NHS Education for Scotland

Transcript of 'Supporting primary care teams experiencing living grief' (NES Bereavement Webinar, 2022) video.

Chair: Dr Graham Whyte, Associate Postgraduate Dean for Grief & Bereavement, NHS Education for Scotland.

Speakers:

- Lynne Innes, Senior Educator with the Grief and Bereavement team, NHS Education for Scotland, Healthcare Chaplain (Staff Support), NHS Fife.
- Vicki Waqa, GPN National Coordinator, NHS Education for Scotland.
- Sarah Giffen, Healthcare Chaplain, Primary Care Chaplaincy Scotland & Regent Gardens Medical Centre, Kirkintilloch.

Support: Philip Smith, Senior Officer, NHS Education for Scotland.

Graham Whyte (GW): Well, good evening, everybody. Welcome to the 14th NES Bereavement Webinar. Tonight's webinar is entitled Supporting Primary Care Teams to talk and be with people who are bereaved or experiencing living grief. My name is Graham Whyte. I'm one of the Associate Postgraduate Deans with the Grief and Bereavement team in NES and a Consultant in Palliative Medicine at Marie Curie in Glasgow, and I'll be chairing tonight's session. I'm delighted to have three speakers with us this evening. Lynne Innes will be leading us off. Lynne's a Senior Educator with the Grief and Bereavement team at NES. Prior to this, Lynne was the NES GPN National Co-ordinator, and has been an undergraduate tutor at Dundee University. She was also a general practice nurse and advanced nurse practitioner in general practice for over 20 years before joining NES, and Lynne also works as a Healthcare Chaplain in NHS Fife.

Sarah Giffen is a Healthcare Chaplain with Primary Care Chaplaincy Scotland and she's based at Regent Gardens in Kirkintilloch and Vicki Waqa is General Practice Nurse National Co-ordinator for NHS Education for Scotland and, in a former role, was an ANP in primary care in the Access Practice and senior charge nurse in A&E in London.

So, welcome to all three of you. Just a little bit more housekeeping before we kick off, but we will be recording today's session and the discussion involved with that. Any questions that you do ask, we'll ensure these are anonymised, so that you wouldn't be identifiable in the recorded session.

Everybody will be muted, so, if you do wish to submit a question please do that via the question box in the right-hand column you've got on your screen hopefully, via the chat function, and we'll endeavour to answer those, depending on time. We'll see how many questions we have time for, but if there are any we haven't had a chance to answer we can get back to you at a later date.

Any questions that maybe come up after the session's ended, please contact us via e-mail at SupportAroundDeath@nes.scot.nhs.uk and we will be putting up the presentation and the slides on

the Support Around Death website at a later date. As always, we'll be sending feedback questionnaire after the session, so, please, if you could fill that in with comments about the session and any suggestions for future webinars would be greatly appreciated. I think that's everything from me, so, without further ado I'll hand over to Lynne for this evening's session.

Lynne Innes (LI): Thank you, Graham. So, welcome to this webinar. It's particularly aimed at supporting primary care teams to help people who are bereaved or experiencing living grief. However, I am aware there are quite a few different professionals that have booked for this webinar, but the aim will be thinking about primary care, but it's pretty transferrable. We're very sensitive and very aware that the themes being discussed today may be upsetting for some people and so we would ask you to attend in the way in which you are comfortable to be present. If you do feel uncomfortable, or any of the issues are distressing, please feel free to leave the webinar or put it onto mute for that time.

That's absolutely fine. Grahams already introduced us, so, you kind of know who we are. Between us, we've got quite a bit of experience in primary care so, I hope we can bring something valuable to this webinar for you.

I thought I'd speak about the background of the workstream and I know there will be a lot of you who are on the webinar who are already familiar with what the NES Bereavement Workstream do, but also, some people who aren't familiar with the work? and so, this workstream is nearly ten years old next year, and it was initially commissioned to develop death certification educational resources and then it's gone on to enhancing medical practice in bereavement care.

That focus has widened quite significantly across health and social care and the work concentrates on developing educational solutions to support staff learning and development, rather than supporting those who are bereaved directly. That's not part of our remit, but we are very sensitive to that as well. So why does bereavement education matter?

It matters because its core business for those of us who are healthcare professionals and social care too. We know that if it's poorly handled there can be a risk of additional harm with negative impact on staff wellbeing.

And we are also aware that the literature suggests that there is a low prevalence of bereavement training with a corresponding high need for it.

And I'm sure we all know that during the pandemic, there has been - the importance of education and staff support around the themes of death and bereavement have further emphasised the need for it. There are lots of different educational resources within the Support Around Death website: lots of different animations and films and e-learning modules and lots of opportunity...There's lots to read. I joined this workstream about four months ago and I think I had never appreciated quite how much the workstream had developed over the period of time that it's been going, and I would really commend you to have a look at the website and have a look at some of the resources.

All the resources I'll be talking about tonight are available on the Support Around Death website and I've given you the site there, but it's pretty easy to find. As Graham said, sad.scot.nhs.uk I've given you some information about the website's use over the last 18 months, because it's gone up exponentially, as you can see, from previously, and I think that reflects the COVID pandemic and that need that identified about bereavement care being so important. The main purpose of my talk, my part of this, was to outline the resources that are available, talk a little bit about recognising loss and the grieving process, demonstrate some of the available resources that may be helpful for you, and consider how we talk and be with people who are bereaved or experiencing living grief.

So, recognising loss and grief: loss is losing something that is of significance to us and grief is the natural process of reaction and adjustment to that loss and change which can then, as we know, bring intense sorrow which can be mental, physical, emotional and spiritual suffering resulting from the loss. It can be a transforming experience and it can lead to personal growth. It doesn't always do that, but it can lead to personal growth.

Each of us experience it very differently and we don't know what the other person's grief is like but we can ask and reach into people.

We are hardwired to cope with grief and loss, and it's really hard - and we know how hard it is if we've experienced grief or bereavement. It changes us and we're not quite the same after it happens to us. There is hope though that may feel bleak and dark, and we learn to live with it, but not necessarily get over it. There are different models of grief.

This is one particular model that you may find useful to consider, and it's a dual process model of coping with bereavement and you can see one side is loss-orientated and one side is restoration orientated. The loss orientated might be what would originally be described as grief work, where we can get intrusion of grief, where we might be particularly upset when we're talking about someone or something that we've lost, or that we're grieving for, and it's that kind of breaking the bonds and the ties and the denial and avoidance. Restoration is, as it says, the restoration, the change, the moving forward, the attending to the life changes the doing new things and the distraction from grief.

As you can see, the squiggly line down the middle there means that it's not a linear process, and we move in and out of it, and frequently we may move in and out of it. It doesn't stay the same, and we don't do one part first, then move to the other.

We move all the time between them. We're going to watch a film now, of Louise, who is a bereaved mother reflecting on the death of her baby. I would ask you to please be aware of and notice your reaction as you watch and listen to the film that we're about to see.

We are particularly sensitive that the themes in this film may be upsetting for some people and once again, I'd ask you to attend in the way you are comfortable to be present, and if you don't wish to watch the video, If you don't wish to watch the video, it's very short - only about two minutes in duration - so please feel free to step away if you'd like to do that. The film was produced by a charity called Abigail's Footsteps and they provide support for bereaved families and they have enabled us to use the film, and we have permission to use the film.

While the film's being played, I'd like you to notice if you can work out when Louise might be moving between loss-orientated and restoration-orientated mode and also consider if Louise was to come into your practice or place of work, how you might talk to her or be with her if she brought up the death of her baby. What might you say or do that might be helpful? I know I'm asking you to think about quite a few things there. If you want to tell us any of your thoughts fell free to put them into the question panel and at the end of the film, we'll read some of them out. Phil, can I ask you to share the video, please?

[FILM]"We've been going to visit the grave of our baby girl nearly every day since she was born. It's always difficult. I mean, it's not something, really, you expect to be doing, going to visit the headstone of your baby daughter. It's always quite a surreal experience. Does it help?

It's a difficult question. To an extent, it does, yes. But what it also does is bring back the memories of that day. Mainly bad ones. But there are some good ones as well. So, friends often ask me if it's any easier now that I have a healthy child, and in a way, yes, it is, of course, but it also sometimes makes me incredibly sad, experiencing the joys of Josie because it just reminds me of what I missed out on with Claire. It's funny - I was thinking about her and I quite like to talk about her. Claire was my firstborn, and I don't think I'll ever tire of being reminded of her. So..”

LI: Thank you, Phil. Are there any answers in the question panel, Graham, at the moment?

GW: I don’t think we have any answers at the moment. I think people are still digesting it.

LI: Thinking about it. Yeah. Yeah. Just to say, that film is based on real-life experiences, however, Louise - the person playing Louise - is an actor. I think when Louise was loss-orientated, she was talking about the memories of the day. That was when she had that kind of little grief intrusion when she was talking about the memories of the day when her baby died. But, in her restoration, she talked about the joys of Josie and thinking about Claire, her firstborn.

The whole film, which actually is a 20-minute film, is available on the SAD website if you want to watch it. It's on the pregnancy loss and neonatal death page. It's obviously quite a distressing film to watch, but it's very valuable to watch.

So, talking with people and being with people who are bereaved, It’s one of the things that we probably all struggle with. I know that I did in general practice and we all probably feel it's something we don't do very well. We actually don't know whether we do it very well or not.

We perhaps do it very well, but we always feel uncomfortable doing it. NES have... The workstream have developed a short video, which we'll see a little bit of in a minute or two about talking and being with people who are bereaved? and on the right-hand side of the screen, you'll see the pdf that goes with that film, which gives you some tips on what you can try to do and what you maybe want to try not to do if it's something you want to have to hand if you're in that situation. I think, for me, the essence of being with and talking with and being with people who are bereaved is always being with them gently and tenderly. It is uncomfortable and it doesn't feel comfortable no matter how often we do it, but be open and sit with that discomfort. I don't like words like, "challenging" and "difficult" and "courageous". I’d quite like us to change our language, to try to use language of companionship rather than fearful language, which I think "challenging" and "difficult" can be.

So perhaps, and I know Kathryn Mannix, who is a palliative care consultant, who has written some books on this, does talk about this using language. She talks about tender conversations rather than challenging conversations and we all find our own vocabulary, but certainly, that helped me to think about those conversations in a different way. It's important to know we can't take people's pain away and we aren't trying to fix or rescue people from their grief.

We're quietly listening, we're creating space for them, and time, and perhaps enabling silence for them just to be. We might want to consider how we close the conversation, and I've heard a few people saying they don't know how to close the conversation or end the consultation, and that can be difficult, but respecting the time available, something like, "Are you OK to leave this here today?". Enquire what they might do next and who they might speak to next. Those can be helpful things to think about. Graham says there's a few questions, a few comments. Graham, if you want to come on and say a couple of them, I think that might be useful.

GW: Yeah, it was just a couple of comments regarding the video, I think. One comment says "It's important to allow time to acknowledge both her daughters, and time to talk." Someone suggested a possible question for Louise, and said, "Do you feel you have enough opportunity to talk about Claire?" There's another comment saying, "It seems very healthy to me that Josie's birth has reconnected her with Claire's death. Joy and loss are two sides of a coin. Sometimes it's good to be able to speak the name of the one who she's lost, who's died.

LI: Thank you, Graham. Thanks. Thank you to the people who put those comments in, the questions. I really appreciate you are engaging in that. So, thanks for that. We're going to move on to the video...Yeah. I just lost my track a wee bit there. The video, the animation that you're about to watch a short part of - not the whole thing - just because we don't have time to show it all. It's also available on the SAD website, and I've given the link there at the bottom of that slide. I'll just move to the next slide now and ask Phil to play this video, this animation.

[Film]: When working in health and social care, encountering people who are bereaved is inevitable. It is important to be aware of some ways to sensitively approach these interactions, to have the confidence to talk, or just listen. Grief is a personal journey, unique to each of us. When a person dies, those who are left can feel their world has collapsed and that what remains is new and unfamiliar. At times, they may feel alienated from people and things around them. When encountering someone who has been bereaved, it can be difficult to know what to say and what support to offer. A lack of confidence, or fears of causing distress can lead us to avoid talking about the person who has died or to those who are grieving, even when we desperately want to acknowledge their loss. This, however, can be misunderstood as not caring, and can enhance feelings of isolation. Don't hide away from the situation out of fear or embarrassment. Do acknowledge the person's loss and offer sympathy even if the death was some time ago. Preparing a sentence or two that you would feel comfortable to say ahead of time can help. This can be as simple as, "I heard that Pam died. I'm so very sorry. "Even just saying you're finding it hard to know what to say is OK too. If you are involved in the care or day-to-day life of a family on a more regular basis you may want to offer a little more support. Some people find it helpful to talk about the person who has died and events surrounding their death - sometimes repeatedly. At times, one member of a family may wish to speak whereas another may not. Don't force anyone to open up, or press for details. It's not about giving advice or having answers.

And try to be comfortable with any silences. Do let them lead the conversation at their own pace. Simply asking, "Would it be helpful to talk about this now?" can be a good way to open the conversation. People can be apprehensive to use the words dead or died. Euphemisms are often used, but aren't always helpful. Where possible, mirror the words and phrases used by the person who is bereaved. Euphemisms can be particularly confusing for children, who might not understand what is meant. Sometimes, we haven't thought about how some phrases will be heard. For example, "How old were they?" may be interpreted as, "Well, they had a good innings," which can be insensitive and sound as if the person grieving should not feel as sad as they do. Even if you have been through something similar, try to avoid saying, "I know how you feel," or "I understand." The chances are you do not. Try not to make reference to your own thoughts, views or beliefs. By saying things as we try to be helpful, it can be easy to fall into some of these pitfalls.

LI: I think I particularly like the section when the cones are around the man, and I think we can probably all identify with that, how...how sometimes, it would be easier not to go and speak to people because they've got cones around them, those metaphorical cones, and I think that's a good analogy of how it sometimes feels speaking to people who are bereaved or if we are bereaved ourselves. The final part, and I'm aware this is a whistle-stop tour of how to talk with people who are bereaved in a 25-minute section, but just thinking about living or anticipatory grief, and this is...In general practice we looked after people with long-term conditions, long-term degenerative conditions, and so, we may be

journeying with people who have living or anticipatory grief. Anticipatory or living grief if where someone experiences feelings of loss before a person dies, and people may experience this in different ways. It can be thought of as a journey and may last for quite some years. And it may be appropriate not to say anything at all, but just to be with people, give them a safe space to talk to cry or just to be.

Affirm with people how they are feeling. People may wish to make memories if they are having anticipatory grief and, in general practice, particularly, we would be thinking about anticipatory care planning with someone who is experiencing...for families who are experiencing anticipatory grief.

People can experience a long period of anticipatory grief but that doesn't necessarily lessen the feelings of grief at the time of death.

And remembering that anticipatory grief can be a long and lonely journey. Be very mindful of that. We're going to play a very short part of the Living or Anticipatory Grief video. It was just produced last year, so, it's one of the newest animations, and we're just playing a very short part of it, but I would suggest or recommend that you go on and watch. The animations are all very short, so, they really don't take very long to watch, but I would recommend that you go on to read it.

Phil, I'll stop talking and let you show the film. Thank you.

[Film]: People may experience anticipatory grief in different ways. Some may feel guilty about the way they feel while others may not recognise, they're experiencing a grief response at all. Anticipatory grief can be thought of as a journey. The path someone thought they were on now looks very different and they must navigate a new and unfamiliar way. This can be a frightening, uncertain or lonely experience. People may feel grief for the person who's changing in front of them. They may grieve the loss of their own identity especially if they have taken on a caring role. They may also grieve for the loss of the future they had imagined together or the hopes and dreams they held for their child. Anticipatory grief may last for many years, although there may be times of stability where life feels more manageable.

Events like a change in a person's condition, an admission to hospital or a move to residential care can reawaken feelings of grief. When supporting someone in this situation, it can be helpful to think of it as accompanying them for a short part of their journey. It can be difficult to know what to say. Saying things like, "At least they're still here," is generally not helpful. Sometimes, it's appropriate not to say anything at all, but just be with them, giving them a safe space to talk, cry or just be. Affirming with people that how they're feeling is a natural response to grief or loss or simply acknowledging their thoughts and feelings, can also be an important first step.

LI: So, finally, just some final reflections. When you're talking or being with people who are bereaved,
be gentle and patient with yourself and one another.

There is a film: 'Coping with death and bereavement as a health and social care professional' and the acronym 'TALK' has been used in it which is: tell how you are feeling, ask for help, listen to each other and be kind to each other. Aim to be present with people when they are bereaved or grieving and essentially be with one another gently. These are just some resources that you might want to…if you want to follow us on Twitter, email us, the Support Around Death website, there are some resources on TURAS Learn and Abigail's Footsteps who are a baby loss charity who provide support and counselling for bereaved parents and families but also, specialist bereavement training for midwives and healthcare professionals.

That's the end of my presentation. I'm going to pass back to Graham now.

GW: Thanks very much, Lynne. That was a huge area to give us a whistle-stop tour and certainly highlight some of the resources, As you say, everyone has been touched, I think even more so in the past two years, by this, so that was really helpful. I think next, we're going to pass over to Sarah and Vicki to more of a discussion forum, I think. I won't take any more of the time, and just pass over to them to take over. Thank you.

Vicki Waqa: Thanks, Graham, and thanks very much, Lynne. Lots of really good resources for you to signpost us to so, thank you for that. Sarah, I'm just going to start by asking you if you could tell me about your role
in Primary Care as a Chaplain.

Sarah Giffen: Certainly. Thank you. And just to say at the start, it's a privilege to be here today. Chaplaincy, as you all probably know, is spiritual care, which is a form of person-centred care that seeks to address and to meet people's spiritual needs, and it may be religious in form, but often is not. It's common for hospitals and hospices to have chaplaincy or spiritual care. I think most of us would be familiar with that. In the last 20 years, there's been an increase of chaplaincy being offered in GP practices, and that's what I do, that's where I work.

The nature of the work is slightly different in primary care settings. The appointments have a generous amount of time At the moment, we're working mostly on the phones, but it used to be that we were face to face in a confidential space and we're hoping to get back to that. There's a good opportunity for repeat appointments and an ongoing relationship with patients.

Obviously, we give space for careful listening, and really, it's a chance for people to voice, and perhaps work through what is difficult for them - loss of all kinds, change, challenge and crisis. Primarily, my role is to work with and to speak with patients who are referred to me. Some are one-off appointments, as I said, some are repeat appointments that come back. Sometimes, it's a case of referring onwards or sometimes referring back to the GP. And sometimes, folk come back again after a period of time when things get difficult again. One of the things I really appreciate about the role is that we're connected to specific surgeries, so there's a real sense of belonging, and belonging to a team and an option for some staff care as well, and perhaps a wider role in the GP practice as well.

VW: Thanks, Sarah. Thank you very much.

How do people go about getting referred to yourselves? We've found that upwards of 75% of the folks who have chaplaincy appointments are referred. A few can self-refer if they know about it, but normally, the referrals are from the doctors, the GPs, but also, from the practice or district nurses if they know about it, from the dieticians and physios, and sometimes even the admin team can facilitate a referral. I think one of the things that's appreciated about chaplaincy is that our waiting times are short and normally folks are seen within a couple of weeks of referral.
And, as I said, we've mostly been on the phones for the last two years, but we are hopeful we're going to get back into in person soon.

VW: I think we're all hopeful - very much so. What is your role, specifically, Sarah, in relation to grief and bereavement?

SG: Well, bereavement is probably our most common presenting issue, or certainly wider loss of all kinds and really, our role is to listen - listen to the stories of loss and to the stories of life before the loss as well, because I guess that's really why loss is so painful.

As I mentioned, we can offer, if folk want it, long-term support, so, it's not necessarily just one appointment on offer. With bereavement, folk come back over a period of time. I guess we overuse the phrase, the idea of journeying with people, but I think that really can be the case in this. And I think, often - and this isn't specific to chaplaincy - any in general practice can offer this, but we can offer a more objective, and perhaps a neutral space, not that it's not caring, not at all, but that perhaps we're not emotionally involved in the way that friends and family are with folks often, so, people can be honest with us in a way that perhaps they can't be with those that they live with, or, you know, other bereaved family members. Folk often mention that as something they appreciate about the chaplaincy service, but, as I say, that could be true of anybody in general practice. Family members often try to protect one another, so, folks do appreciate the chance to speak outwith that network group in a way that they maybe wouldn't do, and to voice some of the stuff that is really difficult. I suppose, because of that, we maybe often see people's very real and very raw grief, and that can be difficult to see, difficult for us to witness, but it can be really helpful to those who have that opportunity to speak to somebody who's maybe not quite as involved.

VW: A real privileged role. My next question was when you're supporting people who've been bereaved, I wonder if you can maybe help us think about options or things that might help these people. I think, speaking as a clinician, there's a real fear there. We're frightened that we do something to make it worse and I think from watching the clips, we can't -well, hopefully we won't, so yeah, some tools would be great.

SG: Yes. I think, maybe, first off, it's just to say that we don't always get it right, but I suppose that isn't a reason not to try.

People are so different and it's impossible to get it right all the time. I know if you even think, yourselves, of your own experience of grief, there have been people who've said things that are hurtful or annoying or insensitive, but normally, even if it's not the most helpful thing, we still know folks are reaching out to us and we appreciate that. I suppose that's important to remember in our work, that maybe we're not going to be perfect, but it's normally more helpful to try, and sometimes, I would couch things, and suggest a number of things so that folks can pick up... For example, if I'm trying to work out how somebody's feeling, and I don't want to maybe suggest that folks are feeling a sense of relief, which can be true in a death in a very complex time. I might say, "Are you feeling sad or angry or relieved or guilty?" And then folk, maybe, can find their own way with that, maybe a little bit more...

So, yes, I suppose I think that's really important to not stop trying. I think sometimes we have enough training to know that a situation is delicate and sensitive, like this, and that can paralyse us, and so, I suppose, some of these things that I want to mention now, I suppose I really hope that it helps us to feel empowered and to step into the kindness that I know you'll all have, and the desire to... I guess that's why you're here today - we're all here - and we all can learn. I was saying to Vicki and Lynne earlier when we were preparing this that I initially signed up as a participant here.

We can all learn. There's always something new that we can learn. We're not going to be perfect, but we can learn things. I guess, going back to answer your question about things that might help in supporting people who are bereaved, obviously, there are the other referral options, so that might be something like Cruse, the bereavement specialists. We saw the clip from Abigail's Footsteps, which is, I guess, more a peer support group for a specific bereavement. I also wanted to mention WAY, which is Widowed and Young. I know folks who have found that a really helpful peer support group, so that might be something you would want to familiarise yourself with.

I think that's for folks who've been bereaved under 50. Then there's the usual support groups of church, family, friends, just people's normal contact groups and activities to encourage folks to re-engage with those. Then there's the chaplaincy option. If you're in hospitals or hospices that's perhaps more common as we mentioned already, but there's the Community Chaplaincy Listening, which is in a lot of GP practices. That's the NHS GP chaplaincy, and that's in Scotland in a lot of GP practices. I work for a little charity called Primary Care Chaplaincy Scotland, but that's nearly entirely in East Dunbartonshire, so that's quite limited geographically.

And those things can be helpful but you're probably on this webinar because you want stuff that you can do rather than to refer on, so, a few things that I thought about that might be helpful and I was just thinking about that little acronym that Lynne mentioned in the last animation that uses the letters TALK, and that's in the animation Coping With Death and Bereavement as a Health and Social Care Professional, and I've just taken each of those and thought of a few things that might be helpful.

I realised I've actually got it wrong, because I have it with TALK, and the first one is Talk again, and I realised as Lynne was speaking, it's 'Tell', so this doesn't quite fit, but anyway, hopefully it's helpful. I was just going to work through that and give a few suggestions, maybe some things you could just write down or think about. So, the first one, well, I have Talk as a suggestion. I suppose, going back to "let's do something", even if we're not going to get it perfect, let's talk to folks, so, it's a wee bit different from Tell. I really like that idea in the other animation Lynne showed about planning what you're going to say. I think they gave the example of, "I heard that so-and-so died. I'm so very sorry." Or, maybe, "I'm sorry for your loss. I've been thinking of you." Something you are comfortable with. I'd even encourage you...it might sound a bit daft - you're all skilled and well trained - but write down the sentence or two sentences that you want to use or that you want to try.

Practise it. Look in the mirror and say it. Practise saying it. If you're worried that's going to make you emotional practise saying it in advance so, you can say it to somebody and I think that will help us, and also allow you to think about what it is you want to say because often we feel a bit flustered, or, as Lynne was talking about, were, if somebody's feeling all fenced in, or looking all fenced in, we can feel on the back foot, so, practise something. And then, moving onto the Ask, think about a question you might want to ask when you're doing whatever you're doing or before whatever contact it is that you have with people.

So, you could say something like, "I'm sure it's been very hard. How are you managing?" Or "What is the hardest thing?" Maybe that's more appropriate if you've got longer time, but just something like that, something that suits you, something that suits the amount of time you have, and plan it, and allow people to tell the story of the past. As Lynne said, we're not going to fix it - we can't fix people but, really, if somebody's lost somebody dear to them, we're unlikely to make it worse. We might upset them in the moment, but it's not going to make it worse and being able to share their burden of loss with you might be really helpful. Then, we come to the L for Listen. I guess that's really my job, and that's lots of our jobs, isn't it?

I want to encourage you to see listening as a role in and of itself I know for those of you who are writing prescriptions, doing treatments or more practical things, it's maybe easy to overlook the importance of listening, but I know in my own work, when people get referred to me, having had a conversation with the doctor or nurse beforehand, and perhaps with a family member before they come and see me, they're often feeling so much better before they come and see me and that's because they've had one or two conversations about whatever it is that's difficult, and so, I just want to highlight the role of listening.

It's easy, I think, when you've all got maybe a hundred and...I know some of you will be chaplains on this, but most of you have other primary roles to do in your primary care role, but listening is just so valuable. And the last one is Kind, and as I said, you've signed up because you want to be kind, because you are kind. Just to add to that, let's remember to be kind and to apply all these things: Tell or Talk - whichever you want to use - the Ask, Listen and the Kind to your team and your colleagues as well.

As Graham mentioned, it's been a hard couple of years, and let's try to be kind and give these opportunities for talking to one another as well as the patients who cross our paths each day. Hopefully that helps. I feel I've thrown a lot of things at you.

VW: That's great, and the fact it's being recorded. We might have to go back and process some of that because I was going, "Wow! That's too much there!" So, I'm thinking, any other specific examples that you want to share when talking and listening to people who are bereaved to help us understand, or can I move on to…

SG: Well, there were a few things that come to mind.MShall I keep going?

VW: Yeah, great.

SG: One of the things that's tied with the anticipatory grief Lynne mentioned is folks who are ill perhaps with cancer or some other serious illness. One of the things I've noticed just recently in my work is the fact that folks are really appreciative of the opportunity to have this honest "what if" conversation: "What if I don't get better?" "What if this really is whatever it is they're investigating?" And I think perhaps in society there's quite...

There can sometimes be a triumphalist, you know, "just be positive and fight it" attitude, and sometimes that closes people down when they can't voice their fears. I think we can have a role in that, and that can be a form of helping people to deal with what might be anticipatory grief or the anxiety that comes with serious illness. When there's the loss of a spouse, particularly with older folks, what can you say to someone who's lost the spouse/partner of umpteen years? But again, just allowing them to tell you the story of their life can sometimes bring them joy as they remember the good times. I think that can be a real gift.

Thinking back to that video of Louise, she wanted to talk about her baby even though she had hardly known her, and that can be a real gift to give to people. Normalising the effect of grief can be helpful as well. People often are afraid that they're going mad and if they're really tired and really sad they don't feel themselves at all, so, for us to reassure people that what they're experiencing, although it's awful, is actually normal or natural, can be a reassurance as well, and you can see the relief on people's face when you say, "You're not going mad. This is grief, and almost to be expected." You don't want to make it sound... You don't want to numb it down, but it is something that's to be expected.

And the last thought on that was just to... Lynne spoke about the grief theory of dual processing. Also, it can be helpful to speak to people about the fact that we almost grow bigger around our grief, so, I suppose it's a way of holding hope for people, that it isn't that the grief's going to get smaller, because people don't want that if they've lost somebody very special, but to hold the hope that they will, in time, be able to live again with the grief still there, but it's almost as if their life gets bigger around that grief. I think that can be really helpful.

VW: Just picking up on your bit about people thinking they're going mad, I think that's really pertinent to us in healthcare as well, because that might be the only opportunity to reach out if they do think they're going mad so that's really, really helpful. Thank you very much.

SG: You're welcome.

VW: I'm aware of time, Sarah, so, what's it like working these days? How different is it from pre-COVID? Is it harder or easier on the phone? What's your thoughts?

SG: Well, I think it's a bit of both. I think sometimes folk can be... I think you brought up this when we were planning this, Vicki, that folks can be more comfortable because they're at home. Sometimes that helps people to have a hard conversation, that they don't have the hassle of getting to the surgery and they're more comfortable in their own environment so that can be a plus side. I think a lot of us do find working on the phones hard and it can be challenging, but it can be done well. I suppose one of the things is just to pool knowledge, and to talk to your colleagues to see what helps, but one of the things I know I find hard about the phone is actually staying focused sometimes.

Sometimes, I'll stand up or walk around or sit and doodle something, and that can help me stay focused and not get distracted, just stay focused on the conversation. Or maybe to plan the talks and to plan time. I think you mentioned that as well, if people are having difficult conversations on the phone, to make sure there is actually enough time to work on the phones, to do whatever it is.

And again, I'll just say again how important listening is, because it can feel we're not doing very much - it's just a few phone calls - and yet, to the person who's receiving it, particularly when folks are so isolated, it can be their only conversation of the day.

VW: I love your idea of walking around, because sometimes I think, "Have I said that already? Have I repeated that question?" because you spoke to someone straight after the next. Maybe being in a different setting might make the brain work differently.

SG: It wakes you up a bit.

VW: Yeah. Thank you. Thank you. The last question, Sarah, is: "Over the last 20 months it really has been a different world that we're living in, so how do you think COVID and the lockdown has impacted on people's experience of grief?"

SG: I think it's generally noted or thought that those who have lost folks, and that's probably quite a lot of us as well, over the last 20 months that there are aspects of it that are more difficult. I've certainly reflected on the fact that our societal norms of, kind of, rites of passage... You know, it's highlighted why they're there. They're there for a reason, and we find, you know, people visiting when somebody's died or the funeral, being able to think about who's come, and those things, when they're taken away, have made some people's bereavement journeys really much more difficult and much more lonely, and I guess just us acknowledging that to people, maybe talking a bit more about it to folks can be helpful. Just acknowledge that it's been a difficult road and acknowledge that it's been a difficult road for us as well. As I've said, many of us will have been bereaved in the last 20 months, but also, perhaps we're perhaps busier and more tired, more frazzled, worn round the edges, than perhaps we have been, and so...maybe we might be better at acknowledging our own - even within our teams or whatever - at acknowledging our own limitations and boundaries and challenges, and that, if we can share it, can only be good for us.

And I suppose there is so much to be grieved over, isn't there? It's been a sad and difficult time. And yet, I suppose that being sad isn't the worst thing. It's a natural thing, and it's a sign there have been good times before. I know that sounds a bit "trying to find a silver lining" but... grieving and sadness is a part of life, and I suppose being able to share it in whatever way, whether it's more personally with

our colleagues or in a more professional listening environment with those that we work with is really helpful.

VW: Sarah, thank you so much. That's really invaluable. Thank you for taking the time – even though you were meant to be a participant - and sharing your expertise. It's really been invaluable.

SG: Thank you. I sincerely hope something's useful. Thank you very much.

GW: Just to echo my thanks to Sarah and Vicki for helping facilitate that. There were lots of really helpful hints and tips there, and certainly, some good resources that you've highlighted Sarah, if you want to come back on, and Vicki as well, we might have time for one or two questions I'm just looking at the question panel here. One of the ones we have spoken about... Somebody asked if the chaplaincy service is available to support all religions? You touched on this, but is there any more you want to say?

SG: Yes, it is. It's open to all. We really, I suppose, focus on the fact that it's spiritual care so, any religion, or none, it's open to. And whether people want to talk about specifically things of faith or not, we see spiritual care as human need, so, it applies to everybody.

GW: OK. Thank you. Probably for yourself again, Sarah, but someone's asking about the availability of the service across the country. You talked about East Dunbartonshire and the charity you're involved with, but do you have an idea of how easy it is for people to access this across Scotland?

SG: Well, Lynne might have a better idea as to the spread of Community Chaplaincy Listening, which is the NHS Scotland initiative, which is very similar. Lynne, do you...? I know it's strong in Tayside and Fife.

LI: Yeah, I think... I don't know for sure. Some of the Community Chaplaincy Listeners are on the webinar tonight because I can see some of their comments in the questions. Unfortunately, they can't come on and speak. I don't know exactly how many... how widespread it is across geographical... around Scotland, but my understanding is it is in most boards. But it might vary in size, you know? I know that in Fife, there are around 20-25 listeners and Tayside also have a big listening service, but I honestly don't know about other boards.

GW: OK. Thanks for that. There were some comments on the chat. You talked about WAY, Widowed And Young, for those 50 and under, and someone's mentioned that there's Way Up as well for those over 51 and mentioned something about Team Verrico, which is for support for those with a cancer diagnosis in the family, so, there's some interesting resources there within the questions, so, thanks for that.

Just touching a bit on the pandemic side of things as well, I know we've seen quite a few people who either didn't want to bother people at the start of the pandemic, leading to a late presentation, maybe, or they feel they maybe didn't get investigated or treated soon enough, leading to a delay in diagnosis, and I was wondering, within a bereavement context, have you seen much of that within primary care?

SG: Yes, I think I have seen that. Folks who are ranging from resigned to angry and, I suppose, again, just allowing the opportunity for people to be able to talk about that journey and people very isolated as well, which is slightly different from what you were saying. Lynne or Vicki, do you want to comment on that?

LI: I'm not sure. I don't know, Vicki, if you might know in primary care? I think - oh!

GW: I think we might have lost Vicki Oh, she's back.

VW: Sorry, just very anecdotally that I'm hearing, yeah, that there is definitely an increase, and I think, largely due to people not wanting to, as you say, Graham, trouble clinicians. I don't have evidence of it, but I do hear anecdotal.

GW: We've certainly seen a few cases and you wonder about the impact of that. Or people who maybe haven't accessed the healthcare in the usual way that they would do and a perception that that's maybe led to a delay in diagnosis, but we'll see. OK. Just looking to see if there are any other questions coming up. I think that might have... Just some general comments. People certainly found the session very useful and informative, so, thanks very much for that. I think that's probably just about six o'clock, so, I think we can probably pull the session to a close.

I think it's been an excellent overview of grief and bereavement and what resources are available, but also, maybe how to help and support people within primary care, so, a big thanks to Lynne, Sarah and Vicki as well for helping facilitate that session.

We will be putting the recording up on the website in due course and if there are any other questions that people think of afterwards, please e-mail us and we can try and get back to you that way. We'll also have details of future webinars. That will be on the events page on the Support Around Death website, and if you could fill out your feedback forms, that would be very much appreciated.

Thanks again to all our speakers. I hope you all have a good evening. Thank you.

VW: Thank you.

SG: Thank you.

LI: Thank you.

The film was produced in January 2022 and can be found at www.sad.scot.nhs.uk or https://vimeo.com/675893105

For more information visit www.sad.scot.nhs.uk or contact supportarounddeath@nes.scot.nhs.uk