**NHS Education for Scotland**

**Talking about Bereavement Podcast Series – Transcript of ‘Grieving with dementia: before a person dies and after’ Podcast**

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**Speakers**: Helen Skinner, Nurse Consultant for Dementia, NHS Fife

 Marion Ritchie, former full time dementia carer

**LI:** Hello and welcome to the Talking About Bereavement podcast, which is brought to you by the Bereavement Education Programme in NHS Education for Scotland. I'm Lynne Innes, one of the educators in the team and in these podcasts I'm going to talk about bereavement with our guests who will be sharing and reflecting some of the work and learning they're involved in as they talk about bereavement.

**LI**: Hi, and welcome to this episode of the podcast. I have two guests today, and I'm delighted to introduce them both, Helen Skinner and Marion Ritchie. Hello, it's nice to have you with me.

**HS**: Hi Lynne.

**MR**: Hello nice to be here.

**LI:** Thank you. So I’ll introduce Helen first. Helen has a clinical background in nursing, particularly in the field of neurology and dementia. Her professional career began at the Radcliffe Infirmary in Oxford and the National Hospital for Neurology and Neurosurgery in London. Working here provided her with a solid foundation in understanding the complexities of neurological disorders, especially the rarer forms of dementia. In her current role as a Nurse Consultant for dementia for NHS Fife, Helen plays a crucial role in implementing Scotland's national dementia strategy and delivery plan, and this involves working across various patient settings to ensure the strategy's effective implementation, resulting in a positive impact on dementia care and I know you’ve told me a bit more than that Helen, but I wondered it would be quite nice to hear and your own words a bit more about you and your role.

**HS:** Yeah, absolutely, Lynne. Well, I feel very fortunate to have been the Nurse Consultant for dementia in NHS Fife for the last decade and my role predominantly spans across hospital care, so very much around improving the care of people with dementia, which includes their family and friends and carers around hospital, whilst they're in hospital. But I also do work in the community and I also support care home settings, so I feel very lucky and fortunate to, to have that position, and I work with an excellent team here in Fife that supports me to do that work. Recently as well I've also been on secondment to Brain Health Scotland, where I was doing work around dementia prevention. Now we know there's risk factors for dementia. There's 14 risks factors for dementia. We're doing a lot of work to see how we can reduce the risk of people developing dementia in the future. And I worked on a project in Aberdeen, which was to develop the first brain health clinic and brain health service in Scotland, where people can literally walk in off the street and ask questions about the brain health risks for developing dementia and get support around looking at their lifestyle and things that might help to reduce that risk in the future. So I feel very lucky to work in the field of dementia and it’s you know, we've got lots of things happening across Scotland; national dementia strategies, we’ve got standards of care for dementia, we’ve got a knowledge and skills framework for dementia in Scotland. So yeah, lots of work to do, lots to keep me busy, but feel very honoured and lucky to work in this field.

**LI:** Thanks, Helen and lovely to have you with us. I was just thinking about the 14 risk factors for dementia. How, how might people find out about them because we could maybe put, put something in our show notes for folks if they want to find out more.

**HS:** Yeah, absolutely. There's a, a kind of very seminal piece of work that, a Lancet Commission report that was done by Gill Livingston, so if people, you can just search that Lancet Commission report dementia…

**LI:** Okay.

**HS:** …risk reduction that, that will get you an academic piece of writing about the 14 risk factors, but probably a better place to go to is the Brain Health Scotland website where we have a quiz that people can do, so log on to the, go to the website, click the button for the quiz and it takes you through a series of questions around the risk factors for dementia and it directs you to information and advice and support around you know how you can help to reduce your, your risk of dementia. So, yeah, the Brain Health Scotland website is an ideal place to go to.

**LI:** Thanks so much. I'll come to Marion next and Marion tells me she's a former carer and has been an active member of NDCAN, which I'm going to ask her to tell us what that is in a minute and she's been on the committee there since 2017. Dave, who was Marion's husband, was a pilot with British Airways who retired at their statutory age of 55 and was diagnosed aged 65 with vascular dementia in 2010, unfortunately before post-diagnostic support was available. She became his full-time carer for the next nine years until he passed away in June 2019. And Marion, I wonder if I can come to you to tell me a bit more about yourself but also a bit more about what NDCAN is, which I think is how we see it.

**MR:** Hello there, NDCAN is the National Dementia Carers Action Network, that's what the letters stand for. It's a campaigning group of carers and former carers and it comes under the auspice of Alzheimer's Scotland. So I joined NDCAN because Alzheimer’s Scotland was my go to place. There was a dementia resource centre way back in 2010 and I walked in in a state of I didn't know what was happening, what was going on, what was the future, anything and they were, they were my support at that point and they were my support throughout all the nine years really in a variety of ways. And I, I decided I would join NDCAN when Dave had gone into a care home. And I felt I had at that point I had time to myself, but I also had, I wanted to give something back. I just felt I'd got so much from them. I was also quite angry because I had gone through in that previous year, experiences in a delirium ward, in a psychiatric ward where he was sectioned for what I thought was going to be a weekend, which became six weeks, which became six months, which became a fight to get him home and get him out. And I suppose that's when I realised I, I was suffering a lot of guilt at the time and the only way I could, could focus was to say I'm angry, I feel guilty, but I need to do something about it and NDCAN offered that chance to, to be a collective voice. So, I've been with them for seven years. I've been involved in Brain Health Scotland, I've been to that clinic in Aberdeen to have a look because I lived in Aberdeen for 15 years, I know it well. I've been involved with research, I've been involved with SIGN guidelines which were updated just two years ago, which was great on dementia. And thankfully, they also recognise that a lot of the guilt is actually anticipatory grief, something that people don't think about either. So it's been, it's been a job since I retired, an unpaid job, but a very satisfying job. So NDCAN has been really worthwhile for me.

**LI:** And you said there that you had retired. Did you want to say a bit about what you retired from?

**MR:** My final job, I did lots of jobs. I, I started off in, in a school office in White Hill Secondary where Lulu went and her sister Edwina. I went to see Lulu's final concert in Aberdeen just last year.

**LI:** I went to see it in Glenrothes.

**MR:** Which I thought was amazing…

**LI:** Yeah, me too.

**MR:** …and she had her sister Edwina with her…

**LI:** That’s right.

**MR:** …and I thought my I remember you as a teenager in secondary school. That just shows my age. But I started in a school office. I went into Newsroom in BBC. I then went to Aberdeen for an assistant film editor job. I ended up in Grampian Television as a film editor. I thought I'd, I would never go back, technology changed, I had my 2 girls and then Dave was flying helicopters out to the rigs and he changed on to fixed-wing aircraft. So he was then flying out of Glasgow, so we moved back to Glasgow. And I went back into schools and then I changed career at 50 and did a course in training and I went into IT development and social work.

**LI:** Oh wow.

**MR:** So I ended up having lots of support in filling in forms and things which most people don't have because I worked with social workers and one of the heads of the departments was amazing in, in helping fill in attendance allowance forms and things which are so complicated for most people and it was only through training them to use an IT database that I, I got that support right.

**LI:** Right okay.

**MR:** So yeah, I retired, I retired at 63 because things were becoming quite difficult and Dave needed full time support. And I'm glad I did. I'm glad I had those years. You can't turn the clock back so you have to do what's best.

**HS:** Absolutely.

**LI:** So quite a varied career as well. I'm just noticing from what you sent me, the final bit, which we haven't really said is, NDCAN isn't just about campaigning for improvements and change, it's also about campaigning for the good places and good practices to be recognised and replicated so there is choice, understanding and consideration for both the person living with dementia and their carers. And it's caught my eye there and thought it seemed like a really important thing to, to say that that's kind of what, what you're trying to do. You mentioned there a bit about anticipatory grief and I wondered if you want to say a bit more about that. I'm thinking about we talked about, before the, the podcast about how what, about being bereaved and what it feels like repeatedly and Helen, you also mentioned the SIGN guidelines and anticipatory grief. So I wonder, I wonder if one of you would like to start us off with maybe just talking a bit about anticipatory grief in dementia.

**HS:** I think anticipatory grief, sometimes known as, as pre death grief, is something that is very recognised for, for people living with dementia. As we know, dementia is a condition with various different symptoms, but it's a trajectory where the person living with the, the condition maybe has deterioration in their memory, they may be become less able to communicate, mobility, continence, there's all sorts of things that that can happen. And for that individual living with dementia, it's, it's like things they're losing part of, of who they are and the things that they were able to do. And this happens, you know, at different speeds and different individuals, but it happens way, way, way before, you know, eventually they, they do die and, and the family are bereaved. So I think for, in Marion's situation, and she will be able to speak far more eloquently about this but in my clinical experience, when I've been working with families, the, the family around that individual who, who’s maybe living with dementia, they, they see that, that those changes and it's, it's like they're losing the, the person that they know and who they were and, and, and what they were. And it's happening right before them, right in front of, of their eyes and to some extent have very little control over it so it can be really hard. It can be really hard to see this person that obviously is very dear to, to that family changing in front of them. And, and I, I remember it from my personal experience of, you know, caring for my grandma who had dementia, who was the matriarch of the family. And, you know as, as you know, from being very little, we, we, you know, looked up to grandma and what she did and, and who she was. And then as she started to live with, with dementia and how she changed where, you know, she wasn't able to cook us those meals that, that she used to do. And, and you know, she didn't entertain us in the, in the same way. And it's like you're losing the person that, that you knew and, and that you love and, and that can be really hard. And it's, it's what we now recognise what we, we call anticipatory grief. And it can happen really quite early sometimes even from the point of diagnosis, those, that feeling of grief can, can start to, to be, be present. But I'll, I'll hand over to Marion and she, I'm sure can, can say much more how it, it feels for her.

**MR:** Thanks, Helen and I agree. Helen has said people are different everyone is different. I suppose in the early stages my husband seemed fine. The, the first couple of years, he was able to hide that things were going wrong. So we had a couple of years where we both knew something wasn't quite right, but I think we both pushed it aside. He got his diagnosis in 2010 and it was, it wasn't really a formal diagnosis. There was, as I said, there was no post-diagnostic support so that there was nowhere to go except online. And he did do lots of research online. But by 2014 when we went back for his SPECT scan, it was definitely vascular dementia by that time. And I asked is this early stages and was told oh no, no, no that was back in 2010.

**LI:** Okay.

**MR:** He'd already advanced, I was still working initially because I was nine years younger and I, I couldn't see a future without working. But you could see he was losing some of his independence. I was trying to keep him doing things, but he wasn't safe. He was getting lost. And eventually I was tracking him and I thought, I've, I've got to stop now. Those were still early stages and they were fine. And I thought I was coping well. I probably wasn't coping as well as I thought you don't see what's happening when it's happening to you. You need someone from the outside and when you don't have follow-ups, when you see a psychiatrist and then six months later you go back in and he sees, saw my husband and he would say ‘How are things? ‘Oh, everything's fine.’ And then I would look and burst into tears and say ‘Everything's not fine. This is happening and that's happening’ but then you walk away and here's your appointment for another six months and it's, it feels so alone. It, it just feels terrible and you are constantly saying what's happening next, what's going to happen next? You're constantly planning. And I think by the time he progressed and became much more aggressive and violent, I didn't know how to cope. I was locking him in the house, he was climbing out windows, he was knocking doors. I was at my wits end by that time. I, I was scared quite a lot of the time. But what I didn't really see was the rest of the family because my daughter would be home and she asked me to put a lock in the door because she was scared. And I couldn’t understand why she was scared because I wasn't thinking of her feelings either, so I think anticipatory grief goes along with guilt. There's a lot of guilt in dementia. You keep thinking, could you do things better…yeah, you can't in the end, but you think you can.

**LI:** I wonder what it is that makes you think you can and, and you know, that drive to kind of, to, to make it better when it actually is really too hard to make better.

**MR:** I, I, I was always quite an organised person. I, I like to be in control of things and know that this is how it's going to work, and this is what we're going to do, and this is what the outcome will be. That that's just how I've always worked. So not having that control, not knowing what's coming next was quite, quite difficult to cope with. And you go along to your GP and they will say, here's some antidepressants. I think you're just depressed. You’re not the, the antidepressants I, I understand, take the edge off that anxiety. And they do, they do help immensely. I've, I've actually realised as well recently because I've had a couple of friends who've recently lost their husbands from cancer. And very similarly, I've watched the last six months of her husband's life and his deterioration. And I from the outside could then see what she was dealing with and that she was, even though it's, it's a very much a dementia thing because it takes so long, even in that short period of time, she was also experiencing the same anticipatory grief because she was in her head, she was trying to work out what was going to happen next. And I was watching for all the signs of deterioration. It was, it was a very strange feeling being on the outside this time and looking in on someone else and trying to say to her, you may go to the GP, he may say you're depressed. Please consider taking the antidepressant. You don't have to be on it forever, but it might help. And thankfully, my friend has and the other friend hasn't. But that's their choice but…

**HS:** Yeah, I think it's really important to recognise that because depression in that pre grief stage is very common in carers who, who are caring for people with dementia. And we're very lucky, Marion mentioned about the, the SIGN guidelines…

**LI:** Yeah.

**HS:** …that we have for dementia. So it's SIGN 168 which is around assessment and diagnosis and care and support for people living with dementia. Within that, that guideline, we've now got a whole section on, on grief, which is great that it's, it's been recognised and a really useful resource for, for staff, health and…

**LI:** Yeah.

**HS:** …social care professionals and families actually to, to go to and read through, lots of useful information in there. But there is a section within the SIGN guideline around how depression is often associated…

**LI:** Okay.

**HS:** …with pre, pre death grief, anticipatory grief in, in people with, who are caring for someone with…

**LI:** Yeah.

**HS:** …dementia.

**LI:** Yeah.

**HS:** So it's really important as professionals that that we recognise this and, and we can provide that support for that individual should, you know, should they be experiencing something like that. Not everybody will experience it, but you know, some people will do.

**LI:** And are you noticing Helen in your work that, that that is something you're doing increasingly or is that always been something that's been kind of part of your work?

**HS:** Yeah, I would say we, the, the anticipatory grief is something now we recognise much, much better. I think we're more prepared for dealing with it and, and you know, always talking about grief and, and bereavement. It's always a difficult thing. And, and I remember, you know, my, my first time when I cared for a patient who died on a ward and you know, it's, it's obviously hugely traumatic for the family, but for healthcare staff as well, you know, it can be quite hard and at now, you know, I feel like we've come a long, long way in the education that we get around bereavement, the support, the, you know, information as health and social care professionals to help us deal with that. So I think that it's much better and, and as a workforce, I'd like to say we're more knowledgeable, we're more skilled in dealing with bereavement. But yeah, I think it's something it's really important in, in the years I've been working around this field is now we recognise that anticipatory grief that right from, you know, the point of diagnosis and, and even before diagnosis, you know, Marion's, you know, mentioned about, you know, changes that she was seeing…

**LI:** Yes.

**HS**: …in, in her husband. And I think that it is really important to recognise it and not be something that we shy away from having a discussion, you know, with carers and, and even, you know, people with dementia as well. So, you know, we talk a lot about anticipatory grief and, and how it might be for family carers, but the person with dementia, especially if they're diagnosed maybe quite early with the disease and, and have insight into maybe what's going on for them, they, they also can experience that anticipatory grief as well. And, you know, sometimes it's about the loss of the life that you maybe planned, especially, you know, people that I've worked with who've been diagnosed with younger onset dementia, you know, maybe they were still in employment. And you know, we all have plans about what we might do when we retire. You know, I'm, I’m you know, heading towards retirement myself. And, you know, you start to plan what you might do, But some, sometimes, you know, you might get diagnosed with a condition, could be cancer, you know, dementia, but sometimes it changes everything and everything that you maybe saw was going to be your life in your future and, and what you plan to do can sometimes be, be taken away from you. So I think it's important to recognise, you know, people with dementia sometimes still have that insight into what's happening and, and, and, and living with that, that condition. So, so that anticipatory grief is, is huge for, for carers of people with dementia, but people living with dementia can experience it as well.

**MR:** Totally agree, Helen, I, I didn't really think about my husband and knowing now that I went through boxes and found all these printouts from the Internet. He, he had been planning ahead. He'd been thinking about how he was going to progress. He, he was researching vascular dementia. He didn't realise he was going to end up with aphasia and lose his speech so quickly. And in the last two years, he had no speech at all and thinking he was a clever man how, how did his brain work, what, what was happening, how did he feel. The, the care home manager used to call him ‘locked in’ because she said he understood so much, but he couldn't communicate. So a lot of it was looking at visual, how his face, how his eyes, how he reacted to what we said, if he seemed happy or sad or understood or how difficult was that for him. And all of that time I, the guilt that comes back again is why didn't I recognise that he was suffering as well. And suffering is not a word that people with dementia like to use. But he was in a way, he had no control over that either. And he was another man who was very much in control of his job and what he did. He had, he had plans for his retirement. He thought he would build a kit car. By the time he retired he couldn't understand the, the mechanics of it or how to build it so he just bought a sports car and had drove for a couple of years. Losing a licence when you've driven all your life is so difficult and not being dependent on other people.

**LI:** Yeah.

**MR:** It is, it is so hard for the person with dementia as well and it's one of the things we, we also have the Scottish Dementia Working Group who are people in early stages who are…

**LI:** Right.

**MR:** …amazing.

**LI:** Okay.

**MR:** They are absolutely amazing people. They get out there and they accept their diagnosis, and they stand up and say yeah, I have dementia but look at me, I'm still living well and they are. But for us in NDCAN, we're sitting on the other side saying we know what might be ahead. And it's so hard to watch these people who are amazing as they progress because it just brings back all the memories of our own experiences as well. But yeah, anticipatory grief is there.

**LI:** I suppose it’s a bit yeah, anticipatory grief for those people that you're talking about as well, isn't it?

**MR:** Yeah.

**LI:** Knowing what's ahead of them because you've, you've lived it. And…

**MR:** Yeah.

**LI:** …obviously being involved with NDCAN, you're, you're, you're still kind of living it, aren't you?

**MR:** Yes. And every so often I say this is the end. I have to leave dementia behind. But it never really leaves you. It really doesn't. And there's, there's still a lot of work to be done to, to get rid of stigma, to get people talking about dementia, to get it out there. It’s, it's, we didn't talk about cancer when I was young. Now look at all the research and everything. And I'm delighted that Brain Health Scotland exists and is, is advancing so quickly and getting that message out to children in their STARS programme. I was thinking you were asking about putting on a link. Alzheimer Scotland's website also links to a variety of things as well.

**LI:** Okay, yep, we can add that too.

**MR:** And people tend to think Alzheimer's oh I don't have Alzheimer's, I have a different kind, but it covers every kind of dementia. It answers questions, you can search for lots of stuff and it will signpost to, to good information.

**LI:** Yeah.

**HS:** And I'd like to just, just oh, sorry, I was just…

**LI:** No, no.

**HS:** …going to say NDCAN the, the carers group and the Scottish Dementia Working Group that that Marion mentioned there, people living with dementia, they are fantastic groups and they are such a huge resource and support to the, the charity Alzheimer Scotland, Brain Health Scotland, but also NHS boards and social care in that they, they help inform us and they, they shape our practice and what, what we do. So Marion contributed was part of the group that developed the latest SIGN guideline. So it's, it's just so fantastic that we have people like Marion that are prepared to help. And you said there about stepping away from dementia, Marion and that, you know, it's with you, it's hard to do, but we are so grateful to people like Marion that, you know, are contributing to things like the SIGN guidelines, which are such important documents that are shaping practice and we've got that lived experience from people living with dementia, from carers who are caring for people with dementia that can help to shape what we do and, and guide what we do in practice. So we're very lucky in Scotland to have such fantastic groups like NDCAN and Scottish Dementia Working Group.

**LI:** I was just wondering, I mean, you've both touched on this a bit, but if our, our listeners, or health and social care staff, what, what are the specific ways that they can offer to support people? And I, I don't mean people working necessarily in dementia care. I mean people working in ordinary kind of general wards and, and GP practices and across kind of the host, the whole spectrum of healthcare and social care. How can, how can we support people living with dementia and their families or carers?

**MR:** I think we can, we can put some leaflets in GP practices to start with.

**LI:** Okay.

**MR:** I quite often go to my own one and I handed in a whole lot of leaflets on, from Alzheimer Scotland on just are you concerned about dementia. Here's a place to go and ask because folk are sitting in waiting rooms and hospital waiting rooms. They're bare walls. I'd love to see them covered in posters and things, things, anything that makes you go up and take a photograph on your phone while you're sitting for six hours in a waiting room and then research on it if you're worried there's, there's not enough out there. There's plenty, as I say about cancer, but there's not enough about dementia. So I'd like to see more. I'd like to see people who see, in general wards, there are now so many elderly people who will have dementia as well. They're not in for dementia, they're in for other things. But they have dementia. And I often see, I've gone to visit people in hospital and you see food sitting on a table and then it gets taken away because the person didn't eat it. Maybe they didn't eat it because they don't know how to eat it. They don't know what the cutlery’s for. They need help and staff are so, so short staffed in hospitals. They have so little time. I'd like to see more volunteers going into hospitals and helping. I've volunteered in, in the care home after my husband died and spending, spending an hour when you've got an hour and the staff don't with someone who needs 1 to 1, they will eat better. Their, their nutrition improves their, their whole wellbeing improves because they've had some, some food. And just that touch of someone is…I sat with a lady who didn't speak and all she did was look at me and I told her about all her food and ‘oh this is a lovely chocolate cake, smells amazing.’ Just having that interaction sometimes and the time to spend. I'd love to see more people volunteering to go in and do things as well. It can take…

**LI:** Yeah, yeah.

**MR:** …an hour of your time, but it can make such a difference to someone.

**HS:** Absolutely.

**LI:** What about from your perspective, Helen, in terms of…

**HS:** Yeah.

**LI:** … and I know we had dementia champions, don’t we?

**HS:** Yeah, yeah, yeah. We've got dementia champions that work across acute and community hospitals who are really there to be a role model and drive improvement in the clinical area and support education around dementia in the clinical area. And they do, they do a fantastic job. I guess for me, one thing for me and, you know, thinking about, you know, bereavement and that anticipatory grief, I think for health and social care professionals, I would advocate that the this, it's not just the person with dementia. So like Marion said, the person with dementia might be brought into hospital. They might have had a fall or a chest infection. They might be admitted for, for another, another reason. And I think what's important for me is to see that that whole family unit when you're, you’re caring for someone with dementia. And I always say to staff, you know, when I'm, you know, out in the wards or I’m delivering training, when you care for someone with dementia, you're not just caring for the person with the condition, you're caring for those around that individual as well. And we can be very focused sometimes on, you know, looking at whatever disease process that, that might be going on for that individual. And that's important to, you know, to make sure that we treat that. But sometimes just taking a moment maybe to speak to a husband or a wife or the child, you know, adult child, of maybe that, that person living with dementia and, and just ask them, how are you, you know, how are you getting on? Because sometimes you know it, they can be in a crisis situation and it is all focused around the person living with dementia. But it's almost like, you know, we need, we need that carer to, to be well as well. If you know, to be able to look after that, that person. So I think sometimes just taking a moment just to step back and asking the, the you know, the carer, the husband, wife, adult child, you know, how are you, how are things at home? Because we, there is lots of support out there to, to help with people. We in, in Fife, we're really lucky we've got Fife Carers Centre and we've got hospital link workers that, that work in all our hospitals who were there to support the carer. Obviously, carers of people with all sorts of conditions, but obviously dementia does make up a big part of the individuals that they see. So making sure that the carer has that right support and to help them in, in their caring role. So I think that's, that's really as important as actually, you know, caring for the, the person with dementia as well.

**MR:** I think too, when someone goes into hospital, your caring role doesn't stop. The nursing staff will say no you just go home and have a rest. But you, you're still may want to be part of it. And I had to ask in the, the six months Dave was in the, in the psychiatric ward, can I come in and, and do meals. I know I'm not supposed to be here at meals, but can I be here and he'll eat more and he'll get better and he'll get out sooner. But it's very much a this is a, a protected time and you mustn't be here. And it's, it's just negotiating that so that the carer doesn't feel discarded in some way. Not everyone will want it. Some people will say it's great to have that break, but others don't. And you sit at home feeling even worse because…

**HS:** Yeah.

**LI:** Yeah.

**MR:** You don't know what's happening.

**LI:** Yeah, yeah.

**MR:** So that little bit of asking…

**HS:** Yeah.

**MR:** …what would you like? Would you like to be involved? Can we work around this? Could you maybe take someone into a room away from the dining room? Always just, just asking.

**LI:** Yeah.

**HS:** Yeah, it's really important. I think in Fife we have a scheme or I don't know what we call it really, but it's called Partners in Care where we invite family members to be part of care. And I think unfortunately the pandemic has made a real blip in that because obviously during the pandemic, people weren't able to come in and visit people in, in hospital. You know, we, we went into God crumbs, what, five years ago now when we were probably in the thick of it, weren't we? But you know, visiting stopped overnight. So for people with dementia that was really tough that, that was a really hard situation to be in. And we did, there was some scope that if the person with dementia was quite distressed, then they would let a family member come in. But on the whole, visiting stopped so that Partners in Care, where we involved family members, whether it might be to come and read the paper, it might be to help with personal hygiene, as Marion said, like eating and drinking, we would involve family members as much or as little as they wanted to. And yeah, the pandemic kind of stopped all of that. So we're just kind of coming back from that really and in Fife, I've actually got a meeting on Wednesday about it, where we're going to review our Partners in Care scheme and give it a bit of a relaunch so that we get it out there and that, you know, it's very open and, and obvious that we welcome family to come in and support care as much or as little as they want to. Because there's some people like Marion mentioned, they might not want to they, they might be exhausted themselves and, you know, at crisis point and they need to have that that time for them. But like Marion said, if she wanted to be involved, then we should be, you know, open arms and welcoming family to, to come and be part of, be a partner in care, which is why…

**LI:** Yeah.

**MR:** …we decided to call it Partners in Care.

**LI**: I suppose you touched a wee bit there about people's wellbeing and, and, and how the family members or carers of, of people with dementia, living with dementia, how they kind of are looked after. I suppose, I wonder how, how you, how you both look after yourselves. Marion, obviously you've continued to, to give a huge commitment to NDCAN and Helen, your, your ongoing role as dementia nurse consultant. So I wonder, what do you do to keep yourselves well?

**MR:** Well, I suppose I've always kept myself busy. I think busy makes you not think about the things you don't want to think about, I suppose over, it's taken me six, almost six years now since Dave died and in the interim I've lost my sister as well. I cared for her for six months during the pandemic and lost her in a hospital during COVID, not very pleasantly compared to Dave's death as well. So lots of guilt around that as well. So I've, I think in the last couple of years I've been able to say to myself, you can't change the past. You can't change what you wanted to do or what you might have done. And if, if I'm going to have any future myself, I could have another 10/15/20 years who knows. Maybe I've just been lucky that I've, I've, turned myself around and said let's get on with life. That's what he would have wanted. That's what my sister would have wanted. I’ve had quite a supportive family and my two daughters and my niece who have said to me, it's nice to see you getting out, going on holiday again, doing things for you. And in the last couple of years I decided I would go and do an art class. And that has been helpful because that's been a three hours of once a week of switch off and relax and focus for me. And it's been so rewarding. I’ve been part of a choir as well. And I, I also do amateur musicals. And just being able to do something which has nothing to do with dementia has been a big thing for me. It's focused my time. I, I still have all these connections with dementia. And when I say I would like to, to give up on dementia, I'd like to see we're, we're thankfully we're getting new carers coming forward, cares for current and past carers recently bereaved and they bring a, they bring a new focus and new insights. Unfortunately, some of the things they're going through, I went through 10 years ago, nothing's changed very much, which is a bit disappointing. But at the same time, they're bringing new ideas, they're bringing new views. And that's where it has to move on. We have to keep moving. So maybe I'm getting too far in the past and that's sometimes how I feel. I'm, I'm resurrecting things and I'm bringing up that grief that I don't want to bring up all the time, but it doesn't hurt so much now. So I am beginning to manage my own self-care and say take a step back. Don't let it upset you. Don't let this happen look forward stay well, keep fit. So it is, it's self-care. I'm, I'm looking after me for the first time. It's been a long time and it feels good.

**LI:** Good.

**MR:** It really does, but I, I don't know how I get that on to other people. I'm trying hard as I say with my two friends who have, who are going through, one is, one of, her husband has Parkinson's and again, she's, she's now going into the similar anticipatory grief because she's planning ahead of all the things that might happen. And I can see everything going through her head and what how, how it's affecting her and another friend who's just lost her husband and was very sudden. And it's how it's working for her as well. But, but at least I can be there for them without being involved in myself. So I've, I've learned to do that. Probably because I also was fortunate to have counselling and there isn't enough counselling support either I don't think. I don't think it's recognised that it works for a lot of the people. And then I also was part of carer groups and peer support is such a massive support when there are other people going through the same thing. And again, I don't know if, if professionals have groups they can signpost people too. I didn't find, I had to look for things. I'd like there to be much more information out there about carers groups, support groups that you can just pick up and go and join. Even if it's an online thing where you don't have to, to be in person with someone if that's not what you like. Although I think in person is much better because you get that relationship and people are much more open.

**LI:** What about you…

**MR:** But yeah.

**LI:** …yeah Helen, what about how, how do you…

**HS:** Yeah, so I, I think what Marion said, it's been important is looking after your own wellbeing and things. And I, and I think when you, you work busy, you know, full time and, and I'm also studying, I'm, I'm doing my clinical doctorate, you know, life is, is just a race a lot of the time. And I've husband, two children and, but I've noticed a change in the last kind of two to three years. My, my children, one's through university and one's in second year at university, so they're not as dependent on you. So I've found I've had a little bit more time just recently, although we decided to build a house. So that then took up a lot of time, but, but that's given me a lot of pleasure. We're now living in the new house. We're loving it and we're out in the countryside, which is great. I guess for me, having worked at Brain Health Scotland and learnt a lot more about the risk factors for dementia, it's made me look at my own lifestyle…

**LI:** Yeah.

**HS:** …and I'm, you know, I hold up my hand. I'm not the most kind of energetic, you know, I wasn't a big exerciser. But it's now become a little bit more kind of as I think as I'm getting older and going through those life changes and things, it's made me think about actually, I can play a part and I can do something, you know, for my own health and wellbeing. So I recently started to learn to play golf with, it was in Perth, they did a, it's called GIGL is Get into Golf for Ladies and literally we do have a giggle when we go around the golf course, but I've done it with one of my close friends. But it, it, you know, it ticks the boxes. It's getting you outside, it’s getting you…

**LI**: Yeah.

**HS:** moving…

**LI:** Yeah.

**HS:** …it's learning a new skill as well, which is, is good for the old grey matter. So I've loved that now. I've got my own golf clubs, I've got my own golf trolley. So I can't say I'm, I'm very good, but we have lessons and things. So that's really good and I'm really enjoying that, and I've just started to be a bit better at exercising as well. So just in the new year, my husband and I joined a gym and we did it together, which we don't normally exercise together. He's got a road bike and he goes off and does that and, and I kind of walk the dog and do more of that. Anyway, we joined the gym together and we did a six-week block together. And, and that's been, you know, really good actually for that social thing as well and getting out and meeting other people. Again, it's really good for your brain health, keeping those social connections and, and things. So yeah, so I guess that's how I, I switch off at the moment is yeah, enjoying my new house and starting to get a bit more active and, and exercising. So yeah, keeps me busy.

**LI:** Yeah, I'm definitely going to look up the 14 risk factors for, for dementia.

**HS:** Absolutely, yeah.

**LI:** I've recently joined a gym as well for the first time in my life and I have been going at least twice a week, trying to go…

**HS:** Yeah.

**LI:** …three times a week. And I suppose learning like some of the classes that I go to, I feel like I'm hopeless in them because I don't really know what I'm doing. But I think I'm just hearing what you're saying and I kind of knew this, but just being reminded of, well, actually it's good to learn a new thing…

**HS:** Yeah.

**LI:** …because you know, it's obviously keeping your, your brain really active. So I'll not feel quite so bad when I can't put my leg in the right place or whatever I'm meant to be doing.

**HS:** Good for you.

**LI:** So I'm aware we're coming to the end of the podcast and I just wondered if you had any final, anything final you wanted to say? I suppose focusing on bereavement and dementia.

**HS:** I, for me personally, look at some of the resources, you know, the educational resources around bereavement, the SIGN guideline definitely have a look at. But what I would say my take home message to, to health and social care professionals is don't be afraid to speak to people with dementia and their, their care partners about bereavement, about anticipatory grief. It's not, you know, I don't want it to be a taboo subject that, you know, people feel uncomfortable to talk about. I think the more we can bring it into the open, the more we can be open and honest about it. We can help people support people so that, that, that, you know, death is going to come to all of us at some point. So the more we can do to support people in that journey as, as we all head towards it, is, is to talk openly and freely about it. And so that, you know, we can support people, both the person with dementia and, and their carer as well. So don't be afraid to talk about grief would be my take home message.

**LI**: Thanks, Helen. Marion.

**MR:** I suppose I would say don't be afraid to, to talk to someone if you're struggling. Everyone struggles and death is, is often a release from the illness. And sometimes you feel guilty that you're glad the person has died. And it's not that you're actually glad, it's more that you're relieved that they're no longer suffering. And that, that goes across everything, not just dementia. There are lots of illnesses that you see someone suffer at the end and you think, I wish this was the end. And then you feel guilty for wishing it. And that guilt and grief go together very much, in hand in hand. So I would definitely say go and speak to someone, speak to a counsellor, speak to a GP, speak to anyone who can signpost you to some help and get your life back because you deserve the same life and you deserve to, to have the best life you can. It’s, it's short.

**LI:** Yeah.

**MR:** We don't know…

**LI:** Yeah.

**MR:** …what's ahead of us.

**LI:** Yeah, yeah.

**MR:** You don't, you might be healthy now. You don't know what's ahead in the next 5/10 years.

**LI:** Yeah.

**MR:** So you have to make the most of what you've got.

**LI:** Thank you and thank you both so much for, for joining me today in, in this podcast to talk about dementia and, and bereavement. I'm very grateful for both of you and for your contribution. So thank you so much.

**MR:** Thank you.

**HS:** Thank you, thank you Lynne.

**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. Thank you.

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