Transcript of Interview with Roxanne Varey

DAVID: Welcome to our Dementia Dialogue podcast where we are discussing changing and adapting when dementia enters a person's life. This is one of four themes we're exploring in our series, Living the Dementia Journey. Our goal in sharing personal stories is to help us better understand what it means to encounter dementia, to gain some insight and to learn how we can live fully in the face of such a challenge. Dementia Dialogue thanks our sponsor and partner, the Centre for Education and Research on Aging & Health at Lakehead University, Thunder Bay, Ontario.

Our guest today is Roxanne Varey, who is living with dementia. Roxanne was diagnosed four years ago in mid-life and all that encompasses - career, marriage, and family. When you listen to Roxanne you can hear the smile in her voice. Our conversation touched on Roxanne's experience in the workplace, her diagnosis, advocacy work and her and her husband's adjustments. I think you will sense the honesty, humility and humour that Roxanne brings to her life.

So, the thing that we're approaching during this first set of conversations is around people's experience of changing and adapting to a life with dementia.

And I'm wondering if you might just talk a little bit, kind of give the listeners a bit of context, a little bit of your story, perhaps before you developed dementia, and then we can kind of get into the story of what life has been like since that occurred.

ROXANNE: OK, kind of looking back now I can see when I'd gone back to school I was having trouble with accounting, and it was the multi-level steps in doing the accounting, and for whatever reason that had become a struggle for me and it hadn’t been in the past. But I think the real catalyst for me was that I lost two jobs. I was working as an admin assistant, and I lost the jobs because I wasn't able to perform the duty. And this was a real shock to me. I’d never lost a job because I wasn't competent or capable, and it wasn't challenging or something I didn't feel I could do. And so that's what kind of headed us off to go see a doctor. But of course, at the same time, I was having some trouble with speech, and so my husband and I more were thinking along the lines that I might have had a mini stroke, because I do have controlled high blood pressure.

DAVID: I see. You've mentioned that you had lost two jobs. This must have been quite devastating for you.

ROXANNE: Yes. One job that I had liked I was really loving it. But I found what I was having to do was to write the steps down. You know the computer thing that I would have to do. Now some days I didn't have to. That's the quandary that one faces in this. This is not always consistent. And I was shocked with one when they let me go. The second one, I guess because I was starting to realize you know something's up, it wasn't as devastating. And I was more beginning to see I am having trouble doing this job right.

DAVID: Were these jobs in small organisations or larger businesses?

ROXANNE: One was a smaller organization, and then one was kind of a government community housing, a larger organization.

DAVID: In your conversation with the employer around this, was it seen as a performance issue or did, you know, was there some talk of your situation from a health perspective?

ROXANNE: No. It was never really brought up from a health perspective. It was from the performance. And even at that time, I think when there were some mistakes made, my judgment was not what they expected in rectifying it. And still to this day, I struggle with judgments- have trouble trusting it with the binders to put together and again with many different sections in the binders. And so, I find what I can do about three steps and then after that it just goes elsewhere. I just evaporate.

DAVID: I see. And then that would begin to perhaps set up kind of a cycle of self-doubt, I suppose you could say.

ROXANNE: Yes. The place that I was then employed at a very large Crown corporation called SaskPower. I had great success there, and the reason being because they were such a large organization they had print screens and everything was done out that you could refer to. And I let them know later on about my diagnosis. I don't think I had a diagnosis at that time, but was suspecting something was wrong, again thinking more along the lines of a stroke. Then when I got it, went to them, and they had like an HR department, which is bigger than what the other ones were. And they talked to me about how they would have been willing to modify duties. And I think I would have stayed on with them. I just had a contract, and they were happy with me and my job performance was good. And I did open up to them. And there was a risk telling your employer this is what you have, and how they're going to respond to it. And I was really grateful for their reaction.

DAVID: Yes. That sounds really progressive for an employer to respond like that.

ROXANNE: Yes. And unfortunately, I don't think it's the case with most.

DAVID: No. I’ve done work in this area of trying to make employers more aware of issues related to people in the workplace that may develop some cognitive difficulties. And there's a lot of work to be done. There is some progress being made, and I think some of the discussion around dementia from a human rights perspective is an important perspective for people with dementia or with a cognitive impairment that may still be working.

ROXANNE: And I don't think necessarily all employers realize that some of the adaptations are really cost effective and time effective. For example, one month I had numerous keys, I worked in the mail room when I worked at SaskPower. That was part of my duties there working for the H.R. department. And I would fumble with them, and I just went and I put myself, with my own initiative, different colored stickers on them. So then I knew which one was, and I put this colored coordinating color sticker on the mailbox. And so, then I didn't have to waste time and do it. But, you know, how much did that cost? Very little. But it really helped save time, and again, I was able to perform my duties.

DAVID: Roxanne's diagnosis helped her to understand the hurdles that prevented her from being able to work. But the diagnostic process was a mix of positives and negatives. She sees the need for a dementia diagnosis to be communicated in a way that is both honest and offers positive advice about living with dementia. Let’s hear about this milestone in her journey.

Describe a little bit of the process of seeking a diagnosis and how that worked for you?

ROXANNE: Yes. The process itself I felt very comfortable with. I had a young doctor, and because I was young in age at that time, I was 51, he really explored a lot of avenues with me. I went and got scans done and that didn't show anything. And he did a test for me for sleep apnea. He said that the sleep apnea can give you the problems with the concentration. And the sleep apnea wasn't enough to contribute to the symptoms I’d been having. And then from there we went on to do some cognitive testing. I started with a basic test, which I would recommend to anyone who is concerned about this that they approach their doctor about getting an MMSE, a Mini Mental Skills Evaluation. And my score at that time was 28 out of 30. It's always out of 30. It’s a standard test. 28 is not a bad score, but 28 is not a good score for someone who's 51. So from that, then they decided to send me, I went to a wonderful facility in Regina called Wascana Rehab. And I did 12 hours of cognitive testing.

DAVID: Wow. That must have been a, that was tiring experience for sure.

ROXANNE: Yes. It was over two days. And the first day it was like my experience, it was fun. I told my husband, “oh I feel like I'm in elementary school I get to draw. I get to play with blocks, you know color.” And then the second day, I think they hone the testing, and I started to see my gaps. I started to see where I was lacking. And I remember, at lunch time of the second day, calling my husband, and I was near tears saying I didn't want to go back. I didn't want to finish it.

DAVID: And then knew you were back at the physician’s office, and he shared the results of the test with you.

ROXANNE: Yes. And then I asked for, and I got a, not my physician, the neuropsychologist who gave me the test sat down with my husband and I and went over and explained. Now he couldn't give the diagnosis, this gentleman, but explained kind of where they were leaning, and why they had the summary page. From that, I then had an appointment with the neurologist to go over these results. And when the diagnosis was delivered, it was very cold and very difficult. My husband and I were just shocked. And I I've tried to advocate in the medical community for there to be like a comfort room that, you know, suppose is one of us or both of us had broke down, which is you know quite possible and very understandable, because I was told, here I am 51 years of age, I was told I was terminal and to get in contact with the Alzheimer's Society. Like really, that was about it. It was very blunt. There was definitely this feeling like you know he wanted to get past this and get on to his next appointment. I really try to advocate for that because the delivery of the diagnosis, while I can appreciate that it's not an easy one to give, and I'm not the only one who felt the delivery of the message with a bit callous.

DAVID: Yeah. It's so important to encourage people to, you know, look at their lives realistically, like not to couch the truth in improper ways. But at the same time, to give people a sense of hope, a sense of there's a life yet to be lived, and that there's ways of living that life in a positive way. And that needs to be the tone of a diagnostic conversation, it seems to me.

ROXANNE: Yes. And, I guess, through my experience I've dealt with three different neurologists, and you know, and I was told as needs be you know to get your affairs in order. But one neurologist I saw here in Alberta, I was really pleased. He was the only one. I think all of us do this. When you were given a diagnosis of any kind. What is the first thing you do? You go Google it. Yes. But what he did, understanding our need to just want to find out more information and to be prepared, he sent me a link and some booklets. And he was the first one to do that. And so as much as I said the other way, I want to also say I've been a part of where I felt it was done right.

DAVID: Yes. Well that's exactly you know part of the effort of Dementia Dialogue conversations is to give people an idea of how it can be done differently. And also, we want to connect people to resources and to other people where they can learn how to positively understand the condition that they're confronted with and also then strategies on how to live life in a more positive way.

Now you've come up with some ideas about how to live with dementia in a positive framework. And I'm wondering if you could share a little bit about how you might have left the physician, you know, the neurologist's office, you know discouraged, disheartened, it you know would have been a really difficult time for you. But, in the course of the intervening three years, you've kind of reframed your life. Tell us a little bit about how that happened.

ROXANNE: You know it was a process. I think for me, you know, I was young and some of the typical things they suggested, like being involved in a support group, I didn't find I was a good fit with all of them, because the people were much older. And I'll give Alzheimer Saskatchewan a good shout out there, they went and did through Healthlink, and had it where I went to the hospital, and I talked with other ladies in the province who were younger, who had either the early onset or the frontotemporal. But whatever it was, they were they were done early, and I found that very fulfilling.

All of a sudden, I got this fire in my belly. I don't know where it came from, and I just wanted to have a voice. And I got very involved in my own personal advocacy thing, as you talked about, I did things with media. I met with, in Saskatchewan, this member of parliament. I tried to get on to talk to them, the directors of a care facility that it was getting a reputation that it just needed some things, as well. I spoke to caregiver groups. I did public speaking that I found really felt there needed to be education. And I have faced some stigma, and that was painful. And with my illness, there is the hereditary link. And I was also motivated by the fact that I wanted my children, should they get this disease, to hopefully be dealt with, with more compassion. Not that they were bad. I don't want to say that they were terribly bad. But that they could have been, you know, with a little education, things could have been dealt with better. And I spoke to Rotary Clubs. I even got a chance, I really felt at a certain point in time, I kind of wanted to change my shift from the media more to the education. And that's where it was really key, and I felt perhaps was lacking. So, I was lucky to be invited by a professor at the University of Regina to speak to her social work class. And UBC, in British Columbia, has a great program where healthcare workers will that deal with anyone with dementia or Alzheimer's, they do practical experience, where their students meet up with someone with the disease as part of their curriculum. So then, I tried to go to the postsecondary minister in Saskatchewan to try to advocate to get this to be part of the nursing students' curriculum or the doctors' curriculum. But at that time, we moved, and so that ended up leaving out.

My husband and I have had several heart-to-heart conversations because there's different stages. And it's always a living process. Probably the number one thing that makes early onset or someone that is young that gets this diagnosis is the impact financially. We were hugely impacted. I mean I was 51, and we thought I was going to have at least you know close to another decade of working to build our nest egg. You know, the diagnosis is kind of this cliché, you know, “You only live once.” But I find it very hard to, mentally, force yourself naturally into that position. I think one of the great blessings that has come to me with this illness, is that I enjoy the simple things. I find joy in so many things, and I'm not likely to take things for granted. You know my husband and I, in the first part, it was this big bucket list. And we went big and wild and crazy, and we went dune buggying in California, and we went white-water rafting in Golden, and did a zip line in Fernie. But, kind of [after] you’ve done that and still processing and always moving because it's like walking on eggshells. I just found that it was really important to spend time the family.

DAVID: Adjusting can sound like resignation or giving up. But as our conversation moved on to change and adjustment, Roxanne talked about how she has embraced both social and personal change as a means of improving her life, her relationships and her community.

Coming to terms with a condition like dementia really can be eased by that discipline of learning and living in the moment.

ROXANNE: Yes. It's a shift because it's not just like I say it's a natural way of doing things. But then when I'm faced with a decision now, knowing the illness I have, it makes it easier to make certain decisions, and I think “If I didn't know about my diagnosis, I might not have done that.” And I'm grateful that that gives me a new perspective when looking I’m at making decisions in the present or going forward. Now I need to explain a little bit about, I don’t think we said actually what I have, but I have frontal temporal dementia with primary progressive aphasia. So with that type of dementia, where it’s a little bit different than other people with dementia. My cognitive function can still remain relatively high over the course of time, and this is where I get, well, you know, “You don't look like you have it.” But what is impacted, and where I feel it the most is my speech.

DAVID: Yes.

ROXANNE: The dictionary that I have used to be a hard, hardback cover, and now I'm into a student paperback, and this has probably had me shy away a little bit from some of the media stuff I did, as I'm not feeling as comfortable speaking as I used to be at one point in time.

DAVID: You mentioned that there's a hereditary aspect of this in your family. Has that come up in conversation with them?

ROXANNE: Yes, it has. I know my daughter who's a nurse, and probably you know because she's medically minded, has talked about, you know, "Should I get a genetic test or are things like that." But I have really discouraged my children from doing that at this time and place in their life. This last neurologist I told you about here in Alberta that I saw, he was Dr. Patry. He was really good explaining to me like no one else had done. You know if you do the genetic testing, you have to watch the implications in regards to life insurance and other things like that, and that they may need when they're having their children. And if something happens, mortgages are still to be done. So, I was really grateful for him taking the time and being sensitive to that, and some just don't want to know. It comes on my father's side, and the irony of it is that I was diagnosed with it before my father was. But I asked my father to go and get testing because it came on his line, and I said, you know, I "If I have it dad, more than likely, I got it from you." And so I would really encourage you to go and get the testing. So that to was a weird place to be in.

DAVID: Talk about a difficult conversation.

ROXANNE: Yes. And I saw how that changed over time because, when I first suggested it, it was no way with him and his wife. And then I started, now that's probably because I'm super hyper aware of what to look for now. And then he and his wife on their own thought maybe you know he should get testing, and sure enough it was discovered.

DAVID: On the other hand, that might be kind of encouraging if your father is still alive and functioning, and in a relationship with his wife and with you and others, I assume. And that would be kind of a positive message for you. Do you interpret it that way a bit, Roxanne?

ROXANNE: Yes, and I heard people say, “Oh, maybe it will skip a generation.” But my great grandfather, I have a copy actually of his death certificate, and it puts his cause of death as senility, because that's what they used to call it, back then. And then, my grandfather and all of his siblings, and there were eight in the family, every single one of them got some form of Alzheimer’s or dementia. But it's become a neat conversation now that he and I can talk about or say, “Oh, this is what my score was. This is what your score was. Oh, are you having trouble with this? Do you ever think it's just this?” So my little, fine support group has become my father and I.

DAVID: Now you mentioned that when you were in Regina that you were able to get together with a group of women that, you know, that were more or less your age that were experiencing cognitive difficulty from one condition or another. Do you have access to that kind of a network now? Or do you feel that it's less important to you now that you've kind of gone through the initial stages of knowing you have it.

ROXANNE: No. You know, I would like support. It's very empowering to talk to someone who's perhaps walking on the same path as you. But I did make friends with one of them. And when I moved, we've still managed to keep in touch via Skype, Facebook, those sorts of things. So, I kind of created my own little network. But if there were something locally, or that I could be a part of, that was suited to my needs with younger people, I would definitely be participating in it.

DAVID: Well, I want to thank you very much for this conversation. It's been really delightful. I think we've touched upon some really interesting ideas. I think, you know, the positive energy that always falls through this conversation is really, in itself, an important message for people to hear. OK, thanks.

ROXANNE: Thank you. Bye-bye.

DAVID: Thanks, Roxanne.

If you would like more information about our series and the research underlying it, please go to our website, DementiaDialogue.ca. There you will also find some of Roxanne's poems, as well as other useful resources to help you learn more about Living the Dementia Journey. You are also invited to join us on Facebook, at Dementia Dialogue. Feel free to make a comment or perhaps to share a bit of your experience with dementia. Thanks again to our sponsor for todays episode, the Centre for Education and Research on Aging and Health, at Lakehead University, Thunder Bay, Ontario. Please join us next week for Dementia Dialogue, as we continue our conversation on Changing and Adopting, as part of the Dementia Journey. My name is David Harvey.

Please visit https://www.dementiadialogue.ca/podcasts.html for more Dementia Dialogue podcasts!