Dementia Dialogue; Season 3, Episode 26

Live for Today!
Transcript of interview with Mary Beth Wighton

David - Thanks for tuning in to our twenty-sixth episode of Dementia Dialogue, a recent interview I had with Mary Beth Wighton.

Mary Beth lives on the shore of Lake Huron with her partner Dawn, not far from their daughter, Brianna, and her year old son, Finley. Mary Beth is co-chair of Dementia Advocacy Canada, Canada's leading advocacy organization led by persons with dementia and their care partners.

You may have listened to our Town Hall episode on human rights and dementia that Mary Beth co-hosted.

Today, our conversation centers on Mary Beth’s recent book, Dignity and Dementia: Carpe Diem.

Thank you for agreeing to participate in this interview and more so, thank you for taking the effort to put your journal together into a book form. That's not without challenges.

Mary Beth - Thank you for having me too.

David - To get it organized and then I'm sure you had to do some editing just to make sure that it was crisp for people and clear. Mistakes can undermine your credibility. So I congratulate you on that.

Mary Beth - I just did a spell check and grammar check on it and that's all I did because I wanted to leave it as I wrote it so that someone didn't come in and polish it all up and shine it. Because that wasn’t how I wrote it, that's how my mind was thinking.

So really I just wanted to give it in case I was using the wrong word. Actually when they first read it, the publisher said, “First you say this and then you then you say it's that” and it's like, well, that's my dementia. Sometimes I say I’m fifty-four years old and other times I say I'm fifty-three years old. So there’s inconsistency and I said, well no we've got to keep that

David - Yeah okay that's interesting because a couple of times I know it wasn't so much about chronology but sometimes the same thing might be repeated, not word for word but the same kind of image, memory, perhaps of one of your great uncles or something I think is one of the examples. And I wondered about that. But I now see that it was just you wanted to share the raw material, as it were.

Mary Beth – Yes. So the repeat of Uncle Great Uncle Horace.

David - Yes. Mary Beth, I was interested in the very first few pages of the book you were writing for an audience. You knew that somebody other than yourself and Dawn or your immediate circle was going to read this at some point. And I'm wondering, were you keeping a journal before the time of your diagnosis or did it kind of kick in at the same time as you were diagnosed?

Mary Beth - No, I've never had a journal. I've never had a diary. I never wrote. I never thought I could write. It just wasn't something that I inspired to do by any means. And it was Lisa Loiselle who said you might want to consider writing your thoughts down as you go through this journey. And she was the first person who said that to me. And so I just started to do that. And all of a sudden I realized that I can actually put something on paper fairly quickly and it makes sense and it feels good. And so that's really kind of where it started.

Initially I started to send out my stories to very immediate family and everybody talked. I always enjoyed hearing the responses because they're very individual responses. It was more than, “Great article”. It was they were communicating with me how it affected them. It was very powerful to get that type of information back. And then I would hear, “Would you mind adding this person on your email on this and that person on your email list?” And so the email list got to be at least over one-hundred people fairly quickly.

And also, the Alzheimer Societies started picking up on it, and so they were putting it on their Web pages, to offer person tried and true communications and also MAREP at that time, also started putting it on its website.

When I was in the midst of actually writing it, I wasn't thinking of it's going to go to one-hundred people. I was very much thinking when I read it to Dawn, because Dawn always got the first read, how will she respond to it?

David - I want to go to the not so much the incident of the diagnosis, but your reflection afterwards about making a conscious choice to turn your back on a sense of anger and disappointment and frustration that might accompany a diagnosis like the one that you experienced, and maybe you would tell some of that, in that interlude between the onset of your condition and the final diagnosis. But really making a choice to live your life positively, to embrace dementia, as it were, and then to try and live as fully as you were, as you are able to with the diagnosis.

I'm wondering how you might think we could help more people to make that positive choice in their life?

Mary Beth - You know, and so many people before me have said this, which is: it really does matter at that point of diagnosis, what's communicated.

And we're not doing it right. We still need to improve the point of navigation in which when the doctors actually stating this is the disease that you have and the work that needs to be done to help improve how that said to that person, which is, as we well know, instead of all the negative, go home and get your affairs in order. It's rather, you know, you have this disease but you have a whole lot of living left to do. And until we start using more positive words, more positive examples then people living with dementia, it's that much harder to make that choice of living, living better with dementia. And so I think that right at that navigation point with the doctor, we can do a lot to help that

And also just to help the person meet someone else almost literally right off the hop, “Here is so and so and they're going to give you a call”. And one of the things that I remember looking for was I wanted to talk to someone who had a diagnosis of frontotemporal dementia. And I asked that and I said, “Well, can I talk to someone?” Well, nobody knew anybody. So there wasn't that ability to connect me to a peer. And I think if we could start to connect people to peers immediately, then it's less likely they're going to get onto the Googling and find out all these terrible things, but rather, they're going to hear it from the person themselves that, “You know what? Yeah, not a great diagnosis. Sorry that you're in the game with us”.

That that piece, however, is so important and to have the demonstration in front of you, “I've been living with dementia now for seven years or eight years, it has its bad days, but, boy, it has a lot of really good days.”

David - That's interesting. The peer to peer aspect, I think, is really something unique. There's, for example, the First Link program or other kind of programs that might create better linkages at a professional level, if you will, or at a service level. But it really doesn't go to the point of making that pure connection that you're suggesting today.

Mary Beth – Well, I think it already is quasi-done through advocacy organizations like DAI, Dementia Alliance International, and they do a good job.

The challenge is it's at the connection time. How do we connect people who just receive a diagnosis to a peer? That's what we seem to be having a whole lot of trouble with. So if we're getting a call to the Alzheimer Society, for instance, to call me who just got newly diagnosed, why can't we make one more phone call? You know, we have a database full of volunteers.

David - I wanted to go on to another issue of being in a same-sex relationship with Dawn. I was impressed in your book how totally natural you were in describing that relationship. And I think as you talked about, your initial kind of circle of people were people that were in your family, people that were close to you. I can certainly understand then how the roots of that tone of your journal was in the support of your family and of your relationship.

I'm thinking, though, on the other hand, that it's not easy to develop a relationship with somebody and to create a sense of acceptance within your circle. It's not easy for a lot of people. I'm wondering if you saw a connection maybe between the way you and Dawn resolved to form a relationship and to share it with other people, to be open about it, to invite other people into your life, whether that was kind of practice, if you will, for how you responded to the diagnosis of FTD?

Mary Beth - Well, that’s an interesting question, and I've never really thought about it as how we may have learned from just being out there as to women and how that might apply to being out there with dementia. Someone once said, “Well, now you have to come out twice.”

If you think about it, there's a lot of truth to that “coming out twice.” So with Dawn and I, we have never lived a different way. When we became partners and it was just this is what life is. This is normal for us. And so I don't feel like we have to tell people because it's just we acted this particular way. And I know Brianna would get question, “What do you mean, you have two moms?” And then it would be, we just always told Brianna, “Whatever is comfortable for you, Brianna, those are the words you're going to say. You don't have to call me mom. You don't have to call me anything.”

And so I think as a family, we learned to be sensitive to labels, to not calling people certain things or to be calling people certain things. So I think that whole label thing, you're right, we probably, not even thinking about now, but probably learned a lot about the challenge and the impact a label can have on people because we just we don't like to label people.

David - Thinking back to the title of the book, Carpe Diem, well this is life. This is our life and this is life. We're going to live it the way we want to live it.

Mary Beth - And where that came from was one of my nieces. They came up to visit. I think it was the first or second time since I had a diagnosis that they came to visit me from Sarnia. And this was my great niece. And so she came in and she had this painting. And presented it to me and you could just tell she was beaming with pride and just couldn't wait to give it to me. And it was beautiful. And I said, “Well, I don't know what this means. What is Carpe Diem?” And that's how I learned that Carpe Diem means, “Live for today, for you shall never trust tomorrow and what it may bring.” And it was made by, I think, the Horace comment. And as soon as she said it, we all just looked at each other. We knew that was going to be our family motto.

David - That's a lovely story about how a younger woman gives you something and gives you more than she really realized she was giving you.

Mary Beth - And I think that goes back really to being open to any type of learning from whomever. And that's an important thing for us as well. It doesn't matter what age you are, color you are or what your beliefs are, we can always learn from each other. It’s when we start putting parameters around that, that's when we lose that opportunity. So, yeah, we're very thankful, actually, to her for helping us lend a way to her living.

David - I wanted to explore spirituality because it's a thread that is in your book in many different ways, both speaking directly about spirituality but then I also think of your reflections on Remembrance Day and your ancestors and people that fought in the wars and otherwise. Your discussion about your grandmother coming from Scotland.

Mary Beth - That Haiti trip for me was I think a moment in my young life where it really impressed upon me how fortunate I was that I lived where I live, that I am who I am. It was a moment for myself and I always believed that I was going to go back to Haiti and it had drawn me to it, the people had drawn me to it. There's a smell of Haiti that I will never, ever forget. The smell of death. I can remember that and that very moment and wondering how my simple little chocolates that I brought along can help someone. Definitely it was eye opening and it's truly a lifetime of impression of that.

David - Yeah. I'm wondering if you might think of the connection between your advocacy and spirituality. You were talking at one point a little bit about your mum and her work as a mother of eight. She worked herself but she still had time and energy for working in various community groups or church groups to help other people. And how you really valued that gift that she gave to you. I'm wondering if you might you yourself see a connection between your advocacy work and your spirituality, your kind of roots and Christian tradition?

Mary Beth -I was taught at a young, young age and shown by examples of what advocacy was. And I can remember sitting in a church booth when I was very small, maybe four years old, and the church was making the point that due to the poor wages of the grape pickers in the States, we were to not eat any grapes.
And so this was said to the parish. So I have a very vivid mind and was thinking about we as a collective group can support each other by collectively standing up for what's right. And that's what I was taught. And then my mom just, didn't matter how busy she was, she was always there to help somebody. And what was very important for her was that she was not recognized for it. It was not meant for her to go in and say, “I did all these things today” but to be… I forget what the word is…But just, it's just done quietly and…

David – Humble. It’s humble.

Mary Beth - Very humble. Yeah. And so, yes, I think the spirituality of all that definitely does intermingle. And I am spiritual. I really enjoy those quiet times and soft times. Sometime it's now with my grandson when he's lying on my chest and he's sleeping and he's got that little soft breathing going and I just think, “Holy.”

I think that up until the diagnosis, our minds are so busy and they're so stressed and it's just noise, right? And it's loud and it's overwhelming. And until you can get to a place where you can soften all the noise that's happening in your mind, to then have the ability to rethink things and think about things and recognize that you're not in last stage, but rather very much at the beginning of the stage and physically strong and physically this. So it's that ability then that I can play a part in social justice. But it's really it's like your mind has to have that time to be able to figure it out almost.

David - That's kind of where the journal ends in a sense is where you're maybe saying, “I'm going to take some time here to rebalance”? Is that maybe the right word? To rebalance your life so that you've got time to do that kind of reflection and not self in the sense of selfishness but you're nurturing people around you versus kind of the political action that was so much a part of your life in the last part of the last decade.

Mary Beth – If anything, I think I may not be as busy, but it seems like the things that I'm doing are even that much more strategically important, if you will.

I'm on the ministerial advisory board to the health minister. I just finished a conversation with a dementia advocacy leaders from across Canada because we're going to be sitting down with the minister for a one hour meeting.

So incredible opportunities that I think have come along because of the time I put in, because of the relationships and the projects that have been a part of all that busy, busy time earlier. But now it's so much more, I can kind of pick and choose where my weight I throw behind.

But I am tired at the end of the day. I had t ask Dawn today if I had lunch. So although I may look physically well, the brain is definitely tiring. We're seeing. And I'm stubborn so I don't necessarily like to ask for help. And I'm learning to ask for help now. I'm learning to ask for help actually from other people with dementia saying, “We need a couple volunteers.”

Where before I would just get the work done. Now I'm struggling with it and I'm not able to think quick, think is clearly, forgetting things. So I'm just relying on my peers more now.

David - Yes. Well, I think that's important. That can be in itself an opportunity for growth, can't it?

Mary Beth - I think it's a great opportunity for growth. When, again, I think about the meeting that I'm just coming from. So there's eight of us across Canada who are Dementia Advocacy Canada people and one of the things that I can do is I can help as a mentor. And that's what I see my role as being going forth. Let other people fight the fight. But I can at least provide some guidance.

David - I want to ask you about your kind of take on the situation of dementia within the Canadian context in terms of the achievements that have been made. Have they produced the results you were hoping for? We've experienced this huge tragedy in long term care in Covid, eighty or ninety percent of the people who died were people with dementia. How do you see the Canadian dementia advocacy scene at the moment?

Mary Beth - With this meeting that I just had, we're talking about bubbling things up, the very most important things to try. So when we talked with the health minister, we were hitting the top two. And it's incredibly difficult to try and do that because there's so many issues as it relates to the National Dementia Strategy that we feel are not being met and are not having the weight behind them that they need to. So it's a failure in many ways. And that's a hard thing to say. But it's important that we use the opportunity, a dreadful opportunity, but we use it and we say, “Okay, we now have very clear science evidence of what can happen when you stick people in a very small room and call it long term care.” So, first of all, let's get dealing with just simply housing and whether you have dementia or not, it's not healthy.

And to be calling people's homes beds in itself I think really tells Canadian society a lot on how they're how they're being treated. “We need to get ten-thousand more beds.”
No, that's ten-thousand more homes that you're getting, not beds.

So we have to figure out how we can get off this idea, away from just putting money to making more long term care to putting money into homes. So that's the first one. And the second one is obviously, if we have eighty percent of people now that have died within long term care, we have a very serious issue. And putting people behind locked doors, I just I can't even fathom that we are still doing that, frankly. This is 2021. And when was the last time that we started locking up people with a disease? Like what other disease gets locked up. So why is it okay for people living with dementia to be locked up? That is a human rights issue all in its entirety and people just don't want to look at it. It's easier just not to bring it up, not to be part of the conversation, say it's in the best interest of them and make up all these things. And until society truly stands up and says this is wrong, it's going to continue to happen.

David -Yes. So I'm wondering if you've got any kind of last thoughts that you might want to offer a listener around the work that you've done, the work that you see that needs to be done?

Mary Beth - Some of the important things that I've learned, that to share with others is don't let others tell you how to live your own life. Make the decision yourself how you wish to live your life and go do it.

So all of the different things that you're told, “You can't do this and you shouldn't be able to do that”, ignore them. Just simply ignore them and put in a lot of effort to making yourself the most positive person that you can.

So sometimes it's being an advocate. Sometimes it's you being a painter. Whatever it is in your life that makes you feel good, do it. Do it well and expect something of yourself. So what? You got dementia. There's worse things that we could have. But when you put on an expectation of yourself to be the best person that you can, then you can hold yourself accountable. And I think that's important.

So I guess my final thought is: don't forget to live. Carpe Diem.

David - Well, thanks very much. I really enjoyed reading your journal. I felt as if I was getting to know you better. I wish in retrospect, when we were able to be more physically present to one another, that we didn't have time to talk about some of the things that we're talking about today.

Dignity and Dementia: Carpe Diem can be purchased through your local bookstore or online.

You may be lucky enough to win a copy by writing dementia.dialogue@lakeheadu.ca
Please put *Carpe Diem* in the subject line.

Watch for our next episode, the second in our new series on spirituality hosted by the Reverend Faye Forbes and Lisa Loiselle.

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Thanks again to Mary Beth for being our guest today. Our institutional sponsor for Dementia Dialogue is the Center for Education and Research on Aging and Health at Lakehead University. The Public Health Agency of Canada provides some financial support.

My name is David Harvey.