeah, there's, there are, there's lots of things. And it's, it's about sharing all these options with the parents so that they can then make their choice and then decide what's right for them.

**LI:** So, it sounds like you're, you're doing this all really well. And I suppose I wonder how do you continue? How do you ensure that you continue to do this really well? And training obviously is a part of that.

**MD:** Yeah, training. But I think listening to the parents, the parents voices are so important. They tell us what helps, of what was of benefit and we'll implement that, you know, so it's, it is keeping in touch with these parents, finding out what was good, what was bad, what could we have done better and making improvements, you know, not thinking right we're, we're doing the pathways now. That's us. We're, we're sorted. We're really not. We need to keep going. I don't think we'll ever have the pathways that they're sort of embedded and everybody's just doing it. We, they will evolve.

**LI:** Yeah, yeah.

**MD:** They'll change as, as we learn new things, you know, as, as we learn, we'll change the pathways and improve our care. But yeah, listening to the parents, I think they're, they have the most important voice in all of this. And they can tell us what we're doing right, what we're doing wrong and how we can do it better.

**LI:** Yeah, yeah.

**MD:** That would be, yeah. So, feedback from parents is the thing that we, we treasure.

**LI:** And is there anything that you've heard, I suppose, in terms of the ways to do this even better that you've kind of that you might have implemented or changed as a consequence of hearing that…

**MD:** Yeah.

**LI:** …that voice.

**MD:** In the past I would take baby out to do hand and footprints and take pictures and things like that. And then speaking to, it was hearing a parent talk. And she said she would have loved to have, she never saw her baby's bottom. And I thought, oh god, you know, so now I, I will always encourage parents to, to look at their baby to, to take the clothes, you know, see it without its clothes on, to dress it their self, to do the hand and footprints their self. And I heard someone talking about there's memory making and there's memory harvesting and memory harvesting is when we do it.

**LI:** Ok.

**MD:** That's not making a memory for the family.

**LI:** Ok.

**MD:** And what we want to do is for the family to look back and remember when we made our baby Jack's hand and footprints, when we did those, we did those hand and footprints. That was something we did with our baby…

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

**MD:** …rather than the midwife did it.

**LI:** Yeah, yeah.

**MD:** So, I, I suppose I've changed how I go about making those memories. I think as well just words we use. You know, in the past we, we would have used words like products of conception for an early loss. And to us that sounds, yes, that's what it. But to that family that was a baby, whether it was 4 weeks, 5 weeks or 24 weeks, it was their baby. So, I think now I'll follow what the parents refer to…

**LI:** Ok.

**MD:** …you know, if they call it their baby, then I will refer to it as their baby. So, taking the lead from the parents and really thinking about the words you use and how you use them because that's so important. They, you know, things like that. They can really, you know yourself. If someone said something, it's the words they've used that can something is really grate on you and have a lasting effect.

**LI:** Yes.

**MD:** So just watching your, your, your language, and if you don't know what to say, just don't say anything. Or if you do make a mistake, you, you say something and you think, oh, that was so insensitive. Just saying, I'm sorry that came out wrong. I didn't mean it like that, you know, and I think once it proves you're human, that, yeah, we, we do sometimes get it wrong. So, yeah, just listening to the parents.

**LI:** I'm thinking about, I'm obviously reflecting as you're speaking on what you're saying and thinking about this all sounds so kind and gentle and as a kind of way of being with people that's very precious really. And but, but so important that that that you know that. Yeah, I think what you're describing is, is what we're, what we're all kind of trying to aspire to. And what we've, you know, want to aspire to is to be kind and gentle and to be compassionate and caring and loving and, and, and it feels like that's what you're doing, or it sounds like that's what you're doing.

**MD:** It's what we, we try to do. I suppose there's always that if we had more time, if we had more resources and staff, we could spend longer. But I think we do here, you know, we, we do within sort of maternity and bereavement, we do spend time with these families. We do give them that time. We never rush a bereaved family out. If they want to stay here with their baby for two or three days, then that's absolutely fine. We wouldn't, we wouldn't rush them. If they want to take their baby home and have their baby with them at home, we will make sure we can help them with that.

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

**MD:** Providing cool cots and things for at home. So, I think it is just about giving parents time because it's such a precious thing. They don't have a lot of time with their, their baby.

**LI:** Yeah, yeah.

**MD:** So, it's about making sure what time they do have. We can make the best memories for them, although a very sad time, they can look back on it with a lot of joy almost where they, they, they remember some of it as being a nice experience and the best it could be. So, yeah, it is, it's, it's a, it's an honour to look after these, these families, you know, to be part of their, their journey and their story.

**LI:** Yeah.

**MD:** It really is. And I think we have to not forget that this, you know, they, they, they leave us, and they go on. And there's so many families that I will think of regularly and wonder how are they now? Or but we've got to remember they're going on to, to live with this grief forever, you know…

**LI:** Yeah, I know.

**MD:** …and how, how can we help them to do that in a, a way that's healthy, you know, that they can still live a, a happy life with, within that sadness.

**LI:** Yeah, I suppose as we, you know, reflecting on what you've said as we come to the end of the podcast, I wonder what things you would, you know, what would you, how would you summarise? And you maybe already feel like you've done it actually, but what would, what would be kind of anything you wanted to say to summarise what you do and what you offer?

**MD:** I think, I hope I, I hope that families feel supported and that I'm, I'm not, I'm not trying to be their friend, but I'm trying to be friendly. I hope that I'm somebody that they can trust. That they can know I will do my best. I can't, I can't make it better, but I will do my best to make it as good as we can for some family. And I suppose it's like everything, you know, we, we, with some families, you'll make a real connection with, with others, it's much more difficult. But it's about just trying to say to be the same and give everyone the same level of care and attention so that everyone feels supported and able to, to move on in their life. It's like one person once said to me, you were the midwife I really didn't want to meet, but I'm so glad that you were there at that time. And I always remember that ‘cause nobody does want to meet me, you know?

**LI:** No, no.

**MD:** And it would be great if my job didn't exist. But I hope that when they have met me that I've made a little bit of difference. I've made it a little bit easier for them. Grief is a sad, it's a horrible thing to go through on your own. So, and baby loss can feel very lonely. A lot of especially early on or families that have had a termination for medical reasons for a foetal anomaly or something can feel very alone and not able to talk about it or share it with people. So, I hope I just make their journey a little less lonely. I think that's what I, I hope to do.

**LI:** Well, thank you, Marcia. That was a lovely way to end this podcast. And thank you so much for taking the time to, to be part of it. We're very grateful to you for sharing what you do…

**MD:** Thank you.

**LI:** …and what you offer.

**MD:** No, thank you for giving us this opportunity to share and let people know what we do, and you know, be happy to share it with anybody that's wanting to know anything more. If they want to get in touch. Much more than happy to chat about it.

**LI:** Thank you so much.

**MD:** You're welcome.

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

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