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**Talking about Bereavement Podcast Series – Transcript of ‘Improving care for people following a sudden cardiac death’ Podcast**

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**Speakers**: Helena Davison, Clinical Nurse Specialist and Coordinator, Inherited Cardiac Conditions, West of Scotland (HD)

Dr Caroline Coats, Consultant Cardiologist, Inherited Cardiac Conditions, West of Scotland (CC)

Deborah Robinson, Service user (DR)

**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. Hi, and welcome to this episode of the podcast. I'm delighted to introduce my guests today, Helena Davison, Dr Caroline Coats and Deborah Robinson. And I'm going to come to Helena and Caroline and Deborah to get them just to tell me a bit more about themselves and, and a bit about the work that they do. So Helena, I might come to you first, if that's okay.

**HD:** Hi, I'm Helena Davison. I'm one of the Clinical Nurse Specialists and Coordinators in the Inherited Cardiac Conditions in the West of Scotland. I'm currently leading on the sudden cardiac death and out of hospital cardiac arrest project where we're looking to improve patient care, pathway and support from families following a sudden cardiac death into the Inherited Cardiac Condition Service.

**LI:** Okay thanks Helena and Deborah, can I come to you next?

**DR:** Yes, I'm a, a master's student at University of Glasgow and I was approaching the end of that when my son James died unexpectedly at the age of 23. He'd been perfectly fit and well, there was no indication that there was any problem. And I found him the next morning in his bed.

**LI:** So sorry to, to hear that, Deborah. Thank you for taking part in this today and we're very grateful to you for, for giving your time to do this. Thank you. Caroline, can I come to you next?

**CC:** Yeah, thank you. I'm Caroline Coats. I'm a cardiologist in Glasgow and one of the, part of the medical team within the West of Scotland Inherited Cardiac Conditions Clinic. And this is a service that sees people and families that are affected or, or may be affected with a genetic heart condition. Some of these conditions present for the first time with a sudden cardiac death and that is a group of families that we see in the service. We don't always establish a genetic problem, but we meet families at a time of, you know, real tragedy within their own family. There's a quite a technical process to undertake genetic investigations as well as assessing other family members at the time for their own heart health. So it can be quite a complex process for a family to go through and we've, we've been recognised for a long time how difficult that is. It doesn't neatly fit into standard pathways within the NHS, [inaudible] we're not dealing with one individual, you're, you’re dealing with a family and, and the complexities that go around that. So we were fortunate to receive some funding from the Scottish Government to try and improve care for families in Scotland that have been in this circumstance. And Helena's been leading a project and working with, with families like Deborah to try and understand the bereavement that they're going through and better support them.

**LI:** Okay, thank you. Helena, I just wonder if you wanted to say any more about the project, any more detail about it… for… so that listeners can understand what, what it is.

**HD:** Of course. So really we know from anecdotal reports that there's a real lack of clear pathway and structure for families following sudden cardiac death. Families find that they're having to find their own way to get to the Inherited Cardiac Condition Service and a lack of bereavement support for these families. So we looked to really improve the pathway. So I have worked with people from England, similar project and with the Copenhagen team who worked on the Copenhagen framework and basically tried to structure a pathway that is evidence-based and also prioritises patient care. And we also had focus groups where we had lots of families following sudden cardiac death who previously hadn't been through the new pathway to share their experience. So we can identify key areas in the pathway which need improved. And Deborah's been great and participating in these pathways, these focus groups, sorry. So that's the kind of, how we kind of started the structure of this. And from there that we've, from the focus groups we’ve, patients are able to meet other family members who have also been through sudden cardiac death. And we're really trying to raise awareness around sudden cardiac death and the bereavement side of… that comes along with this. Things such as prolonged grief, PTSD are all areas that we're looking to really improve awareness around and giving people the knowledge and awareness to identify these symptoms early so they can be treated as soon as possible really.

**LI:** Okay, okay and, and Deborah, Helena has obviously mentioned there that you were in… you've been involved in the focus groups. And I've probably gone immediately off kind of script in terms of what we were thinking we might have been talking about. But I'm just kind of interested to hear more what, what that, you know, what that has looked like for you in terms of being involved in, in the focus groups?

**DR:** My family and I found it really very helpful, first of all, just to talk about the situation because there hadn't been anyone to talk to. And so it was really, well, it meant a lot to us to have somebody who actually cared that we'd lost James and just to meet other, other families was, was really helpful because I don't know a single person who has lost an adult in this way. I used to work as a paediatric radiographer and we unfortunately had to often take images before postmortem for babies and children. So this was something I associated as happening to children, not to adults.

**LI:** Ah, right, okay.

**DR:** And yes, it was really comforting meeting other people too as, as well as sort of having this one stop shop, if you will, that, where we could sort of raise any issues or just talk about personal experience.

**LI**: Yeah, yeah. I don't want to upset you, Deborah, at all, but what I was just wondering about would it, would it be nice to hear about James, to hear a bit about James?

**DR**: Yes, yeah, I like talking about James. Some people I think find it a bit uncomfortable but he will always be a part of my life so I like talking about him. James was a real personality and we were very touched after he died to realise that other people felt the same way. We discovered when James was seven that he had autism. He was a very socially outgoing child. He was very intelligent, very curious, liked being with people, was very passionate about his interests and those things continued. When he died he was doing a masters at University of Edinburgh in systemic and synthetic biology, and place to do a PhD at York start in the January, which of course he never started. He was a very caring person and although he was so intelligent, he was also very kind and very humble. I think had quite a close relationship with him because of the issues associated with his autism, sort of issues that he'd he largely overcame. He was very motivated and I think because of his autism he did think in very different ways to lots of people and the university staff said they really love listening to him talking about things because he approached it completely differently. He was very passionate about the things that he was interested in. I think he was someone that wanted to make the world a better place. So he had started off as a software engineer and moved into biology when he became vegan and he was interested in creating alternative proteins and sort of growing meat in labs on that sort of thing. And he was also very interested in open source software. So he thought anyone, wherever they were in the world should, shouldn't have to pay for basics with technology. But he was incredibly funny, had a really good sense of humour. I didn't always agree with his point of view, but I always respected it because he was, he would reflect so carefully on things, but that whenever he made a statement, I know he'd done his, his research, so. But he was good fun to be with, very loving. He was a good support for his sister, too, who only discovered that she had autism when she was 18. And I know she, she finds that support, lack of support, now, very hard. And he’d just met a really nice girl shortly before he died. And one of the most tragic things is that his life seemed to be sort of coming together. You know, he was an adult, he'd lived on his own for the first time the year he was in Edinburgh. He would have been moving down to York for his PhD and life seemed to be opening up for him. And yeah, he's a, he's a huge loss. I still can't get my head around him not being there. He was loud, he was noisy, he was chaotic. As soon as he came home from university was, was just, there was a trail [audible] from the front door to his room, there was, sounded like an elephant coming down the stairs. But, yeah, it's, it's very hard adjusting to life without him.

**LI**: Yeah, yeah, yeah. I'm noticing that. Thank you so much for sharing James with us. That's very gracious of you. Thank you.

**LI:** Caroline, is there anything you'd like to add in there about the, the service or the focus groups or anything?

**CC:** Yeah, I mean, I think, I think Deborah alluded to it a little bit. There is nothing that prepares you for sudden death. It's a very different type of experience than when you're living with a condition and you know that it might be a terminal condition and you and those around you perhaps are prepared. A seemingly healthy adult or child to be there one minute and not the next is, is, you know, unimaginable. It does need a particular approach that differs from bereavement in other situations. And I think that's, that's the real piece of work we want to be able to, to develop the project.

**LI:** So, in, in thinking about that, then what, what, what do you feel? What, what do you feel can be done to enhance the support for people who are bereaved by sudden, by a sudden cardiac death?

**HD:** I think one of the main things would be raising awareness so that GPs, other healthcare professionals are able to identify the early signs of what we call prolonged grief and post-traumatic stress disorder. 7% of the general bereaved population will experience prolonged grief. However, 44% of families following a sudden cardiac death will experience symptoms related to prolonged grief and PTSD. So we do know it's very prevalent. In our focus groups and surveys we actually [inaudible] practical problems [inaudible] which had lots of symptoms and signs of prolonged grief and PTSD. And almost all of our families that we had at least one symptom associated with prolonged grief and PTSD, which shows the true prevalence in this population. And it is so important that we treat it. Prolonged grief is now recognised by the World Health, Health Organisation as a medical condition. So therefore it is definitely important that we recognise these symptoms and address them when families approach your yourself as a healthcare professional and make sure that we treat this, and that will be through counselling, third sector organisations such as SADS UK, Cruse can provide counselling around this as well. The BHF have also have very useful materials as long as, as long, along with, sorry, CRY UK.

**LI:** Okay. And, and I suppose maybe just for folks who don't know, who might not know what the symptoms and signs of prolonged grief are. Are you able to give some perspective on that?

**HD:** Yeah. Symptoms include anger, sadness, numbness, being withdrawn, drawn from society. People react very differently. So some people find that they are acting out in an anger, angry kind of way, whereas other people become kind of recluse and don't want to leave their houses and things like that. Other signs are things as avoidance, so avoiding certain things that remind you of your loved one. So not going into their bedroom, not maybe wanting to go in the car that they used to sit in and things like that. These are really kind of easy to recognise signs of prolonged grief.

**LI:** And as I, I, I don't, I don't know lots about them, but I'm wondering is, is that quite interchangeable then, PTSD and prolonged grief? And how is there a way to, to, or do we, do we not need to kind of define them differently?

**HD:** We do need to define them slightly because they do have different kind of treatments, but a lot of their symptoms do overlap. And we often find that people have prolonged grief and PTSD in sudden cardiac death,

**LI:**  Okay.

**HD:** though they would need kind of counselling sessions, but also treating the actual the, the cause of the PTSD. So for CBT therapies and things like that, but specific CBT therapies, so sudden cardiac death.

**LI:** And you mentioned some organisations there that could provide some support or have materials or resources to provide support. But what, what is that actually like for people accessing the support?

**DR:** I think the first place I found some support was Sue Ryder. And actually I really like their service. So they saw me within two months of James's death, which was very helpful because I think it's very easy to fall into sort of self-destructive ways of coping.

**LI:** Right.

**DR:** Fortunately because I have my daughter who's three years younger than James, I did have to force myself to get up and, and get things done. But I think it was during one of the bouts of insomnia which I had, I discovered British Heart Foundation’s advice on inherited cardiac conditions and then my immediate concern was about my daughter. So I originally used their website to try to do some more research on why James might have died, because his postmortem came back as death unascertained. And then because my, my, my immediate reaction was, you know, what if my daughter has the same thing, there's a condition. I was [inaudible] scared about that. So from British Heart Foundation advice, I, I asked her to go to the GP and ask to be referred to the ICC and the GP hadn't heard of it at all.

**LI:** Okay.

**DR:** So it was all very, it was all very kind of down to, to me to find out it [inaudible] it wasn't readily available. And even when we had the postmortem report and the procurator fiscal suggested genetic screening, that was not implemented. So we, we thought that because it had been recommended, it was [inaudible] be carried out. And it wasn't until my daughter first attended the ICC and met Helena that we realised that nothing had been done. So yeah, so that's how we found the help here.

**LI:** Okay.

**DR:** But it was, it was all done by myself. Wasn't any directed help at all and it was, I think it would have been very easy to miss it altogether. If I hadn't been trying to sort of research information about why James might have died we wouldn't have, we wouldn't have found out about this service here.

**LI:** Yeah, yeah, yeah. Caroline, I wonder, I'm just thinking about how, how we can, how we can do this better. How can we support bereaved people who are bereaved in a kind of, a better way. And what I was thinking there, I, I just lost my train of thought there, when Deborah, when you first spoke, I was thinking that you, it took quite a, you know, it was quite a lot of motivation from you to find out, to do more, to find out more. But, but some people might not be able to do that, for whatever reasons, feel that they can keep pushing to find out a bit more. And so I wonder how, I suppose what I was wondering first of all was how, how do we make that easier for people to make sure that they don't have to rely on their own self-motivation? Because I, I, I would imagine that maybe at this time, after you've had a sudden bereavement, you know, your motivation may not be as it might have been otherwise. So I just wonder how, how we can do that, how we can make that better or differently. And, and I know that's what you're trying to do. But if we're, we're, we're talking, you know, if we're wanting to kind of get this out to, into the community and to general practice and to primary care, how do we, how do we make that better?

**CC:** Yeah. So that's, that's about, I mean this, this is the, fundamentally the, the objective of this work. And this has been a pilot work in the West of Scotland. We've, we've spent a lot of time listening to where there have been gaps in, in experience. And Deborah's mentioned a couple already, the, the point when the fiscal communicates with a family about autopsy results. Primary care, is a place family would [inaudible] would be their, their point of contact for medical care. The police service are often involved in, in sudden deaths and as are, if there are children, schools can be there to support children. Universities, this is in young people and workplaces, you know, people take time off work understandably, when there's a death in the family. So these are all places where we need to educate, we need to provide compassionate, you know, communication skills. So that, because for, for many of these professionals working in these organisations, it, it'll be a once in a career event. So we need to listen to where our patients and families have felt there have been gaps and we need to focus our efforts to doing that. And we've taken, you know, a once for Scotland approach so that we want the model that we've developed in the West to be scaled nationally so that every pathologist fiscal service knows that there is not just a letter saying genetic testing might need to be done. The patient doesn't know if it's been done or not. But, so that there's a human contact at the end of it and that contact comes to the patient rather than the, the family…

**LI**: Yeah.

**CC**: having to [inaudible] ‘selves. So it's a, it's a, a simple intervention,

**LI**: Yeah.

**CC**: but it's, you know, it's putting that human side to it, which is I, I think the bit that's lacking at the moment.

**LI**: Right, okay. I suppose you've, you've said it's obviously a, pilots in the West of Scotland, but you want this to be a kind of once for Scotland approach. Where, where have you got to in terms of that being a once for Scotland approach? Or is that still very much a work in progress?

**CC**: Yeah, it's work in progress. We've, we've had an, an excellent steering group on the project, really with good involvement from NES Bereavement, which is why we're here, but also from Public Health Scotland about collating data from a patient alliance nationally and the national networks. So this is something that needs planning at a national scale. So we've, we've had those discussions, we, we have applied to the British Heart Foundation for funding to support scaling this up nationally, which if successful we, we hope would be adopted by the Scottish Government. We, we’re not asking for a lot actually, we're asking for, you know, a, a, but we're asking for a coordinated national approach to this so…

**LI**: Yeah, yeah.

**CC**: equity of access and, and patients don't get one thing in one bit of the country and some [inaudible] because actually you'll appreciate families are also spread out. So we often hear stories where, where people experience the death in the family and different people get different views on, on what happens next depending on, on where they stay. So yeah, we've done a lot of work within Scotland, but also linking with our colleagues in, in Ireland, Wales and, and England to make sure that this is, the UK, you know, we're, we're all speaking the same language. And, and we've been fortunate that, that the Denmark group who are, are really, led some international work in this area have been brilliant at mentoring Helena in her role and will continue to work with us as we, as we actually continue this work.

**LI**: Helena, do you want to say something about, obviously you're, you're very involved in this, this pilot project, is there something, is there anything else you'd like to say about it?

**HD**: Yeah, definitely. So I think we've been definitely working closely with families to really highlight the areas which we thought needed improvement. And from that we've worked closely with the Crown Court because we knew there was an underlying problem there. So the Crown Office and Procurator Fiscal Service, and we've managed to pass through the pathway to improve the service. So instead previously families would just receive a letter from the fiscal service stating that they should attend their GP for referral. Often people didn't open this letter because obviously it's quite difficult opening these letters or it wasn't quite clear people felt. So we've now changed this so that when there is a sudden cardiac death and the pathologist recommends an inherited cardiac condition referral for the family, the VIA officers in the Crown Office now get in contact with the family and ask, ‘Are you happy for a referral to the ICC service?’. And then if the family are happy for the VIA officer to contact the coordinator, then the VIA officer will give the details to the coordinator so that the coordinator can get in contact with the family, gain access to the post mortem report and really be able to be that point, first point of care really, so families aren't feeling lost in the system. They can really provide bereavement support from the get-go and make sure that the family’s getting to the right service at the right time.

**LI**: And, and just when you mentioned the, the ICC service, is that, is that one service for Scotland that's based in the West of Scotland or is there other ICC services across Scotland?

**HD**: So we have four regional services in Scotland,

**LI**: Okay.

**HD**: but each health board kind of, we have link, like link medics and link nurses that we kind of work mostly with as well. But usually they would attend their regional service to start with,

**LI**: Okay.

**HD**: for the initial kind of point of care, which we do understand requires some travelling. But we offer video calls, lots of phone calls. So we try to gather as much information as possible prior to the appointment so that there's not too much back and forth for families. Can be quite a lot of travel sometimes.

**LI**: Yeah, yeah. Deborah what, how, how do you think this, you know, obviously you've been involved in the focus groups and, and you've got I think obviously a real kind of commitment to making this better for, for other people. Is there anything else you'd like to say about that, that you've maybe not already had the opportunity to say?

**DR**: Only that, I think it's been touched on already that the police would be another useful force of advice from, because obviously with sudden and unexpected death they’re in attendance too. And I think sometimes the information needs to be repeated by many different people because you're in such shock. You're, you're operating on adrenaline only. So you know, for months afterwards. My, my memory still isn't back to normal, and I haven't returned to my studies yet. I hope to do that maybe sometime in the year. But it is such a overwhelming loss and so nonsensical, it, it's still no sense to me because unfortunately we never found a cause James's death. But just to have somewhere to go where people actually care and you're not just a statistic. It's really made a huge difference to my family as, as well as sort of feeling slightly more reassured that my daughter doesn't have anything, but that [inaudible] the same way. I think once you experience loss in this way, your sense of safety just evaporates.

**LI**: Yeah. Yeah.

**DR**: Because I think James died shortly after he went to sleep and I'd been talking to him about an hour, half an hour before that. There was nothing wrong with him at all. So I think just having somewhere to go where people understand, because grief is very specific I think, to the way in which a person died. So while I can talk to other parents whose children died in a different way, there are things that I can't understand about their situation, and they can't understand about mine. So, I, I think primarily the fact that the shock lasts for such a long time and there's so much death admin to do once someone dies. It's really nice to go to one place where you get all the information and you don't have to do all of that sort of thinking and researching yourself.

**LI**: I was just thinking about, I know these were focus groups that, that you were running as part of the pilot, Helena, but I'm just wondering about, are those groups going to continue because obviously Deborah's saying this was a really helpful place and it gave her kind of some comfort and support. Is that something that will continue on?

**HD**: So as we hopefully upscale to national, we will continue focus groups and we are currently looking with the British Heart Foundation to set up a sudden cardiac death family day,

**LI**: Okay.

**HD**: where we can do some teaching, raising awareness, do things like CPR training and things like that, basic life support and also allow for families to meet, speak to one another. There is a lot of kind of consents and stuff around this so we have to be very kind of careful confidentiality and things. We hope to continue this work moving forward.

**DR**: Could I just add to that?

**LI**: Yeah, yeah.

**DR**: I think as well as grief being very specific concerning the way that somebody died, also the person's relationship to the person that's died is also very specific.

**LI**: Okay.

**DR**: So, I know my daughter found it very helpful to speak or, or just to, to meet another girl who'd lost her sister in the same way that we'd lost James. And, you know, obviously partners of people that have died in this way find it helpful to talk to people in situation. So that's another reason I think the, the focus groups are very helpful.

**LI**: Caroline, I know that when you came to the NES Bereavement Leeds group and presented on this work there, one of the questions that you asked was about how to, how to, you know, how to get in touch, how could you get in touch with primary care with GPs to kind of flag up this work and make sure that, that kind of people are aware of it? And I just wondered, I know it was, it wasn't that long ago, but I just wondered how, how that was progressing and how that's, how that's going for you?

**CC**: Yeah. So it's still, it's still a piece of, of work that we, we haven't really tackled. I think as, as well as with like, you know, it's GPs have a incredibly difficult job seeing everything and everyone, at every age. So we, we need to work with primary care to understand how best to put the information, because I think a lot of it is, is probably just lack of knowledge of the processes, which to be fair did not exist 15 years ago. This kind of assessment of families, recognition of inherited conditions is something that is, has only become available as medicine’s developed and genetic investigations and, and autopsy examinations that are more detailed and thorough. So it's still a piece of work that we want to do. If, if any GPs are listening and are interested, more than happy for you to get in touch with us if you want to work with us on it. And yeah, we, you know, we, we really want to work together.

**LI**: Yeah.

**CC**: It's not negative about primary care and the same with police and schools and things. It's, we really want to work with those communities because they know, they know best really. And it's, you know, it's, it’s a huge team of people that could be involved. You've heard already how many sort of aspects there are for a family. It's, it's family relationships, it's the, the impact on work and, and, and it's the same with the healthcare team. It, it may not be a doctor or a nurse or a counsellor, a genetic, genetic consultant, it, a pathologist, there's lots of healthcare professionals that might come face to face with this. Accident and emergency, ambulance services often deal with cardiac arrest in the community. So our, our education really needs to be quite far reaching,

**LI**: Yeah.

**CC**: and we, we already have developed an excellent network and I'm, I’m really grateful to the, the wider team, both the healthcare side and, and the families that have been working with us on this.

**LI**: I suppose as we come towards the end of the podcast, I just kind of maybe want to come to each of you just to say is, is, are there any kind of final messages or words or comments that you want to make about, about this work?

**HD**: Yeah, I'll start. So I think over the past year, we have achieved lots of key milestones of our project, working really closely with, like I said, families, a multidisciplinary team approach. We have a very good steering group with a whole range of healthcare professionals and the BHF being on board, which has been very useful. And we've managed to pass the new pathway, which is really good, and hopefully we'll be up and running and being able to take a more national approach within the coming year.

**LI**: Okay. Thank you, Helena. Deborah, is there anything you want to add?

**DR**: Yeah, I, I really don't know how we would have coped without this organisation, to be honest, because for one thing, we all had cardiac tests ourselves, although I was mostly worried about my daughter. But just up until that point, there was no information anywhere, there, there just didn't seem to be anyone anywhere to, to fill the gap. We would contact people like the GP or, or procurator fiscal or whatever, but there was nothing joined, joined up. And I think just for peace of mind that my daughter is healthy, to have somewhere to go to, to talk about James and to talk about the experience of losing him has been really, really helpful. So I'm very grateful that this service exists.

**LI**: Caroline, anything you'd like to say?

**CC**: Yeah, I mean, just to echo the comments, you know, we wish we didn't have to exist, but we, you know, the message is, is very clear about information and, and education that we need to invest in. And I hope that we can continue to work with the team and, and, and families to make things better in the future. So, you know, I'm grateful for the opportunity for us to, to, to be on the podcast and come back and talk to you in, in a few years.

**LI**: Yeah, yeah, yeah. Thank you all for taking part in this podcast. It's been really interesting. I've already heard about the work from Helena and Caroline, but it's been really interesting actually putting that work into context. So thank you so much for, for sharing.

**CC** / **HR** / **DR**: Thank you. Thank you.

**LI:** If you'd like to listen to more episodes of this podcast, you can do so on Podbean or Spotify, just search Talking About Bereavement or if you'd like to find out more about the NES Bereavement Education Programme or have any questions, please get in touch or check out the Support Around Death website, which is [www.sad.scot.nhs.uk/podcast](http://www.sad.scot.nhs.uk/podcast). Many thanks for listening today.

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