

Dementia Dialogue: Season 3, Episode 32

The Solidarity of Sisterhood: Women Living with Dementia

Transcript of interview with Brenda Hounam, Clara Mersereau and Myrna Norman by Elaine Wiersma

Elaine - Welcome to this podcast on Women Living with Dementia. I'm Elaine Wiersma. I'm an associate professor at Lakehead University in Thunder Bay, Ontario and the director of the Center for Education and Research on Aging and Health.

Today I have three wonderful women who are joining me to share their experiences of living with dementia. First, we have Myrna Norman, who is from B.C. After being diagnosed twelve years ago with Frontal Temporal Dementia, and after several years of despair and questioning, Myrna began to educate herself about dementia. She was fifty-nine at the time.

Since, Myrna has become an advocate for all persons living with dementia and their family and friends and sharing tips and personal stories with others helps to form the bond of trust and also helps to grow a sense of personhood. Through humor, knowledge and being a voice for others, Myrna has continued advocating through her thirteen committee's work and her public speaking. She has written two books, one for children, My Nana, and one for persons living with dementia and others.

Brenda Hounam from Ontario was diagnosed in 2000, and since then she's been an active advocate for people living with dementia. She is the founder of the By Us For Us Guides, a series of booklets for people with dementia written by people with dementia. She has been an advocate, spokesperson and public speaker at numerous events locally, provincially and nationally. Brenda has received the Queen Elizabeth II Diamond Jubilee Medal and has previously served on the board of the Alzheimer Society of Canada. Brenda has also been a co-researcher on a number of research projects.

And we have Clara Mersereau. Clara's biography is written by her daughter Joanne. And Joanne has this to say about Clara:

"Clara is one of the most kind and loving spirits anyone could know. She's always the first to find the bright side if you have a hard time seeing it. Clara was diagnosed with Alzheimer's just over four years ago. However, she will be the first to tell you, "I may have Alzheimer's, but it doesn't have me". In December, Clara turned seventy-seven and shows no signs of slowing down, especially not slowing down her work to bring awareness to living well with Alzheimer's."

Myrna, Brenda and Clara, thank you so much for joining me today. I'm so thrilled to have the three of you here. I wondered if I could start and maybe, Brenda, I'll start with you, since you were diagnosed probably the first, many years ago, to tell me a little bit about your diagnosis and how it came about.

Brenda - I was diagnosed in 2000 at the age of fifty-three, and it took an intense year and a half in order to get my diagnosis. I was working at the time as an industrial accountant, and I noticed myself that I was having problems. I went to the doctor the first time myself. The symptoms were really coming on for quite some time before I broke down and even went to the doctor, which isn't too surprising, I think, for a lot of people.

Elaine - Thanks, Brenda.

And now, Myrna, I know that you were also diagnosed with young onset dementia, the same as Brenda. Tell me a little bit about for you how the diagnosis happened.

Myrna - I was aware, like Brenda said, that there was something not quite right. I was having a lot of spatial difficulties, particularly when I was driving, which should have been a dead giveaway. And also I couldn't do math. I couldn't add two sets of numbers together and I would fly off into the most obscene rages. And so I knew something was really wrong, but it took quite a bit of time and a lot of tests.

Elaine - Thanks, Myrna.

So, Clara, let's turn to you now. You were diagnosed about four years ago. So how did that happen for you?

Clara - Well, one day I was out, because I was a mobile hairdresser for a while and I was coming home and I didn't know exactly where to go. So I came in the house, had a good cry and everything, and I said to Bill, "There must be something wrong, you know, like I didn't know where to go. I didn't know how to get back home, you know, and that really scared me".

And with so much Alzheimer's in my family, with my three sisters and my mother, I mean, I knew, it was a given. So after that, we went to the doctors and they did some testing and they said, "Yep, that's what you have". And I said, "Okay I've got it. It ain't going to get me". And I decided then to just take hold of it and I'm in charge. It's not.

Elaine – So Myrna you mentioned in your biography that at the beginning, after your diagnosis, you had some kind of despair and some questioning. How did you come to accept it? And what turned the corner for you?

Myrna - I'll keep it short. My husband actually was leaving to go to Ontario for ten days, and I didn't want to tell him this happened, my diagnosis had happened the day before. So I got some information about dementia from our computer and I put it in his suitcase and I said, "You'll want to read this when you get to our son's in Ontario. And then you can have a chance to talk to them about this as well". And it was the best thing in the world because I got to spend those ten days really feeling sorry for myself and letting all that pain and anxiety. I cried and I thought, "Why me?" And you know what? Why not me? I'm a fairly strong person, I believe. And so maybe this was in some ways a bit of a gift that I could share with other people. So they don't feel so negative about it.

Elaine - Brenda, I'm going to turn to you because I know that you've been doing kind of advocacy work and similar to Clara and Myrna, but for years and years now. What was that process like of acceptance and moving to that for you?

Brenda - I contribute a lot to my background in the way my family were with trials and tribulations that they dealt with. But I went through all the motions just like everybody else, with the crying and the anger and frustration and the feeling of people treating me different from one day you're normal and the next day you receive a diagnosis and everybody automatically treats you different in a one day time span. And that isn't how it happens.

And so it did take me a while and I did go through those. And I was a single parent at the time, so I didn't have the luxury of a partner to help me through it. But I had two wonderful children that were still relatively young. One was in school at the time. They were perfectly awesome.

And I think in some ways I was luckier with that situation, because I've found over time that younger people are more accepting. And they didn't rob me of my independence quickly. I worked through the loss and the grief and come out the other side accepting and the acceptance came fairly quickly. The emotions didn't pass quickly. The acceptance actually came fairly quickly with me.

If I make a mistake now, I just make a joke with myself and my grandkids joke with me now and my kids joke with me now. And that's wonderful to be able to just have that. We were always that way in our family. And I'm just so grateful that I am still able to have that joking and that laughter. And there's nothing better than laughter.

And as far as is being involved, I was always a volunteer, but I felt very quickly that they weren't accepting of a person with a diagnosis of dementia. I fell into being a spokesperson and advocate and wasn't something I ever thought I would do.

That part for me was very, very different, that the more I met other people of my peers, the stronger I became. And I no longer had sweaty palms when I was standing up there. And the more people I met, the stronger I felt and the more company I felt, every time I was standing up there. I never felt like I was standing up there alone. I felt I was standing with hundreds of my peers.

Elaine - Now, Clara, tell me about you.

Clara - I would not have been doing what I'm doing now, everybody says it has changed me a lot and they're so happy because it's made me feel more comfortable. And got a load off of me. I can be funny or have fun with people and not be afraid, you know? So, yes, it has. It's been a good thing for me. Like I say, it's been good for me, I've seen the worst of it with my mother, so I learned a lot that way. And so to me, Alzheimer's has done wonders for me. Look for the good, right?

Elaine - That is definitely not a perspective that you hear very often, Clara. And I've only known you since your diagnosis and I see somebody who's full of confidence, who cares deeply about other people and who encourages other people around her and is an inspiration. So I think that's just amazing.

So, Myrna, let me turn to you. Tell me about you, because you do a lot of public speaking and you've written books. And how did that happen for you?

Myrna - Since I was diagnosed and since I came to terms with the diagnosis, I have, like Clara, I have sort of an inner peace that I didn't have before. And it's been such a benefit. I've had all these opportunities that I would never have had before my diagnosis. And I'm really thankful for those and thankful for meeting people like Clara, who should write a book, and Brenda and all the others that I've met from sea to sea in Canada, they are all gifts to me. And that's one of the reasons it's so important to do what we're doing for Brenda and for Clara. The more we can learn, the more we can share with others.

Brenda - There's so many blessings that have come our way that I always said my path was and my journey in life had been permanently changed upon my diagnosis and for the better.

Elaine - So I'm going to turn and ask you all to kind of reflect a little bit on being a woman. We don't talk enough about gender. We don't talk enough. We kind of treat people with dementia as if they're all the same. And so for me, being a woman myself, I look at the three of you as incredible role models.

Myrna - It is very different. I think women are usually caregivers and my husband has taken a lot of that role over. The point is, is that sometimes I feel, maybe I feel a bit insecure that he has to have taken that role. But on the other hand, I love that he's taken that role. Sometimes it really, really can be difficult. And it's another one of those things about kind of losing your independence.

Brenda – Myrna, you just touched on something that I have felt all along through my whole journey. And that's being the matriarch of the family. That is what I miss the most, is not being able to be the instigator in bringing my family together and have a place for my family coming together, where I feed them and I look after them still.

That, I must admit, is the one thing that I miss more than anything else. I go to the space of, "But I wouldn't have been able to spend as much time with my grandchildren and had that." When I was diagnosed I had no grandchildren at that time and I was under the impression, with the statistics that were out there, that I would never get to see that. So how lucky am I that that because of that, that's there?

But I find with being a woman when you're diagnosed and a lot of problems occur because of the stigmas out there where they pass everything off with women as being, "You're just too emotional". So they are already setting women aside with pre-stigma even before dementia. And so we're already marginalized because of that. And then once you get the dementia, we're marginalized even more because of it.

Clara - To be perfectly honest, I always ran the house. Bill never did the banking. Bill didn't do any of that because he worked out of town a lot and everything. So I kind of looked after everything. So that was my first thing I handed him when he was diagnosed. I said, "Okay, now you're in charge".

Maybe it's because I've talked to myself so much about dementia and whatnot and not letting it changed my life, so I have no complaints about it.

Elaine - How have relationships with some of the people in your life changed since your diagnosis?

Brenda - Where I noticed the biggest change was because of my age, all my friends were still in the workforce, still busy with life and family, and I think that's where I noticed relationships mostly changing.

But there has been many, many examples of the friendship lost but also new friends gained. But I think what you have to remember with that is in life that happens anyway. You just outgrow some of your friends. So what isn't maybe necessarily due to your diagnosis, it might be a reflection of some of these other things?

Clara - Well, my first thing would be: accept it. And it's going to be shocking. And I tell them, I'd say, even though I knew something was wrong and everything else, you're going to be a little shook up. But take hold of that. Don't let it run you. You run it. Because you're in charge. It's not like it's taken over your whole brain or anything, but really, there's so much out there.

Elaine - What advice would you give to other women who are living with dementia?

Myrna - The first thing is, once you've got your diagnosis or perhaps while you're going through it, is to educate yourself. There's tons of information out there. Educate yourself, try not to be afraid. Try and take it all in while you can. Find your confidence, no matter what route that takes. Maybe it's through art, maybe it's through counseling, whatever that is, that helps you find confidence in yourself. Do that. You'll need that for the rest of your journey and you'll be so glad that you did it. You have to feel good about what you've done, what you can do and what you're going to do. The sky's the limit. Be part of a sisterhood. That makes so much of a difference and go to a support group. My people in my support group are my brothers and sisters. And that's so important. It's wonderful to have someone that's like me to bounce things off. It just makes the world of difference.

Brenda - What they've already said, I think educate yourself very, very quickly. I think that's extremely important. I think that the next important thing is to get into a peer support group, even if it's only one other person that has dementia. Remember, only to live in the day. Don't worry about what happened yesterday. Don't worry what's going to happen tomorrow. Live and enjoy the day. Some days are going to be rougher, but tomorrow could be better. And yesterday it could be worse. So you're doing a happy dance today because it's a good day. So live in the moment. Enjoy life as it is and as it comes.

Elaine - Thank you, Brenda and Clara and Myrna. I mean, your insights are remarkable. And you are, all three of you, such an amazing inspiration to myself, to other women, to other people living with dementia, to your families, to anybody. I think they should all have an opportunity to sit down and have a conversation with the three of you like I did, because they would certainly walk away feeling incredibly inspired. So thank you.

David - Thanks to all three of these strong women for sharing their experiences and reflections on what it means to be a woman living with dementia.

Dementia impacts women in greater numbers, and it behooves us to pay more attention to how it is experienced differently.

Thanks to Elaine for hosting this episode. Elaine chairs our editorial board and as a member of the Center for Education and Research on Aging in Health at Lakehead University, who is our institutional sponsor.

We would like to hear from you about this episode. Please write to dementia.dialogue@lakeheadu.ca

We are also appreciative to the financial support of the Public Health Agency of Canada.
Thank you for listening.

My name is David Harvey.