

Dementia Dialogue; Season 3, Episode 27

Spiritual Care: Filling their Souls

Transcript of interview with Elisa Bosley and Christine Thelker by Lisa Loiselle and Rev. Faye Forbes

David - Thanks for tuning into Dementia Dialogue and the second episode in our series on spirituality. In this episode, our guest host for the series, the Reverend Faye Forbes and Lisa Loiselle are in conversation with two interesting people.

Elisa Bosley is a chaplain in Colorado whose mission is now focused on improving spiritual care and spiritual care resources for people living with dementia.

Christine Thelker returns to Dementia Dialogue for a third time. I first interviewed Christine in our Human Rights series and in the fall we had a delightful conversation about her new book *For This I Am Grateful; Living with Dementia*.

Let's join these four women.

Lisa - Welcome to you both.

Elisa – Religion I think of as a particular faith expression, which is very important to many people who grew up with particular rituals and actions and again, expressions of their faith tradition.

And a lot of those are hardwired into this long term memory. So they're very accessible for people with dementia. But spirituality, I think, is an even bigger category. So you have to have some specific knowledge of religious traditions to meet those needs. But for spirituality, that broader category, that's everyone. That touches on joy and meaning and what brings you comfort and what brings you a sense of safety and assurance. And that is for everyone.

And that's how I would see the difference.

For me I've been part of the Christian faith tradition for my entire adult life. Got involved in chaplain care for dementia after my father-in-law developed dementia. We were very intimately involved in his care. So after he passed away, I combined my love of spiritual care with dementia care and was surprised to find that it was kind of not common, commonly offered, at least in my in my sphere here in Colorado, was not that commonly offered in long term care homes.

Then I started looking on the Internet for resources and found there were very few that were dementia specific. There was very common agreement that spiritual care was needed and helpful for people with dementia. But there wasn't a lot in the, "Here's how to do it and here are the resources to do it." So because I had so much background in that, that's where the website came from. I thought, well, other people I'm sure are looking for these resources. I can happily, freely provide them.

Lisa - So when you talk about the website, you're talking about www.spiritualeldercare.com

Elisa – Yes www.spiritualeldercare.com that I launched after I realized the materials I was creating for myself, these dementia friendly worship services, non-denominational worship services and Bible discussion guides, and then later hundreds of professionally recorded hymns, because the musical part is so huge for this population. It's such a big, big help and comfort to sing these old familiar songs. So making those recordings, I hired professional musicians and it was a great project that took much longer than I had originally anticipated.

So those are all up on www.spiritualeldercare.com

Christine - Oh, that's so good to know. That just lifted my heart so good to hear that. It reminded me when I worked in dementia care. All of these services where dementia clients weren't allowed to go because it was thought that they might disturb other people. So even though they were held within the building, they were excluded and it was really sad. So a friend of mine here who does a lot of different singing performances and stuff for seniors, actually, I talked to her and she started coming in once a week just on that unit. And you're right, all of those hymns, all of those old songs that were so familiar to them. I'd bring them all to the dining room and I'd get them all coffee and they would sing and other people that worked there would go, "We didn't even know she could talk". And it's like you're not even trying to engage them. Now, you can see that this has touched them in that spiritual way. This is something that is giving them comfort and they feel good.

So that's wonderful that you started sharing all of that because it's so important.

Elisa - It's cliché to say that I received more blessing than I give, but it's absolutely true every single time. And as you point out, Christine, in the songs in particular, I regularly, regularly, people who may otherwise be non-verbal or barely verbal will start mouthing the words to the songs. I will see tears flowing, tears of joy. And they just yeah, it's a really important piece of their spiritual well-being.

Christine - It's a really special piece. When you see those tears of joy, when you see someone who is mostly non-verbal, all of a sudden trying to get those words out and they're tapping their hands on the table. And you can just see that you've provided them that joy. And their soul is just filling up. And it's like you just don't want to stop. You want to be able to give that to them every day. And it's a piece that we really, I think, need to focus more on is that whole spiritual side of feeding people's souls. And when we're feeding someone else's soul, we're fulfilling our own as well.

Elisa - Absolutely true, is that these people have spiritual needs that are not only real but completely accessible and they want to participate and express.

I remember one woman with dementia telling me, "I love your format because you don't talk to us like we're children". And again, this was a person that was sort of partially verbal. And when she said that, I was like, "Okay, well, this is why I do what I do".

Christine - And that's a gift. And the world is better for having you and people like you who tap into that and tap into that for others so that their souls get fed.

We have too many empty souls walking around this world right now, whether it's dementia or anything else. There's too many lost, empty souls walking around and no one tries to

reach them. We gloss over so much of it. And in dementia, that's very prominent. It's why we're still locking people away on dementia units, which we shouldn't be. And we strip them, we strip them of that whole piece of their soul that's so vital.

Lisa - So what more can we do to encourage the spiritual enlightening of people living with dementia, either in long term care or in the community? How can we support that?

Christine - Well, I believe that we really need to have this whole change in how long term care is delivered, first off.

Second to that, the whole education component for anybody working in dementia care is vital. And if it was part of their educational component where you could showcase videos of what that does to people. Get it recorded so that people can see how their face light up, how even if they've been non-verbal, you see them try to sing and you just see the brightness so that as part of their education, they see how important this role is.

Lisa – We had a conversation in our first episode of the Spirituality series with Jane Kuepfer and we were talking with her about that spiritual care doesn't need to be delivered by somebody who is a minister or has any special training in spiritual care.

What you were saying, Christine, about that education, I think it's so important to add that spiritual piece in education and so that other people who are working alongside those people living with dementia, that they understand that they can be that spiritual leader for them as well.

Christine – Yeah, it's like when I went outside of my parameters of my job and I found Sally to come and I arranged it. And of course, I had to fight management on it. But in the end, when I had them come up to the floor and see, I said, “You need to come and see this”. It's still going on today because I understood that important piece.

So if you can educate and show them how important it is and the results that you get. You have much calmer people because they're content. They feel good within themselves. They feel special for that period of time.

So it really does need to be a much bigger focus. And as you said earlier, at least the musical component of all that, is so important for them. They love it. And you see that in their faces.

Elisa - And the effects do last beyond that hour long or thirty minute long or whatever time of day of worship or a hymn sing. It goes it goes beyond that.

Christine - Well, it's like they find that inner peace. It's like when you go to church and you come home and the rest of your day is very peaceful and very calm, right? That's what you're giving them. So they have this inner peace and they feel fulfilled and they feel that joy and that calm. And, yeah, it's just so, so vital.

Elisa - And I do think bringing it into the building, at least in my case, has been so key because in so many cases, these people cannot, for whatever reason, can't get out to their normal places of worship.

So many, many times I've had residents say, "Oh, I haven't been to church in weeks or months". And I always say, "Well, that's why I'm here. I'm bringing it to you". And they sometimes might be a little suspicious because I might not be from their exact faith background. But just give me one session and they're good to go and they're thrilled.

So I do think, Christine, you're absolutely right that that understanding and education among the care staff is so, so important.

And for them to understand that this is a sacred time. It's not like bingo or some other activity. Those activities are good. But there is something unique about the benefits of spiritual care activities that go even beyond any other sort of group or participatory activity.

And I think the training part is the second really big thing. So there's that understanding and appreciating the value of spiritual care for people with dementia. And then secondly, the training and this goes both to staff in the building and to the community, because in my experience, there may be people who have an understanding of how to provide spiritual care but are not familiar with working with people with dementia, or there's people who are very familiar and comfortable with people with dementia but don't feel comfortable providing the spiritual care. And you really need both. You really need both. So that's, again, part of my passion. It's like you can do this if you have both of those pieces.

Christine - It is those two pieces that come together that truly are the key to it. So, yeah, we go back to the education on both sides, to be able to deliver that to people. And when you see the results of what it brings to their lives, why wouldn't we? Why wouldn't we be spending more resources on those types of things?

Elisa - On those spiritual and religious activity. Again, they have that long term imprint, which is so helpful.

I think there is, in communities, there's a lot of well-meaning, kind people that even would want it to volunteer. They even have a value for the spiritual care for the elderly and for people with dementia. But they're nervous about how do I do this with somebody who's cognitively challenged. So, again, that's that training from that side as well.

Christine - That goes right into the facilities themselves. Why are the people with dementia not included in those weekly services? Because they don't have that understanding of how important it is for them and how it still connects to them, no matter what stage of their dementia they're at. So they get excluded instead of being included.

Elisa - Yes. There was one home I was working in where it was both an assisted living and a dementia care unit, but they were separate and they wanted me to do the church service in the assisted living side. And I really lobbied to have and succeeded in having the church service performed in the dementia care side. And the assisted living people could come. But the staff was worried that they won't feel comfortable. And I said, "I think it's going to be okay. And the people that are motivated to come over to the dementia side will be glad that they did. And the value for the people in the dementia unit is incalculable".

Faye - But even those that don't have a faith background, still have that spirituality that they've grown up with. It comes from their heart, from their feelings. And I think anybody working with someone with dementia has to be able to listen and hear even though they're non-verbal sometimes. You can hear through body language or old songs, You Are My

Sunshine. My mother-in-law used to recite old ditties, "There once was a girl who had a curl right in the middle of her forehead" and she had hundreds of these old ditties. And we would laugh and joke and she would sing along and we would do action songs. I do that in the nursing home that I visit. Action songs. They love the action songs.

Elisa- Yes, that's absolutely right. I love the idea of using humor. That's something. And you're right about people with another faith background or no faith background. I mean, that's really a passion of mine, is to assure people you don't have to be any particular faith background to come and enjoy this. It might take a few tries to convince them to come. But I just keep asking. I always tell people no conversion required. No experience required. Just come and enjoy it. And I even tell them, "If you're not comfortable, you can leave. That's okay."

Christine - There's no reason for them not to be offered the service when the service is there. What it comes down to is facilitating the workers to understand that the tasks that they're doing are not as important as feeding the people's souls that they're in charge of looking after. They're so task orientated that, "Well, we don't have time to get them all down to the room, to the main room to watch this. And we don't have time to sit with them while this is going on". Well, yes, actually, you do, because it doesn't matter if the bed is made this hour or the next hour, right? So that again comes back to that education and shifting things away from that task orientated care to that person centered care.

Elisa - And I just want to add one more thing about what you said about person centered care, Christine, because I think that we've made huge strides in understanding that person centered care is important; the physical needs, the social needs, the emotional needs. And it is that spiritual part, we need to educate people that that is part of person centered care.

Christine - Well, and that spiritual peace enhances all the other pieces. It really does. It's sort of the foundation. It should be the foundation of how the rest of it comes about. And then I think you will see a total difference in the outcomes of what's going on in long term care

Lisa - In the same way that we're talking about spiritual care for people with dementia, going back to actually what, Christine and Elisa, what you both said at the beginning, that providing this care gives you just as much joy and happiness and peace.

And so when I think about health workers in long term care, having them provide that spiritual care or assisting in some way that only enhances their own joy. And imagine then them being happy during the day and how much that lifts them and then how much more they can lift the people that they're caring for.

Christine - And that is a really big component. I just talked to someone the other day about that very side of things. She said, "It's a horrible place to be to work". She said none of the patients or clients, whatever you want to call them, are happy. They haven't been for years. She said, "None of the workers, everybody hates going to work".

So if people are starting their day being miserable about being there, how can you provide any quality to the life of the person they're looking after? So we need to change that whole piece. And if we started it from that spiritual foundation, with the education, with the tools and the skills and the understanding, then that spills out, you're right, to both sides. The

workers will be content and happy and confident. And you have clients who are feeling calm and cared for and cared about and happy to be there and participate.

Elisa - I'm so glad you brought up that point, Lisa, because I often tell people or anybody who will listen that investing in that spiritual care piece is the best return on investment that you will get for your staff and your residents. Not just your residents, but the staff as well. I mean, just imagine if all the staff knew how to care for one another in the most simple spiritual ways. And I'm talking about asking questions like what brings you joy today? That's a spiritual care question. What's a good day for you? You can ask this of staff, not just residents, right? What things are hard for you right now? That's a spiritual care question. I've heard them described as like spiritual teddybears. You give something that's comforting. And just imagine if the staff knew how to do this for one another and if they knew how to do this for their residents. The return on investment, the increased joy and meaning of the care that they are providing and then the care that they receive at their place of work. And it's possible. It's possible.

Faye - And it's all about relationship between the staff and the client and the staff and the staff. And it doesn't matter what your job is in that place of work, you could be the janitor and cleaning toilets or you could be the person that's actually doing physical care for the client. It's about having that relationship with each other and knowing what makes them happy, knowing what puts joy in their hearts and making them feel appreciated and loved.

And during this time of Covid, when there's a lack of human touch, lack of visitation and everything, it's devastating to those that not just live in long term care, but those that work in long term care as well, it's taken away our humanity to such a degree.

Lisa - All right, ladies, thank you for this lovely conversation.

Christine - This has been wonderful. Thank you.

David - Thank you to Christine and Elisa for sharing your thoughts and passion about enriching the lives of people living with dementia through attending to their spiritual well-being.

Thanks also to Faye and Lisa for hosting this episode and for bringing the whole series to us.

Please go to our website, www.dementiadialogue.ca and read the note connected to this episode to find out more information and to learn how to locate the resources Elisa has assembled.

If you wish to make other people aware of this series, we have a poster that you can download. It is also attached to the episode notes.

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My name is David Harvey.