Dementia Dialogue Season 3, Episode 38

Living Fully and Meaningfully

Interview by Lisa Loiselle and Cynthia Huling Hummel of Lynda Everman and Don Wendorf

David - You are listening to the second episode in Dementia Dialogue’s Art and Dementia series hosted by Lisa Loiselle.

Today we welcome Cynthia Huling Hummel as co-host. Cynthia has a background in parish ministry and lives in Elmira, New York. After being diagnosed, she has become a leader in the dementia field, an artist and an author.

Lisa and Cynthia are in conversation with Lynda Everman and Don Wendorf. Lynda has been a caregiver of both her parents and her husband. She married Don after the deaths of both her husband and Don's wife. Lynda is primarily a fabric artist, and after a career as a therapist, Don has deployed his skills as a musician, songwriter and poet in working with people with dementia and care partners.

Lisa - The theme of the episode today is about the importance of expressive arts in self-care. I have been doing a number of these podcasts. For our listeners, can you describe what expressive arts means?

Don - Yeah. I mean, basically, we’re talking about esthetic kind of experiences, artsy experiences that have the power to prompt emotions, to allow for an expression of emotions or emotional reaction, to prompt memories and associations, and to allow some participation and sharing of that kind of experience with other people.

So really, anything you think of as being artistic, but particularly music, visual arts. I don't have direct experience with dance or drama, so I'm not so sure. But people say that, so I take them at their word about that. Writing, poetry.

For Lynda, it's fabric arts quilting and in fact, Cynthia is wearing a stole and Alzheimer's stole that Lynda made for her.

Lynda - The very first one that I made.

Don - That's the first one in’t it? Yeah.

Cynthia - And I love it. I wear it all the time and I talk about your advocacy, the two of you and how this is just one aspect of the many ways that you connect with people living with dementia, with congregations, with care partners, to bring us all together in our mutual caring concern for those living with Alzheimer's disease.

So I just treasure this stole and I've gotten more and more people interested in it, and they'll ask, “How can I get a stole like that?” And so I wanted to maybe open up the questions to talk about how you got started with your stole ministry, Lynda, making these beautiful fabrics stoles and how you've been distributing them?

Lynda - Well, thank you for asking. You know, one of the aspects of the expressive arts is also symbolism. And especially for me and in terms of advocacy. And the way that the stolen ministry started was in 2018, Don and I applied for, with our friend and fellow advocate, Dr. Danny Potts, for a grant to help foster dementia friendly faith communities in

Birmingham, the Greater Birmingham, Alabama, area. We received the grant and in the course of the year we visited, we made about 40 congregational visits and we were able to buy books and DVDs and to visit with pastors, rabbis, chaplains, congregational care staff and to talk about dementia.

On one of the visits, we were sitting in an office and one of the young pastors had a beautiful wooden rod in his office. And from it, he had his collection of stoles. And one of them was a breast cancer stole. It had pink ribbons on it. It was very pretty. I was, of course, intrigued with it.

And at another visit, we were waiting for the pastor to come in and on the back of his door was his collection of stoles, and one of them was a beautiful white wedding stole. And when he came in, I was looking at it and I made a comment and he started to tell us the story of his stole. And it occurred to me that fabric holds memories and that a stole, which is a sacred liturgical garment, just goes such a long way without words in showing our support for families facing the challenges of dementia.

So we were involved in this campaign to foster dementia friendly faith communities and to make it safe and acceptable to talk about it. As a matter of fact, our theme was Let's Talk About Dementia. And so I thought, Well, if a pastor, priest or rabbi (and the rabbis case would wear a tallit), were standing before their congregation, they wouldn't even have to say anything. It would show their support.

Also, we were at an advocacy summit and a pastor came wearing his stole. And I thought, Well, there's lots of opportunities for members of the clergy to wear a stole, both in terms of support and advocacy (to build awareness). So Don came up with the title for our book. We wrote a book called, Stolen Memories, of course, a play on the word. And a friend of ours who is a rabbi asked if I would make him a tallit. My first response was, Well, now I don't know anything about doing that, and I certainly don't know how to do the tied fringe, which has six-hundred, I believe it's six-hundred and four, I could be wrong. But anyway, tied knots at all are very symbolic and representative and he was like, “No worry, you can make a stole-like one and I will tie it and you pray as you tie it”.

But at any rate, the very first stole that I made was first something to celebrate her advocacy and our friendship. And from there, I've made and given away over one-hundred and would be very happy to continue to do so.

And we wrote the book with instructions in case others wanted to join us in the ministry. Every single one has been meaningful to me, but one that really surprised me was after Cynthia's, I made one for our dear friend, who is ninety-two and a retired Presbyterian pastor and has spent his life really caring for and advocating for families facing dementia. And right after I sent it to him, he wrote me back and told me that he had revised his will and that in his will, he asked that at his memorial, his cremains and his Alzheimer's stole would be on the altar in recognition of his work on behalf of families for Alzheimer's.

Lisa - It's such a meaningful way to share your passion with other people.

Cynthia - Lisa, when I went to visit Don and Lynda, one of the fun things that we did that's connected to the arts and dementia is we sang and when we got on this call this morning, I was just loving the costumes. For those who can't visualize that, Lynda came up with a big pink southern belle hat and Don had a top hat on. You're looking like you're ready for an Easter parade. What was going on in Alabama today?

Don - Well a huge part of our lives right now is doing remote Zoom singalongs. We used to do them in person with several of the local respite care programs. We love these programs. We can't say enough about them. You know, part of what we do is singalongs. And today we had an Easter or spring oriented kind of theme to it. We try and do themes and we research songs that people will probably recognize from their childhood or that are meaningful, that represent the theme, but that also you can you can sing too.

But we supplement that with all sorts of visual stimulation, too. So we will have kind of costumes that we wear and that was for Easter Parade. We did that this morning. And I'll have some trivia information; Easter Parade was by Irving Berlin in 1933, but best known in the movie in 1948 by Fred Astaire and Judy Garland, Easter. So we put a lot of time into that, and it is right now since we're so shut down with the COVID stuff, is probably the most meaningful interaction that we have, particularly with people who are living with dementia and to some extent with their caregivers. Some join in on the thing and some don't.

But there's a whole philosophy underlying what we're doing. It's not just fun.
But it also is to accomplish a number of things. It's to give these people who are living with dementia a chance to socialize, a chance to be competent. They're singing.
We had somebody who had previously been a choir director, direct all the people. This was when we were in person. We had, again when we were in person, there was one guy that had a harmonica that he carried with him everywhere, and he brought out that harmonica and he played it, the same thing with a guy with guitar.

So we're trying to let people show competency. We're trying to let them express feelings. We're allowing them to be creative. It's an artistic esthetic sort of thing, so they can be creative. One guy had, I don't know where he got a hold of this finger puppet. Remember that? Doug? And he called it Leon, and he had Leon direct the singing for everybody. It was hilarious. But he was shining, I mean, he was doing something great. The focus wasn't at all on what he could no longer do or had trouble doing. It was very much on, Hey, here's this guy, and he's being funny and he's sharing this thing with all of us.

Lynda – Oh and Phyllis and the tambourine?

Don - Yeah, my tambourine lady.

Lynda – Oh and she was fabulous and I can't remember if Cynthia was with us or not, one time when we were at Bringing Art to Life and we had the woman who had previously been a church organist and we had a keyboard.

Don - That was when Beth and Jeff were there.

Lynda – Oh that’s right. And she got up and played. And another man who was in that group, he had Parkinson's disease, I remember this about him. Don had an extra guitar and handed him the guitar, and he played along with us. It was just so much fun.

Don - Well, and the arts, again going back to the arts. And I think that's particularly the case with music. I mean, I'm a musician, so maybe I'm a little prejudiced, but I think that other people are figuring out the same sort of thing. It just has an amazing power to let things emerge, reminiscences, memories, sharing, connecting. And it's sometimes it's very surprising. It's fairly routine in these kinds of sessions, to have people who really would have difficulty maybe even having much of a conversation with you.

Cynthia - You know what I wanted to ask you when I was there, Lynda, I remember seeing you had piles of quilts that you had made for each one of those participants in the Bringing Art to Life program that you had created with somebody special in mind that would be awarded at some sort of ceremony, I don't remember all the details.

I was thinking about quilting as art and how you use that to help people with memory loss and how you've shared that with families and with other participants.

Can you say more about that, how you got started on that?

Lynda - Well, I'd love to tell you all about that. So that's an outgrowth of a program that started at the University of California, San Diego at the Alzheimer's Disease Cooperative Study. The Alzheimer's Disease Cooperative Study was founded in the 1990s. It's a partnership between the National Institutes of Health and the University of California, in which they are the host for national clinical studies. And there is a consortium of, I believe, about twenty-nine Alzheimer's disease research centers across the United States.

So a friend of mine who was a quilter, started the Alzheimer's Disease Quilt project, and it was a way to, another name for quilt is a comforter. So it was a way to thank people who were participants in clinical studies and also to emphasize that you're not just a number. No, you're a person. But to thank them and to honor them.

This program is ongoing in which quilts are given to participants in clinical studies, and Cynthia has received one, but I decided to bring it to Tuscaloosa and with the Bring Art To Life program I had the students, as they got to know their participants, tell me about them. I had a set of questions that I'd asked them, “What was your partner's hobbies? What did they do when they were growing up? What kind of music did they love? What did they talk to you about?” And so the students would provide me with that information, and I would make a personalized quilt for each of our participants. One of them, we told you about the woman who had played the organ at her church. Her name was Merle. She played the organ and she had led Bible studies. And that was so meaningful to her and to the students and the things that the students learned.

I mean, I think one of the most wonderful things to come out of the Bring Art to Life program is you think of the students enhancing the life of the person with dementia, but the person with dementia is also enhancing the life of the student. They are transformed.

Don - There are people who have changed their majors into fields related to aging or dementia.

Lynda – The students write about…At the celebration dinner, the students stand up… and the person with dementia and their family attends. The students attend and everybody attends. But the students stand up and thank their participants and tell them what they learned from them. It's always very moving.

So anyway, I made Merle a quilt. It had pianos on it, and it had music on it, and it had the words like from gifts of the spirit. You know, like patience, love, peace. And I presented it to her and she was so touched and she wasn't the only one who did this, but she wanted a picture made with me and the quilt and her. So we did do that picture?

And you know, we had said that music touches you in so many ways and it stays with you.

Another experience that just really was profound to me that I always remember is, as I said, Don would go every semester with a band to Bring Art to Life with his musicians and then come to the celebration dinner a couple months later at the end of the semester.

Well, one semester he had a conflict and couldn't come to the celebration dinner, but I went anyway. So I'm walking into the room, and one of the women who was a participant with dementia is coming in with her family and she spots me. Now mind you, I only have met her once, and it's been two months since I've seen her. And she comes right up to me and the first thing she says to me is, “Where is your husband, the musician, is he going to play for us?” I met her once two months ago. She has dementia and yet she remembered that experience and wanted to know where he was.

Let's not discount what touches people's hearts. And that's a great part of the beauty of the expressive arts. Of course, there are words to music and poetry and such, but there are so many other components that tap into so many levels of our memory, of our emotions, of symbolism to us. A comforter is comforting. It is. It’s love and warmth and caring and someone willing to put the time in for someone who is valuable enough to receive a gift. So the expressive arts are lovely.

Don - And well, let me take it to another direction too, is that they can allow the person who may have some communication difficulties associated with the process that's going on in their brain to be able to express themselves. And it is so important for us to listen to the voices of people who are living with dementia. I mean, they're the ones that are in there. They know what it's like, they know what they're going through, and it's so important. We can learn so much. But it's also so meaningful to them to be able to give to us this information and this help and this this assistance and to tell their stories.

Lisa - So how do you use the arts then in continuing to live well with dementia, right? Because it's you're living with dementia. So talking about all the expressive arts and all of this wonderful thing that you all participate in, how do you use that in your own self-care?

Lynda - As a person with dementia or as a care partner?

Lisa - I'd like to hear both perspectives.

Cynthia - Well, as a person with dementia, I just love doing art, making art, creating art, sharing art. I've been taking online painting classes. Now I'm thinking about Lester Potts, Danny's dad. Last week we worked on ponds and landscapes and sea turtles, but it's fun to sit here and paint with my instructor on online. They were great. This one group of folks called the Memory Maker Project, up near where I live, provided everything. I was mailed all my art supplies and then I sit down with my art instructor and I've been able to not just make art during that segment of time that we call our class time, but just during the week to de-stress, to help me connect, to help me focus. I love doing that.

I love singing with my guitar and I've been doing lots of that. Especially offering, as Don said, concerts on Facebook Live for the church; some are offered for the adults doing hymn sings and some are singalongs with kids, silly songs or kids songs that connect to faith. And it's just been a great joy to do both of those things. And it activates all kinds of memories.

Before COVID, I was in a choir and we did the major works; the Brahms Requiem, you know, big works by Beethoven. And being able to actually read music and sing in a choral group, it's a different kind of singing than my being in a country rock band, which I love doing too.

But having those experiences just builds those synapses and gets those creative juices going and connects me to other people, and it brings me great joy. And so I'm very blessed.

Lynda - It takes your mind off your troubles.

Cynthia - Oh yeah, you can focus on your troubles, but it's not going to change things. I could sit and be very depressed about my diagnosis and then just kind of cocoon myself. But that doesn't change things. But by getting out and doing things, especially creative things, it just takes your mind away from it. And you focus on the positive. You're in fellowship with other people and it's great joy.

Lisa - What about for you, Lynda?

Lynda I like how Cynthia said it, “de-stress”. I got back into fabric arts when my late husband had dementia. There came a time when I needed to really spend more time in the house with him versus if I were out in the yard. I just needed to have more, use of word “supervision” of him or keep him company. And so I took up knitting at that time. I started knitting for a tremendous group that I love, Project Linus, and I would sit and knit blankets, hats…

Don – That would be given to children

Lynda – That would be given to children in hospitals from newborns to age eighteen. It allowed me to do something for others, taking myself out of myself, but also to keep Richard Company. And I enjoyed that.

And then later I found out about the Alzheimer's Quilt project. I loved that because as a matter of fact, even though they're in San Diego and I'm in Birmingham, I just mailed them a quilt about a week ago, in memory of my late husband, that had a farm theme to it because he'd spent some time on a farm.

When I'm doing things like knitting and quilting, I'm involved in the colors and the fabrics and the pattern, and it's very relaxing. So I love that and the quilts that I made for Danny's program, some of them have a lot of images in it because my intent, which I told the students and the families of the participants, is you have this lap quilt, so it's about four feet by four feet. But for one man, for instance, it had bingo cards, it had footballs, it had basketballs, it had a song lyrics in it because those are all things that he loved.

So picture yourself with, say, a coffee table book, but your coffee table book is a comforter that sits on your lap and you're just sitting there, next to your sweetie and you're like, “Oh, look at that basketball. I remember when you played in high school”.
So it's a storybook on your lap. I'm all about the fabric, arts and, of course, music, although I'm not a musician, but I love all of that.

Lisa - Sounds like it's very, it's almost like transformational or you’re transformed onto another level.

Lynda - You know, to make a quilt and give it to another family where the patient (because they are a patient. They’re in the hospital) is involved in a clinical study is especially meaningful to me to do it in memory of my late husband.

I remember sitting in those sterile hospitals with people poking needles in his arm or sending him off to an MRI and to have the human touch of someone come in and offer you connection, love, understanding, it's just it's meaningful. And most of the people who contribute to the Alzheimer's Quilt project are former caregivers themselves. So it's very healing in that regard to pay the kindness forward that others have given to you.

Lisa - Now, Don, what about you and being in involved in the arts and your own self care?

Don - Yeah, part of what I got into, I was taking care of my late wife, Susan, who had vascular dementia, and I had already written a self-help book about marriage. I'm a retired psychologist and marriage and family therapist. So I wrote a book about how to do a healthy marriage based on my years of experience, sort of being a psychologist, but mostly by being married. And I wrote it in song lyric form, of a rhyming verse. I don't know that it is good enough to be called poetry. Not all of it ever got put to music, but I started doing that about the emotional struggles that I was experiencing and I knew other people were experiencing as a caregiver.

And that really did a tremendous amount for me. I hope it's been useful to some other people. I did it in song lyrics because I hate self-help books. I can usually get maybe to page thirteen, sometimes fourteen, and I just throw the thing down. It's repetitive, boring.

So I wrote it in that form because I wanted it to be more accessible and user friendly and memorable, and that kind of stuff. And it was a way to put a lot of humor in there. But I found that I was writing, like I'd have a particular theme or section or topic that I was working on and things would just pop into my head, maybe while I was out running for exercise or in the middle of doing some caregiving process, giving Susan a bath or feeding her or something like that.

So it was very nurturing to my spirit, but it was also very helpful in letting me see myself from outside myself. So I gained a fair amount of insight and awareness about what was going on with myself by virtue of putting that in an artistic form and working on it, refining it and stuff like that. So I really credit that with helping to keep me going. And I did manage to play some music with other people during those times, too, because that was a lot of years.

Lynda - And actually, had he not written that book, we would not have met.
One of the songs that he wrote for Susan is in our book, Painted Bits of Bark and Stone and Tin.

Don - Right, very good. Let me let me say something about that, about the song, because it tag teams on what you're saying there. The song, I wrote this actually for Susan and recorded it and she got to hear it. This song is Painted Bits of Bark and Stone and Tin because right from the very first that I met her in college, what she would do to show people support or affection or encouragement or whatever is she would paint a little something on a rock that she found or a rusted tin can lid that somebody left in the gutter or something or a piece of bark. And that really, to me, illustrated who she was. It said something about who she is as a person.

And one of the hardest things for her about being so incapacitated with her vascular dementia (and strokes) because it was all these multiple strokes. I mean, she was almost blind. She couldn't feed herself. I had to do pretty much everything for her eventually. She didn't feel she could give anything to anybody, which is who she was. She was a giver of simple gifts. In fact, that old Quaker hymn, Simple Gifts, also I thought really illustrated something about her.

So at a point where I was very much struggling with caregiver burnout and it was so hard physically, emotionally, I was anxious to know what's going to happen in the future. We were having such a hard time. And I was getting irritated and frustrated and angry and just really being nasty. And it was not pretty at all. But that song and that metaphor for who she was, in a musical artistic sort of way, helped me remember, “Wait, a second, she's not giving you a hard time. She's having a hard time”. Yes, you're having a hard time, too. You're having a hard time together. But that's who she is. That's who's in there. It may be hard to access or to express now.

So that was very helpful for me. And I think that's a helpful thing for other people too, is to carry around with you that sense of this is the person, like Lynda was talking about with Richard, this this is the person.

Cynthia - Are you going to give us a tune?

Don - I really hadn't been….

Cynthia - Grab that guitar, grab that banjo. I see it over there.

Don - We'll do this one. This is nice.

******Sings song******

Lisa - Very lovely. Oh, Cynthia's got her guitar as well! Are you going to play us a song?

Cynthia – Yeah, sure. My mom always loved this song. Well, my guitar is a little out of tune…

******Sings Song******

Don – That was fun, Cynthia. We haven’t done that in a long time.

Cynthia - I know! Well, when we get back together, we'll do it again with harmony. We'll bring in Danny Potts…

Don - And bring it down!

Cynthia - Yeah, it'll be fun to get together again.

Lisa - Thank you all for sharing your beautiful talents with me and with the audience. And I hope we can do this again sometime.

Cynthia - Thank you, Lisa.

David - Thanks to Cynthia, Lynda and Don for joining Lisa and sharing with us both their talents as artists and articulate advocates for people with lived experience and for talking about how new channels of expression offer hope for folks confronted by dementia.

Our series on the arts continues in December. Be sure to visit the art section of our resource page at our website: dementiadialogue.ca
to read more about Cynthia, Lynda and Don and to view some of their work.

We want to hear from our listeners about how we can improve our podcast, make it more accessible to people and reach more listeners. To do this, we're holding three separate focus groups in November. Please consider joining one of them. The groups will be professionally facilitated and will last only one hour. For more information, please write to dementia.dialogue@lakeheadu.ca
It is not too late to join one of the groups.

Thanks to the Center for Research and Education on Aging and Health at Lakehead University, our institutional partner and to the Public Health Agency of Canada for its financial support.

My name is David Harvey.