

My name is Amanda McCarren and I am Head of Development for tide and I'm also the National Lead for tide in Scotland and Northern Ireland. Tide, it stands for Together In Dementia Everyday and we're an involvement network for carers and former carers of people with dementia, and the main aim of tide is to give carers a voice, to help them understand that their lived experience and that their knowledge is valuable and that hopefully we can influence some kind of change, by them being able to speak about their experiences in different areas.

What do you hope to raise awareness about at the conference?

Well for us, one of the kind of, unspoken elements is about when you're caring for someone with dementia, you'll experience grief and bereavement before the person dies and that's something that's not really recognised or accepted. It's typically accepted that grief is when someone dies, so a lot of carers find it really difficult to identify that within themselves, and also to gain any kind of support or access support from professionals because again, they themselves don't actually recognise that they could be grieving because they see the person's still alive and they think that it might be something else, such as depression or anxiety.

What did you cover during your presentation?

Well really it was round about, we call it living grief and bereavement, and it's a piece of work that we've just done recently across our full network, so across the full of the UK, and it was first of all decided by carers themselves that they wanted to talk about this topic, so we thought that's great, let's give them a platform to do that. So, we began focus groups and we also did an online survey and we got the biggest response we've ever had across our network to this so we understood it was something that people were really passionate about and that they wanted to talk about it. And following that we thought well, we've got all this really good data and research, we don't just want it to end there, so the carers themselves actually then produced two resources, one booklet is peer to peer - carer to carer and the other one is for professionals, just to raise awareness about this subject and some of the things that they were feeling that they can't always say out loud. And we also produced a small video as well which kind of went into the background of the research and also gave more feedback that we gained from the carers across the network.

What else would you want people to know?

Transition points are usually a big trigger for grief and bereavement, such as when the person they are caring for goes into hospital, or into a care home, or if they have quite a significant deterioration in their condition, then that can be a trigger point. But also for carers it's also important for them to acknowledge that if they've given up employment or their relationships have suffered or they've had to maybe give up a lot of their hobbies and just time for themselves, and that again can be areas where that can trigger off grief and bereavement for them. And the third most important one as well is the, kind of, the dual kind of conflict between what you thought your life was going to be like and

what your life is like now. And when you see other people live life side by side who are doing things that you thought you were going to do with the person, or the life you thought you were going to have, that can really trigger off feelings of grief and bereavement in carers.

What are the implications for bereavement support?

Well, we feel at the moment that grief and bereavement is just something in general that people don't like to talk about, and that again if you take it into this context, this is something that again carers felt is something that they didn't feel comfortable talking about because people didn't really acknowledge it, because when they talk about it, they say things like 'Well, you're lucky the person's still here', so they don't really acknowledge it as grief and bereavement. So, some people will just, kind of, you know, push it down and not really talk about it, so what we felt was that it's important in the grand scheme of things in all, kind of, bereavement support that this is recognised and acknowledged. And then also, as the person continues to deteriorate and eventually does die, it's also still a huge journey for the carer as well and that there needs to be support after that as well, so after death, a lot of the times the carer has a massive void because the person's no longer there, and everything that consumed their life is not there anymore. So, it's about how do we help them to get support in that, so, it's just for us a kind of, continual journey, that has different points in it and we feel that it fits in to the kind of bigger picture in Scotland in that it really needs to be highlighted.

What are your key take home messages?

I think for me it is just really important that people are willing to listen to carers and I think that's it because I think, partly the first thing that people worry is about how can they fix it, or they try to fix it – it's a natural reaction. And I think that with grief and bereavement you can't fix it, you'll not take away that pain and you'll not make that person necessarily feel better but I think if you just give them space to be able to be honest and you acknowledge their feelings, and that you tell them that it's normal and it's ok, then I think that goes a long way to helping them and then after that, if there's other things that you can either signpost them into or help them with, I think that would be really important.

The film was produced in March 2020 and can be found at www.sad.scot.nhs.uk or <https://vimeo.com/392433143>

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

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