

Dementia Dialogue: Season 3, Episode 25

Being Fully Alive: How Spirituality Endures

Transcript of interview with Jane Kuepfer, Rev. Faye Forbes and Lisa Loiselle

Cynthia - Hi, everybody, I'm Reverend Dr. Cynthia Huling Hummel from Elmira, New York. I'm a person living with early stage Alzheimer's disease. I'm an Alzheimer's advocate, artist and author. I'm also a retired Presbyterian pastor. And I'd like to share this prayer with you:

Dear Lord, bless those of us who are living who are diagnosed with Alzheimer's or related dementia.

When days are difficult, wrap us in a blanket of your love and comfort us with your presence and your peace.

When nights are dark, give us a star to follow; a night light in the heavens to remind us that you're there guarding and guiding us and lighting our pass.

When we're discouraged, give us hope.

When we're hopeless, give us faith.

When we're weary, carry us close to your heart.

When we feel depressed or angry, soothe us, wipe away our tears and our fears and help us move from why me? to what's next?

We thank you for care partners, for family and friends who are walking with us on this strange and sometimes difficult journey.

Give us all strength and courage and a sense of purpose as we join our hands and our hearts to help others we meet along this way.

Help us all to cultivate an attitude of gratitude each and every day.

Remind us to look for blessings in every day and holy moments; walking in the rain, singing a familiar song, reminiscing over old photos.

Lord, we pray for doctors and nurses and others who care about us and for us.

We pray for the researchers who are searching for treatments, therapies and cures.

Most of all, we pray for a world without Alzheimer's.

Thank you, Lord. Amen.

David - Welcome to Dementia Dialogue. With this episode, we begin a four part series on spirituality and dementia. A new episode will be released each month between now and early July. Our series is co-hosted by the Reverend Faye Forbes a Nova Scotian mother and a priest in the Anglican Church. Faye has been diagnosed with dementia and is now a leading advocate.

Faye is joined by Lisa Loiselle, an independent researcher, a long time facilitator of the full participation of people living with dementia, and the convener of this series.

I cannot introduce this series without mentioning my friend Ted, who I have been not able to see for over a year because of Covid, during which he moved to a long term care home as a result of a rapidly progressive frontotemporal dementia. Ted is a deeply spiritual man, and I witnessed how his spiritual core helped him first try to understand, then to cope and finally simply to find comfort for both him and his partner, Kath.

He derived meaning, strength and compassion for himself and others from his faith. I look forward to seeing him soon and witnessing how his spirit sustains him still.

In this episode, Faye and Lisa are in conversation with Jane Kuepfer. Jane is an ordained minister and the Schlegel Specialist in Spirituality and Aging at the Schlegel/ University of Waterloo Research Institute on Aging.

Faye - I'm Faye, and I want to introduce the first topic of this first episode. It's on spirituality and dementia. I'm so excited to have our guest with us today. So welcome this morning, Jane.

Jane - Thanks, Faye.

Faye – What does spirituality mean to you?

Jane – Spirituality is about connection and it's also about meaning; the depth and the essence of life. What really matters. And then also that transcendence; there being more. So spirituality is about connection, about meaning. Bob Atchley, who wrote about spirituality and aging, talked about spirituality as our capacity to perceive experiences as spiritual. And so thinking about the spirituality of dementia, we realize that spirituality isn't something that's dependent on cognition, but it's more than that. It's about being fully alive.

Faye - You know, I like to define it myself as something that makes your heart sing.

Jane - I love that.

Faye - I've always been a very spiritual person and in so many different ways, not within my faith, but nature and in music and in art.

Jane - Yeah, that's a wonderful way of looking at it. Religion, I see as a system or a structure. Religions come with a community attached, that people might be part of. Where spirituality is things that you don't have to follow certain religion in order to access in your life. But religion can be a tool within it.

Faye - People, when you mention the word spirituality, automatically think of religion and faith belief. They don't think of it in other aspects.

Jane - Yeah, true.

Lisa - So how do you both express your spirituality?

Jane – There's different dimensions to it. So of course I'm a person of faith as well, being a practicing Christian and someone who has been in leadership in the church and from the spiritual care for others. I'm definitely rooted in practices of my faith, prayer and participating in sacraments and things like that of being part of the church community is all part of my spirituality.

There is also definitely a part of it that is about just breathing, about staying grounded, about connecting to the Earth, to God, to other people. Countering the scatteredness of life is a big part of what spirituality is.

And then there's also the aspect of being in relationship with the world in service and helping make the world a better place. Being part of hope and peacemaking in the world. That's important to me.

Lisa -Yeah. Community. What about you, Faye?

Faye - Well, I'm very much like Jane. A lot of my spirituality is rooted in my faith, being an active Christian in my church and in my parish and helping those around me and the relationships that are formed.

But there's a lot more to it. I really enjoy just being quiet, usually outside, but the weather's not always applicable to that. I watch the birds at the feeder or the animals walk through the yard and connecting with nature and the Creator in those regards. Just being in awe and wonder of how everything interconnects not just in nature, but in our own relationships as well.

If the snow is falling and it's pristine outside after the flakes have landed, it's beautiful and calm and peaceful. It's like a Christmas card scene. And then the kids come along and they slide down the hill and they put footprints all over the snow and that serenity is gone. And I was sitting outside the other day thinking, it's too bad that everything is disturbed with footprints and everything. And then I thought, no, because as they were running up and down the hill and sliding and making snowmen and everything, they were laughing and they were having fun.

And that's as spiritual as the serenity was. It's just different.

Jane - Beautiful, too. Vital. Alive.

Faye – So having those moments and finding joy in whatever it happens to be. I'm always a person that looks at the cup that's not just half full, but overflowing.

Lisa - For a lot of people in our population, when they think of someone living with dementia, they often think about the physical care required, think that's the necessity. But as human beings we're much, much more than that, we're more than our physical. Can we just talk about the spirituality in relation to dementia and dementia care? Jane, can you tell us a little bit about that?

Jane - First of all, I want to say that how we think about dementia and what it means is a spiritual question. What is going on with dementia? How do we understand ourselves as human beings? Where is our identity grounded? And from a spiritual perspective we see not so much the loss or what is missing or gone. What is present, what is more vital and life giving and the that core being of the person that doesn't go away.

So how we think about dementia is a spiritual question. Being spiritual isn't dependent on cognition. I think spirituality is a real resource to us in dementia. I like to think of the aspects of spirituality that endure as dementia progresses. So in contrast to diminishment that we might see physically or cognitively, there are these aspects that endure and can even become stronger.

Another aspect is belonging. Being held as part of a group is so important and powerful there as well. When people are living with dementia, the community can hold the memory and carry people along when it's harder to do individually.

Then there's also the aspect being able to connect with the moment and human interaction as well. Touch all part of a spirituality that can be a resource.

People who are along the journey of dementia can help us think about the experience of dementia in new ways.

Lisa - Why is it so important, though? Why is spirituality an important component of your life?

Faye - For me, it brings joy. It brings purpose to my day. It brings a calming sense of relief, less stress, less anxiety. And I'm speaking as a person who is walking that dementia journey because little things can disrupt your day totally.

Spirituality, in whatever form it happens to take at that particular moment is what lifts me up.

But life is constantly changing, isn't it?

And when you're diagnosed with dementia, the first thing you want to do is cocoon yourself and stay away from people and wallow in that diagnosis and it's spirituality that pulls you back up.

Jane - And it strikes me that that's a lot of responsibility put on people living with dementia. That it shouldn't just be the responsibility of those who are living with it to find those connections and to pull themselves out. But it's so important that our community gets better at doing that, along with people living with dementia. That we become more familiar with the experience, less fearful, countering the stigma, as we often hear, continue friendships to work with change, to walk alongside people.

It's awful to lose one's place in the community to which one belongs. So how can we do that better? It's just so vital to be known and to be remembered and cherished.

Faye - Spirituality can reduce the fear that comes with the diagnosis. That fear can be eliminated and hope then blossoms in its wake.

Jane -I'm curious to hear you talk some more about that. What does hope feel like?

Faye - I heard a story a long time ago about this man who was on a plane and he was deathly afraid of flying. As he looked out the window across the aisle, the rain was coming down and the thunder and lightning was there and he was thinking, "We're never going to make it off the ground" and his worries just went up. And when he looked out the window on his side, he saw blue skies. It just tells us that no matter what we face in life and how bad those storms get, there's sunshine behind the clouds and things can change.

And to me, that's hope. I lost my husband when I was thirty-three. I raised three girls on my own. That was one thing I learned when my husband went through cancer, to look for the sun.

Jane - That also makes me think that when you mentioned that life certainly is not easy, that spirituality also gives us permission to lament, to acknowledge that all is not perfect in the world. But there's something we can do with that. It's okay to be sad. It's okay to be

angry. We can (from a Christian perspective) we can take that to God in prayer and expect to be heard and then be transformed in that, in what has been and has been lost, perhaps, or for what remains the little things in life.

Faye - It's funny you say that we're allowed to lament and mourn our losses. If we don't, we're bottling them up and we'll become like a volcano that just erupts at some point in time. And I think of years ago when people died, you had a funeral and everyone was mourning. Yes, they were sad. They were allowed to be sad. Yes, they were allowed to cry. Yes, they were allowed to miss people, but it went on and on.

And now when someone dies, we don't call it a funeral anymore. We call it a celebration of life. And we can still mourn. We can still lament and we can still cry. But we remember the things that that person gave and we could cherish those as opposed to feeling sorry for ourselves.

Jane - So it gives us permission to move on. Acknowledging what we've experienced, we don't have to be stuck

Faye – During the journey you have to find, depending on where you are, find different ways of communicating those emotions. You're still the same person that you were inside, in your heart and in your soul. You just can't express them in the same way that you did before.

Lisa - So, Jane, as a spiritual care provider, how do you support that for people who are living with dementia and their care partners or families?

Jane - Largely with presence, of being with people, taking time to truly listen. I find often memories can be jumbled, but they're there and to take time to hear the words or to sense the emotions that people are expressing. Be in the moment with people and to get to know people that I can know what their resources are. For whom something like particular prayers would be familiar or certain hymns are favorites and what sparks joy or peace. Whether they've had other passions in life that have lifted them up during times that are difficult. To find out what grounds people and help them to connect with those things that ground them. And it may be going outside, going for a walk or seeing pictures of grandchildren or physical touch, just being a shoulder rub.

Faye -I find when I'm visiting the long term care homes and doing spiritual care there, presence.

Lisa - Are there any specific supports or resources out there that they don't have somebody like a Faye or a Jane, where can they reach out for supports or what kind of supports would be available to them to continue to be able to experience their own spirituality?

Jane - There are more things being produced all the time, things like books that would have in good readable print maybe words to a verse of a familiar hymn like Greatest Thy Faithfulness, How Great Thou Art, something like that. Be like a one page with lots of white space and the words and then a beautiful picture on the other side so that people have something that both you read familiar words and that can connect them to those hymns have been significant in the past.

Same with scripture. There are some resources produced that are specifically for people living with dementia that are more accessible in that way. I love YouTube. It's gotten to be better and better over this pandemic and great recordings of hymns, sometimes with the words projected as well that you can listen to together and just be transported to a place of connection and transcendence.

Those are specifically Christian examples. There are some resources for other faiths and for connecting with spirituality more generally. Things like sitting down with them with a notebook and taking time to write down prayers with them. Do something creative together, colouring a picture together, looking after plant, doing something physical together. The possibilities are endless. It depends on the person, and it's rooted in knowing the person to start with, finding out what really matters. And if you are a spouse or a partner could probably find those resources.

Lisa - A next level of that is how somebody working in the retirement home, how can they be in their jobs, where they have so much work to do, how can they support the spiritual needs of the people living in retirement or long term care? What are some simple things that they can do if, again, there's no Jane or no Faye because there's not always a spiritual care provider within long term care or retirement communities?

Jane - It's rooted in the attitude largely of being in relationship with the people that you are tasked with care for and seeing your job as more than a job, but as a relationship with this person. To help them live life, acknowledging who they are and the things that they value. Turning on the right music in a room for them that they would like to listen to us. This being aware what nurtures their soul and feeding that as much as you can all day, every day.

Faye - Working in a retirement home or a long term care facility is not just a job. It's a vocation because you have to have a passion for caring for those people. Otherwise you're not going to build any relationships. It's going to be caring for their physical needs. And the biggest thing is to form that relationship. To laugh with them. To cry with them if necessary. To know them so that you not only know them as your clients, but they also know you, not just as a caregiver to provide the necessary physical things, but they know you personally.

Jane - know the importance of that and the importance of, as a care partner, saying thank you to the people you are providing care for, for the things that they are contributing to your life. The relationship is mutual and being able to give as well as receive is vital to spirituality.

Faye - Enjoy each other. Laugh together. And whether it's you're laughing because of a joke or you're doing laughter therapy. Sing a song together, You Are My Sunshine, My Only Sunshine. Read a book together and it can be a children's picture book. It doesn't matter, but just be present.

Jane - Grab hold of all the things there are to celebrate; the sun shining in the window, the food, the people. There's so much that's interesting if we just notice. It's inspiring,

Faye - You know, just sitting in front of the window and feeling the warmth of the sunshine.

Jane - Much to be grateful for.

Lisa - Well, I am grateful to both of you joining in the conversation today. And Jane, thank you so much for your wisdom and insight in this first episode of our Spirituality and Dementia special series for Dementia Dialogue.

Faye, I look forward so much to our journey over the next month or so and talking to all of these special guests, learning more about each other as well and being present.

Faye - Jane, it was wonderful to have met you. I'm glad. I wish and pray for you in your journey dealing with people with dementia and their families and their caregivers. I know that because of your faith that God is with you and uplifting you on each and every experience and relationship.

Jane - Thank you for that blessing, Faye. It's been a delight to be with both of you today and wish all the best,

David - Thanks to Jane, Faye and Lisa for this conversation.

Please join us for our next episode in this series, Spiritual Care: Filling Their Souls to be released May 18th. Faye and Lisa will interview Christine Thelker and Elisa Bosley. I had the privilege to interview Christine in the episode last fall.

We welcome any comments or feedback on this or any other of our episodes. Please write to us at dementia.dialogue@lakeheadu.ca

You can help us let others know about the series by downloading a series poster from our website and sending it to others whom you think might be interested. Resources related to the series will be posted on our website www.dementiadialque.ca

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