

Dr. Frankie Greenwood shared two of the stories from her PhD “I See You” Exploring the Stories of People Without Dementia Who Have Meaningful Connections with People with Advanced Dementia, (Greenwood 2020).

These stories reflect the what spiritual care might look like in practice.

Tamsin’s story

Tamsin is a Christian minister who said that she did not have dementia on her radar when she first came into ministry. It was after having a discussion with a care home manager about starting a small service in a care home for people with dementia that Tamsin began to think about how much could be done for people.

She began to research ways to reach people with dementia.

Tamsin supports people with dementia in various ways including pastoral visits. She carries out a worship service for people with dementia in a secure part of a care home where people with advanced dementia live. Tamsin asked for permission to do that service when she realised that the people there weren’t receiving any form of service. She tells me that you must *“find different ways of worshipping”* in a care home because not everybody in that care home is able to access what people would say in a standard service.

Tamsin shares that the church needs to *“be better at not losing”* people with dementia.

She also talks about making the sacrament of communion still accessible to people with advanced dementia and shares a story about a lady who has, what Tamsin describes as, *“severe advanced dementia”*. This lady sleeps most of the day but offers brief moments of awareness. Tamsin noticed no-one was going to visit this lady, so she and another person visit and offer an *“advanced dementia communion”* service.

Tamsin tells me:

“And the more I see how, no matter how lost in her advanced stage dementia she is, she knows exactly what’s happening. It’s very precious.”

I ask Tamsin how she knows that the lady is aware of what is happening, and she describes what happens in that communion service:

“So, when I go in and say “hello it’s Tamsin, one of the Ministers” I don’t know if that word Tamsin, that word Minister, if it means anything. So, what I do is I tell her what I am doing. I tell her that I’ve brought the communion cup, and then I hand it to her without any wine in it. And I let her feel the shape of it because the chalice is very particular, and I always choose a ceramic one, because it’s cold.

And so, it’s got a Celtic Cross on it, so you can feel you can feel the shape of it. And I put her hands on it. That’s not immediate, because the first thing I do, she’s got a beaker and I give her a drink of juice so that her mouth isn’t dry and, we talk about the weather, and I talk about church and I mention key words while I talk to her. And then I say that I brought communion to share with her. I’ve brought the church to her and we’re going to talk about God and share God’s love with her, and then I let her hold the cup and then I put it down and then I have the wine, port and I let her smell it.

And then I pour it near her ear, and then I let her hear glug, glug, glug. And then I say “that’s the communion cup now on the table. And it’s not the table of the home you’re in now it’s the Lord’s table”, you know as many little bits, but I don’t do a lot of talking.

And at this point she could have appeared to have fallen back to sleep or not with me at all, but I keep talking. And I make sure I say key things. And then I’ll say: “and I’ve brought the bread” and I let her feel the bread, ‘cos I always buy a round loaf and I always buy a floury one ‘cos I think there’s something about texture and flour. And then I put that on the table and I really appreciate the fact I go with someone else, so when I think she’s not involved in anything that’s happening I’ll speak to the other person because I believe she can hear.

And then I will say “we are now going to share communion, something you’ve done many times, something very precious to you. May the grace of our Lord Jesus Christ be with you...” And then I will take the cup and I’ll say “it’s not the table of your care home, it’s the table of the Lord. And it’s made ready for you because God wants to meet you here.” And then I’ll give her the cup to hold again. And I mean, it changes each time I do it because it depends if I get a moment of awareness, but what is lovely is that when I say, “Jesus sat around the table”, when I unpack it like this, it’s almost as if she’s switched off. But the moment I say: “and it was with friends around a table”. And at that point, I put the bread into her hands and then I put my hands on top of hers. And then together I pull the bread apart and I say: “Jesus took bread, and having blessed it, broke it.” And I tear, and I move her hands, “and said do this and remember Me”. And I know, because I can feel, that in that moment she knows exactly what is happening. Because her, whole being and her breathing is much calmer, and I think that’s the work, I think the whole thing is a calming thing for her. And, her eyes might be shut but if they are there’s a recognition of how she’s more alert in her body. And especially when I break the bread, she’ll open her eyes.”

Tamsin also tells me that she says the Lord's prayer and the lady will mouth the words but doesn't get to the end. I ask if she moves her mouth other than that or if she speaks, and Tamsin tells me that she has lost the power of speech, but that she does try to mouth the words of the Lord's prayer "*and it is lovely.*"

Tamsin finds this experience beautiful but sad. Tamsin comes away drained. Although she says:

"It's so Spirit filled, the room, you walk in and it's an empty room with a lady in it and a radio. And when we leave, it's Spirit filled. And you can feel that. And there's a calmness about her. I think she's calmer and I'm more emotionally drained. (laughing) you know there's a real change, but she is certainly calmer".

Polly's story – Polly is a member of care staff in a residential care home

Polly tells me about her work with Namaste. (Namaste is an approach to dementia care for people who find it difficult to participate in traditional care activities (McNiel and Westphal, 2018) and sessions might include massage, “*personal care...multisensory simulation activities*” (2018, p38) and reminiscence). Polly hadn't heard of Namaste until she went on a course and heard a lady speak about it. She explains that Namaste, roughly translated means:

“I see your spirit within” ... what that's saying is...” even though you're like that, I still see you.” And that's how I love Namaste. Because you are honouring that person, and saying, “I still see you in there.” And for me that's what Namaste is.”

She tells me that when she went on the course and heard the lady speak about Namaste:

“See from the minute she came in and started speaking' about it, I couldn't stop crying. I was like “I really need to do this.” D'y'know how you just think...this is why I'm here?”

F: [Wow!]

[right]

[yeah]

P: This is why I'm on this course. I thought I really need to bring this to the care home. So, oh! It was absolutely amazing Frankie, I'm not joking. And so you got the training on it. Like we got learnt to hand massage, then and see the washing the feet for me is huge. A lot of folk probably think it's very strange. But I think washing somebody's feet is the most amazing thing that you can do for somebody. I honestly do, I think it is so beautiful

In the Namaste room she will put on soft music, the sensory machine with the bubble tube is there, she uses different aromatherapy smells, the lights are dimmed and there are projections on the wall. She describes it as “*the most amazing relaxed atmosphere ever.*” Polly tells people how pleased she is to see them and gets to know what they like and don't like.

She tells me that some people with dementia who walk around a lot and don't usually sit for any length of time will sit and relax. She explains that men who can be aggressive at times will:

“allow you to wash their feet. They will allow you to give them a wet shave. That would never happen on a normal basis.”

Polly tells me that most people who go into the Namaste room are unable to participate in other activities and a lot of them can't speak. She tells me that she brings in people who are agitated and tries to spend time with them:

"Relaxation with a lot of them it's a one to one, because other people would distract. So, there isn't always a lot of people anyway, because you want it to be quiet. You want it to be quality time. You don't want to be just spending that short time, so you want it to be, have plenty time that you can actually spend."

Polly tells me that people become calm in their mood and a lot fall asleep.

For someone at the end stage of life, Polly takes the sensory machine into their room, and creates the same atmosphere as in the Namaste room. She talks about a massage technique that she uses for people who don't like to be touched and we have the following conversation:

"So, they use a blanket. And oh it's amazing I've had it done. And so, if they're lying down, which is a good one to do if they are in their room. So, you put the blanket over the top of them. And what you do is you start up, up at the top and then you start off here y'know, and then just gently, just stroke

F: with the, like over the top of the blanket?

P: [over the top of the] blanket yeah. So, you're not actually losing connection with them and then you'll go down to the h- and then down to their legs and down to their feet. And it really is lovely. It really is. It's so comforting and it's really, really nice.

F: [What] happens to the person with dementia? Like do they change?

P: [Y'] can feel, it's very spiritual. You can feel a peace. You can see, I mean a lot of times you'll see that they'll maybe be stressed to start with. And then you see that changing you can see their face changing, you can see their body changing, relaxing. And again you have this lovely music and if it is someone who has been a church goer, I'll put on hymns and I'll sing knowing that, if they do like that, and then we've got a resident here who likes classical music, so I have bought a classical music cd, but the you know the calm music. So, what you try and do is find out what that individual person likes. It's very individual."

She might try reading poetry, and:

"just really finding what they... 'cos you know by their facial expressions."