

## **Dementia Dialogue - Choices**

Interview with Myrna Norman

**David** - Welcome to a new episode of Dementia Dialogue, where we meet Myrna Norman, an advocate, author and artist living with dementia. Myrna's home is in Maple Ridge, British Columbia, with her husband, Dave. Myrna openly discusses some of life's challenges when you are diagnosed with dementia, but also the choices and possibilities that accompany these challenges.

I'd like to welcome Myrna Norman to our episode today, where we're going to be talking about her work in creating books related to dementia. Her poetry, her work in art, and then her advocacy.

So thanks very much, Myrna, for joining us today. And over to you in terms of sharing a poem that you recently wrote regarding yourself and your experience.

**Myrna** - Thank you. Thank you for inviting me and giving me the opportunity to share what I do. Perhaps it'll help others.

I wrote a poem called ***I Am Not Afraid:***

*I was not afraid until a boy showed his ignorance by attacking me.  
I was not afraid until my voice used a language totally unfamiliar to me.  
I was not afraid until my independence was substantially curtailed.  
I was not afraid until my tasks became too difficult to complete.  
I was not afraid until my presence was no longer requested.  
I was not afraid until going for a walk became wandering.  
I was not afraid until my short term memory was gone.*

*I was not afraid trying to keep up in a conversation that became too difficult.  
I was not afraid when I learned that my journey could be happy.  
I was not afraid when my journey had a few dips, but I was able to proceed.  
I was not afraid when advocating for people with dementia became my life's work.  
I am not afraid.*

**David** – Lovely. In the poem, I noticed that there was perhaps two thirds of the stanzas, the phrase was, “I was not afraid until” and then there was some kind of a negative experience that was related to that. And then in the last third of the stanzas, the phrase changed from “until” to when it became a positive statement. And I'm wondering, can you identify at any particular point where it became a transition from, “I was not afraid until” to “I was not afraid when”? Was there any particular experience that altered your perception?

**Myrna** - I think it's an ongoing process, but each of these events that I wrote about are events that really impacted me, if only for a short time. But I realized, somewhere along the line, I realized that by educating myself, by taking courses and by joining groups, I was beginning to feel that I was still valuable as a citizen and that I could still take part in making my community better by using my dementia as a means rather than as an end.

**David** - As a means to engage in the community.

**Myrna** - That's right. Yeah. And I think it's really vital (if you can) to let people know about dementia.

I know a lady who I think she's in an area close to North Bay, Ontario, and she wears a t-shirt saying, "I may have dementia, but it does not have me". I mean, isn't that wonderful?

For years and years and years, I worked with housing societies, cooperative housing and that kind of thing. And then my husband and I (well, I did and then I hired him to work with me) started a home inspection business. And we did that for a number of years. And it was it was hard work. But, you know, it was so self satisfying. And it was wonderful. And it gave us many opportunities to travel and to meet new people. And it was it was a great choice in our lives.

But it was through that, that I knew that something became wrong because I couldn't do simple math.

**David** - Now, in addition to writing your book, that I'll talk about in a minute, you've also written a small book for children entitled Sometimes My Nana. I'm wondering if you could let our listeners know what prompted you to write a book for children regarding dementia.

**Myrna** - You know what? I always wanted to be a teacher, and because of my life choices, I wasn't able to do that. But I've always felt that no matter what comes up in our lifetime, to learn about the challenges helps us get over them.

And I know that with my own grandchildren, sometimes I didn't want to be around them too much because of the chaos. Sometimes I just wanted to be in a quiet place. And sometimes, as a lot of parents do, I struggled for their name. But it was a different kind of struggle. It wasn't that I just for the moment, it was like, "Who are you?" That kind of a struggle. And I know oftentimes my grand kids would look to me for a game because as a younger person, I was that kind of a Nana and I couldn't do that anymore.

And so I felt that children just needed to have a response to what was going on with me. And I felt that I might be able to help other children, too.

I think this would be great for schools.

**David** - Now, I'm curious, you've read it to your grandchildren at some point? So what was their reaction to it? How did you find their reaction?

**Myrna** - Yeah, they were really pleased with it and gave me a lot of positive feedback, all the while saying that they (they are very sweet) and say that they understood and it was okay.

And sometimes they tease me about it. And that to me meant that it was a healthy communication we were having because it wasn't a heavy rock. It was like a few pebbles and we were able to pick those up and move on.

**David** - Do you see a connection between talking with children about dementia more openly and the issue of stigma that is so pervasive in our society regarding dementia?

**Myrna** - Yeah, I think children are really open. They're like little sponges, I think. And so I think it's just healthy to give them the proper language, to let them know that just because Papa or Nana or Grandma aren't responding to them in the way that they normally would, that doesn't mean that it's their fault. Children have a way of taking everything on their own shoulders. And so I think it's necessary to teach children from the ground up.

And I think if we just all took the time to understand, there wouldn't be so much stigma. But there's stigma about everything; oh yeah, chubby, not, whatever. But if we teach our children to accept, I think that's the best way we can solve this problem.

**David** - We came to this interview because of the publication of your book, *Dementia Strategies, Tips and Personal Stories*. I want to thank you for writing it. I found it refreshingly honest, simple in a very positive way, as if we were just sitting down for a cup of coffee at one of our kitchen tables. And you were willing to talk about a few things that are embarrassing; embarrassing to anybody who is aging, but particularly embarrassing, perhaps, to a person with dementia.

So I thought that was really lovely on your part to express that kind of openness. I'm wondering if you might tell us a little bit about how you came to write the book and what was the process that you went through?

**Myrna** - You know, I think I've wanted to do it for a very long time. And I do have a blog called *Dementia Middle Stages*. And my intention was to take the blogs and put them into a book. But I decided that I didn't have enough sort of things that really had happened to me that had profound effects.

And there's a couple of items in the book that I was absolutely mortified that I did. And I thought I bet other people feel that way, too. And it's nobody's fault. It's just something that happened. You didn't plan it. It happened. And so get over it kind of. And I thought I could make that point by putting those things into the book.

And thank you for saying it was like sitting at a table. I wouldn't let my husband nor my publisher change any of my language. I wanted it to be just that, just sitting, having a conversation.

**David** - We haven't talked about the nature of your dementia and when you were diagnosed. So I wonder if you might just speak to that for a couple of minutes so people understand when you say the middle stages. What does that mean to you?

**Myrna** - So I was diagnosed 12 years ago after having symptoms for two or three years that were serious enough that I knew something was wrong. I was having major spatial difficulties. I couldn't do math and I would fly into these huge rages. So I talked to the doctor after some time, two or three years, I talked to the doctor. He sent me for some X-rays or CT scans and told me, you have frontotemporal dementia. And I had eight years to live and go home and get your affairs in order.

Well you can imagine, I had never even really heard, I had heard the word, but I didn't really know what dementia was. And so over these years and I did get my affairs in order right away but I don't remember what they were. It was all just scary.

It was wonderful, in hindsight. My husband had to go away the very next day after I got that. And I didn't want to tell him because he was going to visit family in Ontario, but it was the best time. I spent two weeks feeling so sorry for myself in total despair, crying, just wondering why it was me, et cetera.

And then I decided that I had to get up and get on with it. And so I did my best. I didn't do well. I've seen another few doctors over the years and I've been diagnosed with everything from that frontal to Lewy body because I have tremors and hallucinations. I had a stroke so now I've got vascular perhaps.

I think a lot of people are like me. We don't fit into the box. In fact, I think everybody's like me, none of us fit into the box.

So it's been a roller coaster ride.

But I think there's two choices; you can either decide to do, just go with it and follow your life to the end, or you can say, well, at least while I'm here, I'm going to do something with it.

So I managed to get on some groups.

**David** - I suppose that's then part of the idea of the book. It runs through the book that you're sharing some of your experience, you're sharing some of your observations of other people to encourage people to kind of recognize, I'm going to use the word embrace, kind of embrace their diagnosis and not struggle against it, but live with it, take it for what it is and live with it.

Would you say that that's kind of the central message of your book?

**Myrna** - Of my whole life, I think, yes.

Yeah, I agree. I remember a person who was a facilitator for Alzheimer Society said to me once, "One day you're going to be thankful for this event in your life". And she said another thing, she said that was so important was, "There's a committee of jerks in your head that are going to try and convince you that this is terrible. Kick them out. Listen to the one that say live life well".

**David** - Yeah, I like that. That's in your book. I like that phrase, "a committee of jerks". The Committee of Jerks is in all of our heads, I think, regardless of our situation. There's always a tendency for us to be hard, too hard on ourselves, perhaps too hard on the world in terms of how we've been treated. And it can be really disempowering, I suppose.

**Myrna** - And we do have choices.

**David** - Do you want to elaborate on that for a moment?

**Myrna** - Well, I never knew in my previous life that we actually had choices. I thought we were dealt this road, we went down it and we did our best and that was it. But I've learned through having dementia that we do have choices.

And so I've chosen to live life as well as I can. And that's why the book was so important, because I could put the kind of foibles that I've experienced and now they're funny. The very first time or second time or third time, I repeat them and they weren't funny and now

they're hilarious. Like, so what? And what a story to tell your your grandchildren, you know?

**David** – Yeah. Oh that's right. To not take oneself too seriously and to have a sense of humor that is forgiving of yourself.

In the poem you read when we began our discussion, the last stanza reads, “I was not afraid when advocating for people with dementia became my life's work”.

Advocacy has obviously become a big part of your life. How did you first get involved in dementia advocacy work? What was your introduction?

**Myrna** - Soon after ,well, about three years after my diagnosis, I found the Alzheimer Society. I phoned them. They took me in and were going to train me as a facilitator. I was not ready at that point in time. But they also passed me on to a support group and that support group opened my eyes to everything dementia advocacy could offer. And if you took the dementia away from it, it's just advocating for people to let them know that they have an opportunity to be happy, that they can do things and that they can carry on.

I stayed on the Alzheimer's support group for well, this will be my tenth year, I think, and through that I learned that there were lots of other avenues. I started a purple angel group in my hometown. I'm on a committee that helps with dementia community support. So we have a dementia friendly community support group in our town.

And then up came offers to speak publicly and I did that. And now I think I sit on fourteen committees and I'm very busy but because of that, and this is the one thing about this interview that I want people to know more than anything, staying socially active is the best thing to keep your brain building new roadways. It's imperative.

**David** - Yes. OK, so that's the core advice to people. I think sometimes, you've touched on it in your poem even when there was a stanza, where people stopped inviting you. And I think that happens to people. It happens to people. It happens to their care partners that you can become very isolated.

So how did you overcome that? Just through reaching out to groups like the Alzheimer Society or kind of rebuilding your social life, if you will, or filling in the gaps?

**Myrna** - Filling in the gaps, I would say more. There was much more I was interested in doing.

And people would ask me things and I didn't have answers and I would search out answers. And searching for that, I found another avenue that I could help in and it just sort of mushroomed.

And it's made me such a better person than I used to be. It has it has really helped me to grow.

I couldn't tell if I was to take a step, if that was going to be a step in water or that was firm ground. When I was driving, I felt like I was moving in the opposite direction that I was moving in. All kinds of things like that were happening. And so I knew I needed some help there.

**David** - The poems that you read and that are in your book, then there are the two books for children and the Dementia Tips and Strategies, and also your speeches, are all works of art. And I notice, our listeners won't be able to see it, but I notice a painting in the background of your room there and you mentioned that you had taken up painting.

**Myrna** – You know, that's a really strange thing. When I was developing dementia, at least enough to know that there was something going on, I said to my husband, "You know, I think I would like to paint". I'd never painted, never took a class, never painted.

And he went out and bought me an easel and some paints and that canvas. And I painted some things and I liked it. My paintings felt like little babies to me. Things that I had created.

And I think through my art, I have learned... it's probably helped with stigma if one could really analyze it because everything I see now, I look at with a new eye. So when I'm looking at the sky, I see it differently. When I see the snow on the mountains, they're defined now, whereas before it was kind of a blur.

So I think my artwork has helped me find myself, express myself, sometimes even share negative things on a canvas. And sometimes they're just for me. You know, I don't sell my paintings. I just enjoy doing them. I think it's been amazing.

**David** - Interesting. I really like that idea of painting in your case, but kind of sharpening your perception of the world. Yeah, that's a very interesting idea.

**Myrna** - Where we live in B.C., there's a lot of mountains and I've always lived in B.C., so the mountains are very, very dear to my heart. And I remember once I started painting and I would look at a mountain, it looked so different and I realized it's because I hadn't opened my eyes before. So if I wasn't seeing the landscapes in the way they are, what else wasn't I seeing? So I try and really take in everything that I can now. So it's made a huge difference to my life and my soul.

**David** - Yes. Yes. So it kind of enables you to be creative and more self accepting or more self affectionate for the work that you've created. And it also sharpens your perceptions.

**Myrna** - And I think in that way, I think it basically helps to remove stigma because you're not passing by. You're not you're not taking a quick glance. When you're talking or looking at a person now, I'm engaged with that person. I don't see what's happening around. I'm engaged with that person. I just think it's amazing.

**David** – Yes, yes. Well, that's wonderful. And I think the poems and your books and also your speeches as a form of art. So you really have multifaceted avenues by what you are able to express yourself.

**Myrna** - And it's been so wonderful to have that opportunity and to sort of be blessed by sharing that with others who get a little bit out of it.

I hate that word, “Oh, it makes it worthwhile for me” because we shouldn't be doing things because it makes it worthwhile for us. But it's wonderful to share some little tidbit that you know will help somebody else.

**David** - And also, when you share that, you're encouraging other people to perhaps do that themselves, whether or not they'll become as accomplished or as known as you are, for example, doesn't really matter.

But taking time just to sit by yourself and write a poem. I'm sure when you're writing a piece of poetry, you're not thinking of it being performed. It's really your own personal reflection. And it's a way in which people can kind of unpack what's in their mind and put it out on a piece of paper and appreciate it.

**Myrna** - And a number of people who bought my book have suggested, as you have, that it should be used as a teaching tool. And I think that's awesome.

But what I want it to be most is a way for people to feel that they're not that different than anybody else. You know, fundamentally, we're all the same. And so having differences is a plus.

My differences now have made me a better person, and that's all right.

**David** - Okay well, I'd like to thank you very much for our conversation. I've really enjoyed it.

Myrna's book, *Dementia Strategies, Tips and Personal Stories* can be purchased by writing [The.Normans@shaw.ca](mailto:The.Normans@shaw.ca)

Her booklet, *Sometimes My Nana* is free through our website and can be downloaded from there. As well, her poem, *I Am Not Afraid*, is also available on our website.

Myrna has kindly donated a copy of her book to a lucky Dementia Dialogue listener. To win the book, please send a note to [dementia.dialogue@lakeheadu.ca](mailto:dementia.dialogue@lakeheadu.ca) and put Myrna's Book in the subject line.

Thank you to our listeners for your attention and also for helping us reach more people. If you listen to us via a podcast platform like Apple or Spotify, please consider giving us a review.

Thanks also to the Center for Education and Research 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.