



Transcript of Interview with Louise Milligan

David: Welcome to another Dementia Dialogue podcast where we're discussing changing and adopting when dementia enters a person's life, one of four themes we are 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 Center for Education and Research on Ageing & Health at Lakehead University Thunder Bay Ontario.

Our guest today is Louise Milligan whose husband Gord passed away a few months before our conversation last November. Gord was diagnosed with dementia seven years ago at the age of 64. Louise lives in London Ontario. As Gord's journey progressed, Louise sought out additional information and support from the local Alzheimer Society, other community services and health care providers. Marshalling these resources can be a challenge to a family.

Our conversation also touched upon assisted living and long term care but we will be sharing these portions in future episodes on the theme, the System Journey. As you listen, keep in mind the word 'permission' which came up early in Louise and Gord's conversation. It seems to emerge as a theme throughout Louise and Gord's journey and it enabled Louise to make adaptations for Gord, her daughters and herself seemingly without the guilt and misgivings that so often surrounds dementia.

Thank you very much for joining us today. As we mentioned in our conversation, the theme for this particular series of Dementia Dialogue is changing and adapting to the condition of dementia. So I'm wondering whether we might just start out by describing a little bit about yourself, about your husband's situation and also your family context.

Louise: Sure. So my husband and I met, it seems like a lifetime ago. We were both students, both fish biologists and that's where we met and our careers took off and it was great and we had two children, Emily and Annie. And then in December of 2010 that world turned upside down because that's when my husband was diagnosed with

dementia. He was 64 at the time. Our children were nine and 14 at the time. He was a university professor and people would say "if you exercise your brain daily and you have all that plasticity in your brain that you'd be much less likely to develop dementia". That didn't apply in his case. So life changed for sure, for sure.

He stopped working because he was deemed unfit to work. Interestingly enough when the doctor said that to him, it was just like this great relief for him because he was struggling a lot at work because he couldn't do it and he couldn't understand why he couldn't manage, He couldn't manage to go into his lecture hall and give a coherent lecture, or plug his laptop and things that he could do, have been doing for 30 odd years without any issues and he was frustrated and stressed because he couldn't do it. I saw the stress and I didn't understand why he was so stressed out about doing things that he had done seamlessly for so long.

It was almost like once the doctor said "you're off work until you're able to return to work and I don't think you'll be able to return to work" and his posture changed. It was like- he sat up straight and was like this huge burden off his shoulders. And he was so relieved to not go back to work. When it came time to clean his office out, didn't even want to go back and do it. So up until that I have to be honest, I was very frustrated with him and what I saw. He is just checking out because he became a bit more distant, a bit more apathetic but somewhat disengaged and I couldn't understand why. So it was causing a challenge in our relationship, that's for sure. And then once the diagnosis came down, I was like "OK that's what's going on". So from my perspective as well, it helped me understand what was happening.

David: Now what was the path to the diagnosis? How would you have ended up at the Aging Brain Clinic?

Louise: Well that was a very interesting journey. In 2008 we were on our way to Toronto Airport and we got into a car crash. My husband was driving. I banged my head. I don't recall anything at that point in time> He was worried. "Why did he make that judgment call to make that turn when he knew it wasn't safe". His mother had dementia so he was worried at the time that this was the beginning of something not right. So he made an appointment with his family doc and then went and had a CAT scan and told me that everything was fine. There was nothing to worry about. So that was like OK. So I checked that- put it in the closet because it's nothing to worry about. I, at the time, said,

“Oh he's stressed out”. Therefore when you get stressed, you get forgetful, not realizing that a cause of distress was the fact that he was forgetful.

He had a very compassionate and kind department chair at work who saw what was happening. She had walked this journey with her mother and she knew what was going on. She had several chats with him about his teaching because it showed in his teaching primarily and he would come home and say things like Moira, that was his Department's Chair's name, wants me to go see the doctor. She's worried about my driving. And I am going -he was watching he was working in Guelph, so he was driving and I was going “So what's going on here. I don't understand”. So finally he says, “Moira has made an appointment for me. I'd like you to come with me” and this was the workplace doctor at Guelph. So I said, “Sure I'm going”, and we went. And she had written up a letter explaining to the doctor things that she had seen at work that were causing concern. So Gordon read that and he said, “Oh yeah, well that's probably fair.” And I looked at this man who I thought, “Wow, okay”. The doctor administered that Mini-mental test know we have to spell a word backwards, etc. And when I saw that he struggled with that and couldn't draw that clock that showed 10 to 2, my heart just sank. So that's what led us up to the diagnosis right.

I had been in communication with his family doc expressing some concerns about odd behaviors.

Because of patient confidentiality of course, we never really communicated. So I really don't know what happened between him and her at those visits. It could have been that she said there's something going on and he forgot or chose not to tell me. I don't know.

So once we got that diagnosis from the workplace doctor, although he didn't really say dementia, he just is not fit to work. I went to the family doc and it was kind of surprising in many ways that she got the report and we met with her and she says “Oh well, here's a prescription. We'll start with this drug and then we'll see you in a month”. And I was like, “Whoa whoa whoa whoa whoa whoa. What are we giving the drugs for? What's the diagnosis here” and she kind of looked at me and said “Well, it's Alzheimer disease, of course”. And there was no peer supports there's no “this is a hard diagnosis to hear”, this is going to be challenging, here's some places you can go or do you have questions”. That just “here some pills. Come back to see me in a month”.

So anyway after that, Gord and I had a very good conversation. We stopped for coffee and he gave me a huge gift at that time. I didn't realize how much of a gift it was until after the fact. He said “this is going to be really, really hard for you and any family. You need to make the right decisions for you and your family, that your lives can move

forward.” And at the time, I didn't appreciate how powerful that was because he gave me permission which was wonderful for him to do so. I think probably because he saw what his mom went through and his awareness of what his path looks like, would look like, that he was able to give that gift.

David: That's really interesting because so often we hear of people that extract a promise from the other person to care for them always, care for them at home and be with them.

Louise: Don't put me in one of those homes.

David: And it's interesting that your husband,

Louise: I think that speaks to the kind of person he was. He was a very caring and generous man and he recognized particularly for our children who were young, only 9 and 14 at the time, that this was going to be really too hard for them to manage. Because he saw what his mother went through, although his mother was in Calgary at the time, and we were in Ontario. He still saw and experienced what she went through and didn't want his children having to go through that.

David: I'm interested. You had coffee after this visit with this doctor who just kind of dropped the bomb and said, “See you later”. How, did you talk about how you were going to approach sharing this diagnosis with your daughters?

Louise: Well, we did talk about that a bit. Gord was very reluctant to put that burden on them at that point in time. I said, “Well what are we going to tell them that why you're not going to work”? “Well you know, I'm retiring” which is basically what he did. I said, “All right” he says. I said but at some point it's going to become obvious. And by the time it comes obvious that may not be that he's able to have that conversation but he didn't want them constantly looking at him differently constantly be vigilant all the time because he thought it wasn't fair to them. And at the time I understood. But what made me sad in hindsight is that they never really then had the opportunity to talk to him

about the disease and how it was affecting him. Because once they became aware of them the disease was a one sided sit down and talk to him about what was going on. You know I think they had kind of figured it out. Yeah. Yeah. Yeah. And they were. And so it was a lost opportunity which was that it was his choice so I had to honor that.

David: Can you talk a little bit about how you yourself kind of adapted or coped or what did you do to adjust?

Louise: I guess the first thing I did was learn more about the disease and understand what it was. How it was going to progress? What I could do as a partner to help him and also what I needed to be able to do as a mother to keep my children healthy and growing and whatnot. So I turned to the Alzheimer Society which was a great resource. They had lots of information, lots of very wise people there [who] were able to help me a great deal.

Gordon, being a scientist, was very interested in the disease so he also learned a lot and connected himself actually with a clinical trial down at the Aging Brain Clinic at Parkwood Hospital and that was really quite good. It gave him purpose because he said, "OK you know this may not help me but it might help others. Maybe if our children should develop", because he was concerned that there might be a genetic predisposition in his family. He said, "I want to be able to do something for them". So it was really quite a good a good experience for both of us. It was it took time but it was okay, it was okay to give that time.

And one of the arrangements he made that when he died that he would donate his brain so they could do the neuropathology on it and understand more about the disease. And that's what happened at the end when he did die. So I supported him in that and I had to because the way the study, which had to have a care partner who could make observations about behaviors and things along those lines. It was very much both of us engaged; that worked really well. It opened a lot of doors and we met a lot of interesting people on the way and gave us lots of different opportunities for different kinds of supports. So it was really very good for us.

I modified my work life such that I tried to take on a little bit less responsibility, so that I had a bit more flexibility should something arise. I was able to take whatever time was necessary to manage it. I can't say I did that was a great success but I tried. And as the disease progressed, I worked within the system to get opportunity. So he did attend the

day program at McCormick Home which at first, he wasn't so keen on but then he quite enjoyed it. So that day program was a big help and so he went there three four days a week. Then it became clear that he needed a bit more support at home, so I was able to get in a personal support worker to spend the days with him when he wasn't at the day programme. Then when the bus came, it came at 9:30 in the morning so I was able to get someone in for like an hour and a half to allow me to get to work.

So I put those kinds of things in place to help take the burden off. Because one of the things I found with my children, is Gord would often get home from the day program three thirtyish-four o'clock. I often didn't get home from work until a little after five, so often there was about an hour or so where it was him and the girls. At the time I didn't appreciate it, until it was shared with me afterwards that that was a tough hour for them because they felt they had to constantly be watching dad that he wasn't going to do anything weird. Unfortunately he did say some things that were harsh and I tried to say, "It's not your dad, it's the disease". And still when you're young, it hurts when your dad says things that aren't really nice. So there were some, it wasn't all rosy for heavens no. And there were some challenges along that way and we tried our best to talk them through and help them understand what was going on. It became clear to me somewhere around the fall of 2012- late in the fall of 2012, that I just couldn't manage with Gord at home anymore. It was just too much, was too much stress on our family.

David: So it was a fairly rapid very rapid situation between diagnosis.

Louise: And two years later, it was quite clear he couldn't stay at home because things-like well what was the tipping point was, he set the microwave on fire. And that was like "OK. We're in danger here". And he didn't know what to do should there be a fire. He didn't know how to pick up the phone and call 911. So it was clear that "OK. This is not safe". So we're on the CCAC list for long term care. I had done that early on recognizing that yeah it can be a long time. So the sooner I get in, the better. Up until then we had done some respite care. So he had gone to stay at McCormick Home or other McGarrigle Place for a week or so at a time, to give us some reprieve. And so I took advantage of those opportunities.

So in January of 2013, I had made arrangements to move into assisted living because there wasn't a long term care spot available yet but I knew he couldn't stay with us anymore. So I found assisted living that felt they could manage. And at that point then he started going to day programme six days a week and then on that seventh day which

was typical Sunday, so we would spend the day together doing things. So it wasn't like he was abandoned or anything like that but it just took the intense pressure off of us to have to manage the day to day challenges of living with someone with dementia.

David: It's interesting you know his willingness to take advantage of that day program work. It seemed that he was fairly accepting of the idea of living in the assisted living...

Louise: I mean I made it look. I took all of the bedding stuff that he was familiar with me. It is familiar as possible. He didn't object at all.

David: It's almost like he was honoring that permission that he had given.

Louise: Yeah I said some ways, I think so. I don't know. I don't know if consciously he was aware but somewhere deep inside maybe there was that awareness piece.

And then and he stayed there until July of 2013 when there was a crisis and he had to move. Fortunately the spot we wanted was available and he would move into long term care. Again it precipitated quite quickly. Everything being ok, to things being a bit challenging, to things being impossible for him to manage.

David: Yes, yes. How did you get, you mentioned you know stress that it would seem to me that there would be a tremendous sense of or a loss of control...

Louise: Oh, total loss of control. Absolutely. I just didn't know which way it was up or down. I didn't know what the best thing to do was. Fortunately the physician who was caring for him in the clinical trial, Michael Borrie was wonderful and he was a great support to us throughout this. I called him my knight in shining armor because he came and rescued us from that Form 1 day and was able to negotiate and discuss with the assisted living home to take Gord back. So he was great, great support there. And at the time, I think it was relatively new or maybe it was just forming a cohesive unit, the Behavioral Support Unit. So we engaged with them to help understand how we can respond to behavior. So it was a bit of a training. Training for me, not so much training

for Gord because you can't really train.. No. No. Training for those people who are interacting with them to say: OK like if he grabs your hand tightly and you pull your hand back he just hangs on more tightly. So if you just let him hold it, and then start with your other hand, rubbing the back of his hand, it relaxes and releases and then whatever. Because otherwise, it could escalate up because otherwise it would escalate.. Let's just deescalate. So as it turned out, there was simple little things. So I had made basically a two by four board with things that he could play with. You know like nuts and screws and bolts and that kind of stuff and also when he was so that could be distracted to that and he would play with that for a little bit. So those kinds of things helped. But that took some time to get there.

David: It sounded that you really did take advantage of or seek out and find some people to provide support to you and some information to give you some strategies on how.

Louise: Because I knew, I mean this was foreign territory to me and I had no experience. And I knew I couldn't do it by myself. And I knew. So through the learning series at the Alzheimer Society, I learned a tremendous amount about the disease. And there's lots of things that are common with people. And there's lots of things that are different. Those commonalities are enough that you can learn strategies to cope.

David: I'm wondering how did your daughters feel then at this stage of the disease not that you can speak for them but your observations as a mother?

Louise: I did talk to them about, before Gord moved out of the house into assisted living. I talk to them about you know, this is what I'm thinking. What do you think? And they were like "Oh what a relief". They were relieved. They didn't want their dad to go but they understood that he needed to because it's just too much for him at home. They found that move to long term care really hard only because it was difficult to visit. Seeing other people might because you have this vision of folks in long term care, you know, sitting in wheelchairs and staring blankly out into space and that there were folks like that. And it's hard to see your dad in a situation. I mean I found it hard. I mean every time I would go there, I'd have to steel myself and go and visit because it was not easy to go in there.

David: Gord died in June...

Louise: He died, second of June 2017.

David: And how was that in terms of months preceding his death?

Louise: Well I knew, I mean, there were certain things that happened along that journey that you think OK and the end is getting closer. One of it is he lost his mobility totally. So he was totally wheelchair bound. That was one thing. And he had trouble feeding himself. So he went from needing to be fed regular food to the minced foods. He was having some challenges chewing, to having some challenges swallowing. So we went to like the mushy baby food kind of thing and then he just totally lost interest in eating. So when that happened, when he was struggling with the swallowing and you know pocketing the food, I saw enough with other residents to know that it wasn't long after that happened that the end would be near. So that started happening sometime probably late April, May and by early June he had died.

David: And how were, you know in your family situation with your daughters are at the end of life?

Louise: Well I told them point blank, "You know that your dad was dying and this is what's going on and did they want to be with him at the end?" And both of them decided they didn't want to, which is fine because they didn't want them with their dad that way. And I understand that.

So I would stay with him for as long as I could. I wasn't going to do 24/7 hour, 24/7 vigil. Lit was too hard.

David: If he had ten siblings.

Louise: Yes perhaps, if we could sort of take turns and we did have kids there. I mean they were older by then but still you know my youngest was only 15. So it's still young alright.

And so the night, that morning, he died early in the morning and the night before. We used to have a thing where we would on Friday nights, the end of the week. Kids would get a pizza and be watching the movie or something and we'd sit in the front room and he would grab his glass of scotch and I had a glass of wine him and we would just sit and chat about our week and catch up. So I thought OK you know I'm going to do that. So it took him some scotch, a glass of scotch and you know those little sponges that they have. We just dipped that sponge in the Scotch and put it in his mouth and he (sound of sucking) So he was enjoying that taste of scotch. That was really quite lovely. Yeah that was lovely. So I left that night around 10:00. The nurse, before her shift ended, "well you know he really couldn't breathe". You know like it's really hard to watch them breathe. Like it's hard work. And so she started giving him a bit of morphine to help ease that that are using and then by 3:00 in the morning he had died.

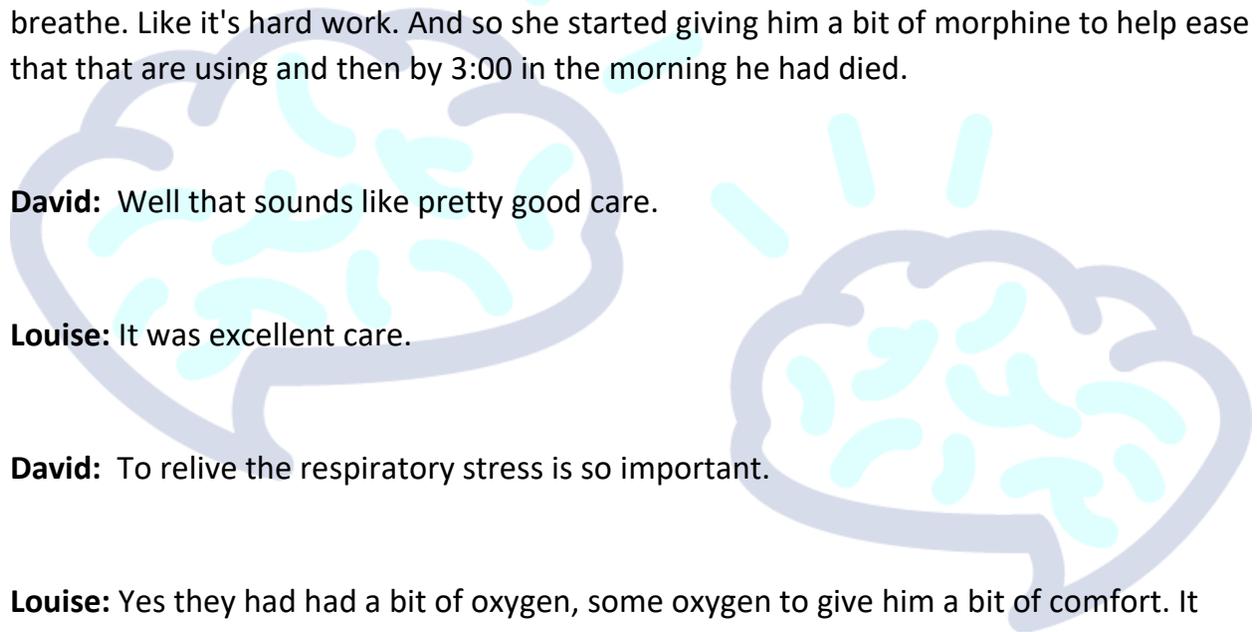
David: Well that sounds like pretty good care.

Louise: It was excellent care.

David: To relieve the respiratory stress is so important.

Louise: Yes they had had a bit of oxygen, some oxygen to give him a bit of comfort. It wasn't to revive. It was just to comfort to relieve that work of breathing.

David: I think we're towards the end of the interview. Louise, I'm wondering, one of the things that we're hoping to achieve through podcast series is to help people acquire a deeper understanding of what they might be faced with in their situation. I'm wondering if there's any particular lessons learned that you want to leave with our listeners.



Louise: I would say, if nothing else, be prepared because if you're not, it can be very scary. And there's lots of opportunities. You can go online and learn from materials that are online. Talk to other people who are in this situation. Learn from them and learn from professionals who live this day in and day out through their work - like folks at the Alzheimer Society or memory clinics or family doctors or whatever resources that you have and don't be afraid to reach help because it can be really isolating.

David: Thanks Louise.

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

