<u>Dementia Dialogue; Season 3, Episode 29</u>

Culture, Diversity and Spirituality

Transcript of interview with Roberta Bishop and Elder Mary Wilson by Rev. Faye Forbes and Lisa Loiselle

David - Welcome to Dementia Dialogue's third episode in our spirituality series co-hosted by the Reverend Faye Forbes and Lisa Loiselle.

In this episode, Faye and Lisa talk with Roberta Bishop and Elder Mary Wilson.

Roberta works with the Rainbow Resource Center in Winnipeg, serving the 2SLGBTQ+ community.

Elder Mary Wilson is a healer serving the Indigenous community.

Roberta and Mary also cared for their moms, both of whom had dementia. We join them in conversation.

Lisa - So with us on this episode today are Roberta Bishop and Elder Mary Wilson.

Roberta is here from Winnipeg and she's the operations manager at the Rainbow Resource Center.

And Elder Mary Wilson is a spiritual teacher, healer and artist, also from Manitoba.

Thanks for being our guests today.

And of course, Faye Forbes is here as my co-host.

Mary - Nice to see everybody. So I'm going to open with some words. My name is Ogemow Nasszya Hiskanawa and I am a Wolf Clan Mother. And so it becomes my responsibility to make sure things are balanced and coming together in a positive way. It's my responsibility to bring blessings down.

I call on Creator at this moment to bring blessings to us all,

To keep us safe from harm's way,

To bring us clarity and good thoughts and good feelings to the work that we do.

And I call on you, Creator, to remind us through nature to be mindful of how we put our feet down upon our Mother.

And I call on you, Creator, to keep our lives happy and whole.

And I call on you, Creator, to bless everybody here, the people of the Four Directions and to all our relations.

Lisa - Thank you very much, Elder Mary Wilson, for that opening, that special prayer for us. Let's begin with telling us about yourselves and what you do. And let's start there.

Roberta - My name is Roberta Bishop and I am the operations manager at Rainbow Resource Center. The Rainbow Resource Center is almost a fifty year old community based organization supporting and providing educational resources for the 2SLGBTQ+

community in Winnipeg and in Manitoba, and indeed to, now with virtual connections, we have interest and folks coming in from much further beyond the borders of Manitoba.

We provide services for a wide range of individuals. Our youngest clients accessing services would be about four or five years old, and I think some of our older members are over eighty.

Of particular interest to me, both personally and professionally, is the Over the Rainbow group, which is the group of adults. We say fifty-five plus or minus. And we are also a recognized member of the Manitoba Association of Senior Centers so are recognized as such as being a senior's center, and we provide support in addressing social isolation of our older adults.

Today happens to be Friday. And I know that there's a virtual craft workshop going on. And next Friday is yoga, virtual yoga. And we have coffee twice a week so that that keeps active and interest.

I have been out of Manitoba about thirty-five years. I am a misplaced Maritimers, very proud of my maritime roots and my maritime heritage. And those are all parts of who I am.

My interest in the topic, having dealt with family members who have experienced dementia, as well as some folks that have come through the Over the Rainbow group and have moved down the road in the journey through dementia.

Mary - So I'm Mary Wilson and I certainly have some ties into Alzheimer's and dementia with my immediate family; my mother and also friends of mine who are in their fifties and suffer from Alzheimer's and a little bit of dementia.

So it comes to me not only as a healer of the people in our community, but also on a very personal place. So, yeah, it's of great interest. And as a healer, it's also something that I deal with on a regular basis as well.

Faye - Yeah, Alzheimer's and dementia affect many people and we all look at spirituality differently. And as a healer in your community, how do you see your work as a spiritual healer? What forms does that spirituality take?

Mary – Well I do lots of different healing work. I am classified as a traditional expert, which means they used to use the word Shaman but because it's so many negative connotations now, people have associated to things that are not as positive, that's why they call me an expert.

But I see it in the medical field because I work in the medical field as well as a healer. So I see it in the medical field. And how we can address things is as little bit different, traditionally, than what we would get from a Western perspective. Because in our perspective number one, we have a wraparound system where we take care of the people, we take care of our elderly people. Our original way of being is to live together. And so when one gets ill or has different issues, then the family collects and we address it as a family. We don't do it as an individual. From a Western model, it's this is the diagnosis and this is what you have to do. And from a traditional place, we look at the Western recommendations, but we also have our own medicines that that help us. And we also

have different types of healers that work with the individuals to help them to have peace in their lives.

Because from a place of Western view, if there is an imbalance, that means that there's a problem. In our in our way of being, if there's an imbalance, we work together to bring that balance.

So, for example, my mother who had Alzheimer's and dementia, what we did is, she did end up in a and a home, but we were there all the time bringing her the things that we need. Because she was not traditional (it was the other side of my family that was traditional, not my mother. My mother was actually Irish.) she chose the Western way of understanding. And that's okay. But we also did things like herbs, vitamins. She was very much into natural healing. So her dementia was very, very different. When she started "visiting relatives" and started talking to people, we trusted that. Maybe she wasn't alone, that maybe she was seeing things that we could not.

So as a healer, we look at that very differently. We say, "Okay, then what did they say? and how did you do?" and what was the message in that? And if it was something really negative, then we would say, okay, well, maybe it's time to put this in the diet or that in the diet or there's so many different breakthroughs in medicine in today's world and there's so much more on the way.

If we work together, I believe that Alzheimer's and dementia will not have the same impact that it does to our people today. My girlfriend, who has Alzheimer's and she is I think fifty-eight now. And but what we do is we put her with things that are going to stimulate her. For example, we put her with children. She absolutely loves children and her memory is intact with children. So we give her more of that. We give her a special diet. We make sure we've got all the folic acid and some of the things that help to bring clarity to the brain. We do meditations, we do healing, there's so many more things. It's kind of like a yoga for the brain. And so that's what we do. We support rather than deny. And I think that's where it's a little different. We bring in the support rather than deny that anything's happened.

I also lost one of my very best friends to dementia. He passed in his late seventies. But when he was putting his gloves on his feet, it was hard on his family. But what they did was also an alternative medicine that, yes, he also ended up in a home, but he listened to beautiful meditations and we didn't treat it as if it was a problem. We treated him as an individual and as a soul. And I think that is something that we have to always be reminded of and mindful of is that that is an individual that has had an incredible life and he is a soul and his soul is in a journey, and that journey needs to be respected rather than just be an inconvenience.

Because I know from when my mother, because this is quite a few years ago, she passed away quite some time ago, but it was very inconvenient for a lot of people. I think the inconvenience was so harmful, so harmful to her as a soul. And so I worked really hard. When she started stealing other people's chocolate, I said, okay, she remembered chocolate. She didn't remember my name, but she knew chocolate. So we gave her chocolate, you know what I mean?

So we treat the individual as an individual and not as a problem in society or as problematic. Each person has their own journey. Each person has their own way of being. And in that way of being, what lessons are they teaching us? Are they teaching us humility? Are they teaching us how to be humble and how to be loving and caring? What is the teaching that comes from these things? And what in our fast, rapid, technologically based scientific zapping (that was pretty good), where does that individual fall? And so rather than let them fall, we pick them up and we carry them until they don't need to be carried anymore. And isn't that what we're supposed to do as human beings?

Lisa - Yes, that's beautiful.

Faye - Just the way that you do things like that brings such a peace to that person and a comfort to that person and the respect that you show them as individuals. The Western world is now talking about individual care and one-on-one care and person centered care, I guess is the terminology. And you've been doing that all along.

Lisa - It's more like a relation centered care where you're building that relationship and love and peace among people.

Roberta - And it's recognizing those unique pieces of the individual who make them who they are and help them, coming back to the idea of peace and finding peace.

For my mom, my mom always loved ice skating, figure skating. Well, when I was fifteen months old, we moved to the Bahamas, we moved to sunshine. And we lived there. And then she moved away when I was eight years old and she moved to Africa. So although she had grown up in Canada and she loved ice skating, and I remember that she had ice skates in the Bahamas. They were in her trunk that had the things that she had brought with her. And I would walk around the house and her ice skates and she would say how much I would like that. So in her later years, when she was confined to a long term care facility in Halifax, I had a sticker on the TV and all the staff knew if ice skating is on put it on the TV, make sure. And even though Mum had not been on skates for probably fifty-five years at that point, sixty years, it's like that still brought her some joy. That still brought her some happiness. That still allowed the child within her to celebrate.

So it's knowing those things about the individual that can help I think engaged the spirit on the journey, whatever that journey is. If it wasn't ice skating, it was the beach and beaches and ocean and those sorts of things. So, yeah.

Mary - There's one more thing that I wanted to say is that because of the interruption that our cultures have, there's been an interruption and that's what I call with an interruption, sometimes we don't see that wrap around. Sometimes we don't see that care and that love and that nurturing that we're talking about, Roberta. Sometimes that's not there.

Also in our culture, if we return to what we know is the truth, and that is that we are all related and that every tree, every animal, every being, every person has an important piece in our lives. There is a part that says, what is isolation and what is not being with family? So even if a family cannot for whatever reason or is not available to love and nurture, those entrusted people that we have to take care of our family are meant to be aunties and uncles and daughters and sons and brothers and sisters. And that is why it's so important to respect not only the caregivers, but to make sure that those caregivers that are looking after our elderly people carry those principles in their heart and also express

them because they are there to bridge the gap while we're not there. They are there to bring love and kindness and gentleness and food and nurturing and loving when we are working so they can also feed their family. It is supposed to be an entire wrap around.

So it's very, very important that some of those teachings are handed and that's why I'd like to see more of the cultural awareness for all people, because it is that wraparound. Not that one is better than the other. But that it is important to know the ways of the original people so we can embrace them and do more of that loving, respectful work than it is to deny, because I think everybody can benefit. It doesn't matter what culture, what religion you're from. I think everybody can benefit from those ways of being. If we, as I said, if we look at that before the interruption and how things were done.

Lisa - So, Mary, you were just speaking about the people who support those that are living with dementia in our communities and what kind of capacity they need to in order to support those living with dementia.

Roberta, in your experience with Over the Rainbow and the seniors that are being supported through that program, what are some of the things that you think would, what kind of capacities need to be built for those who are supporting the LGBTQ2S community?

Roberta - Well, I think as Mary has spoken about, it's a recognition and support that we are all in this together and support and the wraparound. Some of the issues and some of the challenges that members of the 2SLGBTQ+ community face as they age and perhaps need to go into care is the reality of stigma.

Historically, it was wrong, it was bad and actually in Canada it was criminal to be gay. Nowadays, there's the whole alphabet of the 2SLGBTQ+ which is 2 spirit, lesbian, gay, bisexual, transgender, queer and the plus indicates there are other identities which are not recognized or perhaps labeled or the labels are not known, but they are still included in being members. That is sort of the non-binary coming under the umbrella, the colorful umbrella.

And one of the challenges and the issues for those who are caregivers of folks, community folks, is that with the issue of dementia, when their realities go back to an early time, even though they're new caregivers, the caregivers that are there providing assistance and who may be queer themselves,

(And I will admit I have trouble sometimes with that word queer, but that's my demographic. And the younger people in many of the caregivers who are coming through schools and programs do identify that way.)

and they may be very supportive. But a person with dementia who falls back into a reality of sixty years ago may be falling back into a time of persecution. It doesn't matter what anybody says to them, they are still terrified. They are afraid that they are going to be thrown into jail. They are going to be afraid that they will be bullied and all those different things.

In my own experience, I remember my mother getting very, very upset and threatening to kill me because I am a community member and she knows that. And she said, "I'm going to kill you. I'm going to kill you." and her caregivers at the end where she was would say, "Don't say that, Margaret. Don't say that. That's your daughter". And I just said to them, I said, that's mom's reality. That's where she is right now. And she's coming from having

lived in a country where being gay or being a member of the community was punishable by death and she would sooner kill me than have someone else kill me.

I couldn't get angry at my mother threatening me for that because that was her reality. And believe it or not, that was her expression of love more than anything. And then trying to educate her caregivers as well that this is where she is and it's okay. We just need to work through that. If the uncle wants to put the gloves on his feet, that's fine. Get him some nice gloves. If it doesn't hurt anybody else, okay!

Lisa - How does that effect, though, Mary what you were talking about and also, Roberta, so we're talking about safety and somebody seeking out support, but where there's a fear of there being no safety involved, then people aren't going to seek out that support. And therefore, there's not going to be a diagnosis, there's not going to be that care that could help them along their journey of dementia. So that culturally safe support that is needed, what would that look like?

Mary - First of all, it's not safe. It's not safe for people under the spectrum. Also, being an Indigenous person with those states in our culture, Indigenous people that are under the umbrella are highly, highly respected. But because of the outlaw of our people and I'm speaking about the outlaw of our people and our way of being, it's a double whammy. It's a double whammy. So there is very little safety.

And so a lot of our people die alone and uncared for because of those stigmas. And any time there's a stigma, I don't care what it is. When there's a stigma, it's based in hate and there is no room any more for hate. We have to switch this up. We have to talk about it. And we need to not accept hateful words. Words are our medicine. So what we say becomes our reality and we have to do things differently.

That's what I say. It's not an option anymore. We have to talk about it. We have to bring new policies because we're living in this western world, but we also have to understand that there's many different ways of understanding Alzheimer's and dementia two spirited people because in our culture two spirit encompasses everything. So in our two spirited way of being, we must protect those who cannot protect themselves. But how do you do that when it was illegal less than, the stigma is up until the 1990s that we have been fighting and it's still there. It's still there. So we have to really, really look at this. And as I said, stop the hate.

Faye - So when you've got these people, no matter whether they are two spirited or on the plus side, but when they're under that umbrella and they're fearful because of the past and because of the stigma, how do you enhance their spirituality? What do you do to enhance the spirituality and give them some comfort and peace and be able to ease some of those fears?

Mary - I think we have a change policy, and I think we have to talk about love rather than hate. I think we need to look at and take this everywhere from the top down, bottom up.

Roberta - And I think that that's absolutely valid. We have to address some of the issues in the system, the political system, the whole societal system and systemically and all that.

But also to come back and say what can we do individually to support people? Traditionally I know with our young people, although we have gone and are attempting to

build and develop strong partnerships with our local church, and it's a beautiful church and there's much to be enjoyed, and that's part of my own background and things like that. That's fine. But there's still some resistance and reluctance in those who have been hurt by the church, formal churches, and there's some hesitancy there.

So what can the individual do? The individual can recognize and acknowledge that there is hurt there and it's recognizing and it does not need to be attached to any formal faith, any formal religion, but it's recognizing that we all have something within us that we don't always understand. But it's there and needs to be nurtured and cared for, and we cannot let the systems quash it.

And maybe someone can't come in to, it's the same as for the Rainbow Resource Center trying to make people aware of us in the community and that we're an okay place to be. Having a community based barbecue in the parking lot before social distancing and when you were allowed to gather more than five people, but to invite the community in and genuinely accept people for who they are and where they are and embrace and celebrate.

So both, as Mary says, from the political; yes, we need to do that. Yes, ye need to change the system. Yes, we have to. We can't change history. We can learn from history so that history doesn't repeat itself.

Faye - You know, from my experience with people with dementia and Alzheimer's and that we as a society think of them as weak and broken and not worthy. And that's part of the stigma that we're trying to get rid of. But when you actually look at them as individuals, they're very strong and they have taught us and can teach us more than we could ever imagine about loving, about strength, about perseverance, about being the same person that they always were, because what's in their heart is intrinsic to their nature.

Mary - Yeah, they used to let her sit by the desk and unplug the phones at the nursing home. They would unplug the phones because my mother was at one time at the hospital as the switchboard operator, with all the plugs. So she would be talking to people, and answering the phones, that weren't there. And she had a great time. They were kind to her. They did things for her that made her feel peaceful when we weren't there.

Roberta - That's so incredibly, incredibly valuable. Unfortunately, some of the folks from the community, the alphabet community, the umbrella community, are terrified that when they go into care facilities, that they will not be able to celebrate who they are and keep those things.

Like it to reenact the switchboard operator thing, I mean, that's perfectly normal. That's perfectly acceptable in today's standards and mores. But there are so many that are actually afraid to recognize their own identities that they have to quash them. That they have to be careful. They also can't, in many facilities, have their partner, maybe their partner of twenty or thirty years who has to come in as a "brother" as opposed to a partner. Those behaviors, that lack of support for the individual or the individual as to who he or she or they are. It's an early spiritual death, which is most unfortunate, which is very, very, very unfair. And the celebration of life.

Faye - It takes a lot of bravery, to be honest about who you are or what you believe or where you've come from. But yet in that honesty we're taught so many things, and one of the biggest things that I hope people take away from all of that is the understanding that

they're an individual, a creation of our Creator and worthy of love, because the Creator does not make junk. He does not make mistakes. They might be different than me, but I'm different than the guy next door too.

Roberta - Firm believer in that. Just as every leaf, every tree and every snowflake is different, but all have their own part and place in the world to be enjoyed and to be loved and to be experienced.

Lisa - So, Roberta and Mary, what do you want people to reflect on at the end of this podcast?

Roberta - For me, I would want people to reflect on the fact that there is something inherent in every single one of us that brings us our own joy and our own uniqueness and our own happiness. We don't always really understand that happiness every single day, but every so often something will come along in life, an experience will come, a feeling that will just say to us, yes, this is what life is. And we hold that dear to ourselves. And it's very unique. It is very, very unique.

And that I would hope that what people will take away is to recognize that, first off in themselves and also as they care for their loved ones, as they work with other loved ones, to recognize that other people have those, too, and to provide the opportunity and open the doors to let those things happen just naturally and to reflect on our uniqueness, our oneness and to celebrate it.

Mary – You summed that up really nicely, Roberta. I think that is really where we're at. And I think that we need to always understand that there's something more than what our eye looks for. And to remember how to love and to stand together and remember to support each other. Like if you have a friend that has Alzheimer's or dementia, support the family, support the people around them, do the wraparound piece because all of us need love.

And so the people that are also walking, make sure that they're good, make sure that they get a meal, make sure that we stand together and make differences that need to be made.

Because as I said, this is about a soul journey, this is not just about a physical journey. The physical journey is there, but there's so much more and we have to, as I said, because the people around them often get tired, so family. We are an extension. We are a part of the family. So let's treat each other like family. Now stand.

Lisa – That's lovely and it really does take a community to support people living with dementia because people can't do it alone. A care partner can't be the only one to provide that support. So we all need to come together as a community and to, as you say Mary, do that wraparound support.

So I want to thank you both for taking the time today to provide us with a bit of a cultural lens, diversity lens on our conversation of spirituality and dementia and to wrap up this series, a special series on Dementia Dialogue in such a positive, open, loving conversation.

Faye - Thank you both for sharing your stories, sharing your insights and helping us be more open and breaking down those walls of stigma, not just during this podcast, which

hopefully is going to start that ball rolling in one respect, but also the things that you do in your everyday lives. So I thank you both for all that you are, all that you give and all that you do. Thank you.

Roberta – Thank you. It's been a wonderful privilege to take this moment in life to share with you three incredible individuals and to also have the opportunity to realize that we may be impacting others as they listened from wherever they may be, whether as a group, as an individual, but to know that there are those who love and care and thank you,

David - Dementia Dialogue is very appreciative of these four women engaging in such a deep and challenging discussion about the similarities and differences among communities who have been subject to stigmatizing behavior and how to find peace when faced with the additional challenge of dementia.

Our next episode is on the experience and issues of caregiving amidst Covid-19. We hope that you will listen in.

We'd love to hear from you. Please write to us at dementia.dialogue@lakeheadu.ca or comment on Twitter or Facebook.

Thanks to the Center for Education and Research on Aging and Health at Lakehead University and to the Public Health Agency of Canada for their support.

My name is David Harvey.