**NHS Education for Scotland**

**Talking about Bereavement Podcast Series - Transcript of ‘Finding hope: An Advanced Cancer Nurse Specialists perspective’ Podcast**

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**Speaker**: Amanda Gabor, Advanced Cancer Nurse Specialist, NHS Fife

**LI:** 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 by sharing with you some of the work and learning our team is involved in as well as hearing from our guests. In this podcast we will hear from Amanda Gabor, who is an Advanced Cancer Nurse Specialist in cancers of unknown primaries, brain, sarcoma and other rare tumours. Amanda has been an oncology nurse for nearly 15 years. She started her career at the Edinburgh Cancer Centre, working in a variety of roles including inpatient oncology wards, outpatient chemotherapy unit and haematology. She moved to NHS Fife to take on the role of a Clinical Nurse Specialist in 2021 and set up a service for cancer of unknown primary, neuro-oncology and sarcoma. She's been doing this role now for two and a half years working as a sole practitioner, which she says can be challenging, but it has also enabled her to develop and grow a truly person-centred service for the people in her care.

**LI:** So, hello Amanda, and thank you so much for, for joining me today on the Talking about Bereavement podcast. It's very kind of you to agree to talk about this. So how are you and how is your day?

**AG:** I'm good. My day is probably challenging, as chaotic as ever, but I'm going on annual leave, so I feel like I'm quite bouncy and I'm on the countdown.

**LI:** Yeah, so you’re, you’re not, you only got a couple of days to go?

**AG:** I’ve got it, well, after I've done this, I've got two days left to work, so not that I'm counting. So, my office say I'm more like Tigger because I'm very bouncy around the office now because I'm about to get into holiday mode. So.

**LI:** Yeah, yeah, you’ll be starting to lower everyone else’s morale now, as you plan for your holiday.

**AG:** I think they’re all a bit panicked that they're going to have to start doing some of my work…

**LI:** Ah right, okay.

**AG:** …and how I'm going to hand my patients over.

**LI:** So, thanks so much for, for joining us. And I wonder if you, I know that you, you support people in, in, in bereavement in the role that you do. But I suppose it's just to find out a wee bit more about what, what you do to support people in bereavement.

**AG:** Yes so, I suppose my caseload of patients I work with patients that have got cancers of unknown primary and neuro-oncology brain tumours is probably the, the main basis. I also do sarcomas but that's a very small part of my job. So, a lot of these patients have quite poor prognosis. Quite a lot of the cancers of unknown primary are best supportive care at the point of diagnosis. So, I suppose you're immediately preparing them and their family for the fact that they are going to die. So, a lot of my work revolves around you know, supporting them with that, you know helping them process that and come to terms with that information and, and the timescales can be quite small. So, you know, sometimes it's a number of weeks. I've had patients that have only survived a week from clinic to then, to then them passing away. So, it happens very quickly. So, getting them, their head round the, the, you know they've just kind of got diagnosed with cancer and then suddenly you're saying there's no treatment and then suddenly they have to face that they're dying and that happens really, really quickly. There's not really any time to process one lot of information before they, you know they, they’re having to move on to the next stage. So, so that can be quite challenging.

**LI:** And how, I mean I suppose I’m immediately thinking about youin the middle of all this as well and, and how do you, what are your kind of support mechanisms and, and strategies for, for dealing with this yourself?

**AG:** I don't always know. I think I'm quite a cheery person so I, I don't know. I suppose I like to say it's, it's quite sad. But you know, I, I like to feel that you know you're, you're supporting them and it's, it's not always sad like there's quite a lot of humour, that there's quite a lot of chat and you know, I built, I try to build a rapport quite quickly and, and find out what makes that person tick, what's important to them. You know, I get to know them, their family, you know grandchildren. You know, I'm asked all these questions and, and then from there you kind of, I suppose you're trying to integrate yourselves into their family and become part of that. And then you know, although it's sad, you know, I'm preparing them to die. But there is lots of stuff in that. Like you know there's lots of happy moments that you know, I had a patient who wanted, she wanted, she wanted to get married. She was older, but she wanted I think to renew her vows. And, you know, I wasn't very hopeful that she would get to, to her wedding day. I think she was a little bit optimistic but, you know, along that way of getting there and she never did make it to the, the date she had for a wedding, but she went, she wanted to go wedding dress shopping. So, she arranged even though she was quite poorly, she arranged to go wedding dress shopping and she sent me pictures. She had champagne. And you know, so you know, I think, you know, although she was sitting knowing she's going to die at some point, you know, there, there is happy moments along that journey. And for some there, there big things like, you know, a grandchild coming along or, you know, wanting to get to a wedding or, and for others, they're quite small. I had someone in hospital who was imminently dying and he just wanted a certain food from a restaurant. He wanted to go home. So, then he could order, he wasn't eating very much. But you know, this is what he really fancied. He really fancied this thing you know, so when he got home, like, you know, that was the conversation I had with his wife. Like did he get that? Did he order it? And, you know, so it's these little things that, you know, seem, I suppose, insignificant, to you know, in amongst all the medical stuff that's going on, you know, might not seem as important, but it's those things that matter. And, and they are the things that give people, you know, when you've got this horrible news and you're facing death and dying and, and, and for some it's the thought of death and dying in a horrible way. You know, people imagine it’s going to be painful. It's going to be horrible. So, a lot of my job is a) telling them it's not and reassuring them that actually we're going to manage every symptom and make them as comfortable as possible. But it's also about finding out what's important to them. Like, what do they want to do with their time? Like, you know, my job is to give them quality time for as long as possible. But what do they want to do with that? And just kind of helping them see that they can still do stuff and encouraging them to, you know, not just kind of dwell on what's going to happen because, you know, we're very vague in our terms. But, you know, yeah, it's just giving them that little bit of hope, I suppose, that there is some stuff that they can still enjoy and, and they do. You know, I spend a lot of time with my bereavement calls after someone's died. And, you know, a lot of that comes up. We talk about funny moments or things that happened and, you know, how that person was. And I think that gives them something, you know, it's not just, I'm not just that medical personnel. It's that, you know, like I say, I like to try and get to know them and who they are and their character and what makes them tick. And just support them.

**LI:** Yeah, I'm really struck when you were speaking before, you actually said, give them hope. That's what it sounded like you were doing, and I was going to ask you, you know, how do, do people do, do you feel like there is hope in those moments for people?

**AG:** Yeah. I think there, there's always some hope. I think some of it's really, you know, it can be very small and, and it can be quite hard to see. And I think it depends how much time someone has. So, a, a lot of what I do is try and help them. You know, I, I read a quote just in [inaudible] and it was talking about like how hope is basically a small, a small bit of light in some darkness. So, and I, and I was joking with a colleague and she said, no, no, you are that light in that darkness. So, you know, and I, and I suppose that's what I like to you know, I suppose I like to think that I am that light. So, you give them this horrible news and then it's showing them that, that that it's not all bad and depressing and, and a lot of that is giving them information like being that constant support and being that contact. So, like, you know a lot of, a lot of people, people deal with things differently and it's about that adaptability. You adapt to how somebody wants to process this and how they want to manage it. So, some people might go a bit into denial. And I'm okay with that as long as I know they are, they understand and you know, we kind of, I kind of work along with them and just kind of give them the important information they need. But I don't push it on them. So, you know if they want to pretend you know like that lady wanted to pretend she was going to get married you know, she know, she knew she wouldn't probably survive that long but that gave her some hope. So, you know we just left her with that. For others it, you know, it's, they want to know everything. They want to know what's coming, and you know it's helping guide them at that. So, like we talk about their symptoms, we talk about what might happen and I had a, a relative that I spoke to and I did that every week up until his mum died, is that he would run through, it’s what he wanted to do, he wanted to run through everything that had happened that week, and all the symptoms and talk me through it. And then he wanted me to then tell him what to expect for that week and, and afterwards he said that was really helpful for him. He really found that, that helped it more manageable because he knew what to expect, he knew what was coming and he was, he was able to prepare for that and that worked for him, might not for somebody else. So, I, I think part of your role in supporting and finding hope is, is understanding what they want from you. Because it's not a, it's not a black and white, this is how we do our job. It's because they're humans. Everyone's different, everyone deals differently. But I do think there's always a way to find a bit of hope like something that, you know, there's something they can do, there’s something they can look forward to like and it could be, I met somebody yesterday in clinic and we went up to see them and you know, we told them really bad news that unfortunately they, you know, we confirmed they had a, a metastatic cancer that we didn't know where it started, that due to her comorbidities, she wouldn't be fit enough for any treatment. So, we weren't going to biopsy. And then, you know, so obviously that, they were all devastated, her and the whole family. And then her hope was, you know, they talked about actually they want to get her closer to home or home and they were, that was their fear is that she wouldn't get out of hospital. And you know, us saying actually, no, we can make that work. We can try and get you closer to home while we work out a plan and then so that people could visit her easier and that was their hope. That's what they wanted, that was what was important to them is to have that time.

**LI:** Yeah, yeah.

**AG:** So, you know it's just working out what people want, what's important to them and what they need and just trying to do your utmost to kind of fulfil that.

**LI:** And I'm really struck that a lot of, of what you're talking about there is actually, is spiritual care actually…

**AG:** Yeah.

**LI:** …and, and exploring what matters to people and what's important to them and, and what might bring them joy and what might bring them a bit of hope. So how does that feel for you as a nurse engaging in spiritual care with, with people?

**AG**: I think it feels good. I think, you know, we, we're always, we preach about holistic person-centred care but I don't think we're always very good at doing it. And I think part of the job, you know, when you go meet someone I think a lot of people stick to kind of medical and, you know, symptoms and you know, but they're all linked. And actually one of I, I, I learned from somebody, you know, when doing my assessments of patients, one of the things I always ask is what's causing you most concern because actually you know, what they talk about, and I, I might get latched on to something that I think’s more important, like they might talk about nausea, and I think right that's obviously the most important thing. But if you ask that question, people surprise you about things and it can be completely something that you think actually that's not even relevant, or that's not even a medical or, but you know, it's what's important to them and what's causing them the concern. So, I think if you put it into their ball court, you find out what they want to talk about and you focus on that and you know, obviously the everything else. But yeah, I do think a lot of us… and it's easier, it's easier to talk about medical, and things because it's maybe a bit more clear cut. But yeah, I think spiritual care is more it's the whole person. It's, it's what's making them tick, what's under… what's their personality, how they're going to process it, what they need from you and, and then adapting to that. So, I think it's really, really important.

**LI**: Yeah, absolutely. And, and, and you know, who supports you?

**AG**: You! So…yeah.

**LI**: Apart from me! That wasn’t a leading question!

**AG**: No, so, so I think that you know, I've got quite a close knit… you know, I do obviously Values Based Reflective Practice one-to-one, but I also do it in a team and I think that's really helpful doing it with the other CNSs, so you know, we, we find out that a lot of our common themes are similar. But I think a lot of my… you know, we talk about resilience and I suppose burnout and you know, and it can be quite easy, a lot of my job is taking on other people's emotions or anxieties or stress, you know, they offload if they've had a really bad experience. You know, it's me that gets all these problems, the complaints about hospital waiting… anything like that, you know, people offload onto me a lot. So, you do absorb and take a lot of that stuff on so it, it, it can be difficult and I'm not going to lie, I spend a lot of time tired but that also could be my kids! But I think a lot of what I do is I use music. I've talked about that before, like I try and build myself up. I take my dog for a walk. If I've had a particularly bad day, I just go walk the dog, but then I'm also in a very good office with people that understand oncology, so obviously having, sometimes having a little rant at them, just about, you know, you know some things that have happened. But yeah, I don't know if it's just I've also built up a bit of resilience. I've been in oncology for nearly 15 years I think, yeah. Over the time I'm just a bit stronger, a bit able to kind of draw a line under it. But I think it's also the benefit you see, so I, I, I call all my patients… once they've died, I call their family. So, I always call and check in and offer support and it's what they feedback to you. So, I, I spoke to a family on, I think on Monday, and they'd actually called me over the weekend and left me a voice message which I always feel privileged that they actually, someone's just died and they thought to call me an hour later to let me know. I just, I, that, that always means a lot. I don't think they realise how much that means to me, because they're thinking of me. But, this, it was a brother and, he would, just said to me that you know through the process he's like just I was always the go to when they were having problems and it's sometimes navigating the NHS system and trying to understand, and they'd had some problems but he said I was always there and I always jumped in and tried to help and tried to resolve and tried to kind of work out and signpost. So, I think it's that feedback that just keeps you going because you realise that there is a purpose, there is meaning to it, and you're making a difference, like, you know, during what is a really, really difficult time, you know, there's a lot of stuff I can't take away. I can't take their cancer away. I can't take away the fact that they're gonna die. But what I can do is try and make the process a bit easier. I can prepare them for what's going to happen. I can make sure that we're prepared, that we've put everything in place to support them and that they know who to go to and who to call, you know, so that they're not having to deal with anything that's unnecessary. So that, I think, makes a difference, when you know you've done that, then it, you know, it kind of gives you that resilience to think actually I did a really good job then because there's always somebody else. There's always another. I talk about battle, but there's always another battle to fight to get, you know, what you want for your patients. So, yeah, that just enables me to keep, to continue on basically.

**LI**: Yeah. I always struck by, how inspirational you are in terms of what you do but also how much you advocate for people. That always comes through very, very strongly actually, that you’re a true advocate for, for the people that you're caring for, including the families of the, the, the, the person that, that may be dying or maybe poorly, very poorly.

**AG**: Yeah. I just feel they've got enough to deal with. I feel like they've got so much on I feel like actually, you know, we should be doing our utmost to make things a bit easier. So if that means that I sometimes phone a GP for them to save them waiting like 10 in queue or you know, if I do an e-mail to get a prescription, you know, and it's little things that sometimes make the biggest difference if they've got, you know, if their burden is so big, you know, having little things just taken off their list or having someone that they can just call one person who's gonna let them know something's normal, cause that's I think the other thing is, what we see as normal, like, you know, we see, we can see death and dying and we know what to expect and we know what things are going to happen. But for them this is completely new. They've got no idea. And I think a lot of people panic about doing the right thing, like knowing are they doing the right things, should they be doing something else? And a lot of that is reassuring that this is a normal process, what's happening is normal and, and what we can do if there is problems. But I think it's just trying to normalise it a little bit about that they don't need to panic, that they can relax that, you know, this is what we expect. Because, yeah, any little thing, they're just not sure whether they should be calling, and they, they take it, they, I think some of them have a blame thing where they feel like, should they have called someone? You know, is this something that, you know, they've done wrong? And it, and I think it's just reassuring that they're doing their utmost to look after their loved one.

**LI**: Yeah. Yeah. I, I wonder how, you know, it sounds like you're doing this really well, I suppose I'm, I'm wondering how… is there any way to do this better or differently, or are there reasons why we find it hard to do this?

**AG**: I do think death and dying is a really difficult topic for most people. I, I mean I have a death and dying conversation everyday basically with somebody. So, I think, you know, you kind of, but I, I just think that's experience. I think if people haven't done it before and aren't used to having it, and I think in hospitals we think everyone should be really good at it, but actually…

**LI**: Yeah, yeah.

**AG**: …how many doctors do have a death and dying conversations in general wards? It's not every day. It's not all the time.

**LI**: Yeah, yeah.

**AG**: You know, and so, yeah, so I think that's something that people need to… if we handle better, I think it makes…

**LI**: Yeah, yeah.

**AG**: …it makes, it easier because I think actually, if you, if it's very clear, there's no inconsistencies, it's very clear what you're saying, then there's no room for people not understanding.

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

**AG**: And I think that's it. So, you know, even though what you're saying is really difficult, I think as long as you've said it factually and it's understandable, whereas if you say something that patients walk away or, or relatives walk away thinking like, what did they mean by that? What, what's that mean? You know, that, I think that leads more confusion and more distress.

**LI**: Yeah, yeah, yeah. And I suppose if there's a bit of ambiguity,

**AG**: Yeah.

**LI**: …then people are not sure what,

**AG**: Yeah.

**LI**: …what's actually going to happen either are they? And…

**AG**: It’s like when people say like, ‘oh, there's no treatment’, you know…

**LI**: Yeah, yeah.

**AG**: …and people can see that as a positive thing, like, ‘oh, there's no treatment, that's great’.

**LI**: Yeah.

**AG**: But actually, you know, what people mean is there's no treatment and actually your best supportive care. But I think it's used, it's the words that we use,

**LI**: Yeah.

**AG**: …like I've heard cancer referred to as lesions, spots, you know…

**LI**: Yeah, yeah.

**AG**: …that people haven't quite got the word cancer.

**LI**: Yeah, yeah.

**AG**: Whereas I'm very clear ‘you have cancer’, you know, ‘it's incurable’. You know, I, I use ‘death’ and ‘dying’, you know, I use all these words really clearly. So that actually I think it, there's no room for, kind of, not understanding what I mean.

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

**AG**: And I think rather than be harsh, it's just you're getting the truth. I think once people know the facts, then, you know, then, that you can help them process that. And that's the important thing is to get the information across in a consistent way, so that you can then help them move on, and like, what do we do next? What do we focus on? What's important?

**LI**: Yeah. And then I suppose pulling out the hopeful aspects of it in, in that moment.

**AG**: I think that's the difference, is if you stay and then work through it with them and talk through it with them, you know that's, that's where you're going to help them find the hope.

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

**AG**: Because it's not just bad news.

**LI**: Yeah.

**AG**: You kind of actually staying with them to hold their hand and say, right, okay, this is a bombshell, but this is how we're going to get out of here. This is what we're going to do and this is where we go next.

**LI**: Yeah, yeah, yeah, yeah. Amanda, thank you so much for, for speaking to me today. And, as always, I leave with lots of thoughts and reflections on what you've said. And, I'm really inspired by, by, by what you do on a daily basis and the level of compassion and care that you have for, for the people that you look after. So, thank you so much for…

**AG**: No, thank you for asking me.

**LI**: No, thank you.

**AG**: Thank you.

**LI**: I hope that you've benefited from listening to us talking about bereavement and the role of this Cancer Nurse Specialist. And thanks so much for listening. Take care and hope that you can join us for future podcasts.

The podcast was recorded in March 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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