Transcript of Interview with Penny Stager

David: Welcome to our Dementia Dialogue podcast, where we are discussing changing and adapting 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 fully live in the face of such a challenge. Dementia Dialogue thanks to our sponsor and partner the Center for Education and Research on Aging & Health at Lakehead University Thunder Bay, Ontario.

Our guest today is Penny Stager. Through marriage to her husband Brian, Penny is part of a large family. Penny's mother-in-law experienced dementia in her 80s, and her brother-in-law, Al, was diagnosed while in his 60s. Because she is a nurse, Penny took a particular role in helping support the family as they cared for their mom. In turn, the family has stepped up to support Al and his wife, and Penny talks about her role there. Penny brings an additional but important perspective to our conversation about dementia. She highlights the important role which each of us can play in the lives of people touched by dementia.

David: And I'd like to welcome Penny Stager to our discussion today on Dementia Dialogue on the theme of changing and adapting as a person moves along the Dementia journey. Thanks very much for joining us this morning, Penny.

What I thought was interesting in our discussion prior to the interview today was the fact that you've had an experience with two people related to dementia, and I'm wondering whether you might just describe who those folks are and a little bit of your relationship to them.

Penny: My mother-in-law had Alzheimer's, and she passed away three years ago. And also her oldest son, my husband's brother, Al, has early onset dementia and he's now 69 and probably was showing signs probably ten years ago.

David: Yes, okay. Now how old was your mother then when it became apparent that she had developed dementia?

Penny: In her mid to late 80s I guess.

David:I see. Okay, so she was over eighty. Now could you describe a little bit of her living circumstances.

Penny: Yes. My in-laws had a farm and when they retired from the farm they moved to the cottages at Fairview, Mennonite in Cambridge, which has their separate little cottages, totally self-reliant. And their plan was to move from there into the apartments when the time came and into long term care. But my father had a stroke, and that was really when we first became aware that my mother-in-law had some problems. She was forgetful, and we didn't notice when he was at home. I think he probably jogged her memory about things, like Mom I thought you made the tea, and she'd say “oh yes” The kettle boiled, and she would go and get it. That kind of thing. But then when he got sick and went in the hospital, she seemed to be having a hard time with that.

She was forgetful and relying on the family quite a bit. She moved into the apartment because it looked like he wasn't going to be able to come home. She was having a hard time preparing her own meals and losing things, and then it progressed. She was kind of distended. She was putting on weight, and we weren't really sure what was going on with that. And the staff would check every morning to see if she'd had a bowel movement. She would always say yes, and then she ended up in the hospital. She had another ten days of delirium with restraints, and the family stayed with her round the clock. She ended up with a colostomy, which she had no idea what it was. She was always pulling it off and just couldn't understand what that was all about. She went from there into respite care as she got better, and then she went to a nursing home and another nursing home and didn't end up back at Fairview. And we wanted her to go to Sunnyside, which she did eventually, and it's a fantastic facility.

David: I'm wondering about the delirium and the restraints. That must have been a pretty emotional experience for the family to see their mother in that kind of a situation.

Penny: Yeah. She was pulling out her I.V. and her catheter, and, you know, seeing things on the wall. Yes, it was difficult. But we felt that it was necessary for somebody that she knew to stay with her.

David: Yes, okay. You're a nurse, so you would have understood and perhaps anticipated that delirium might be a consequence of the surgery and because she had also had it when she had her hip repaired. So you had gone through that experience already. I'm wondering if there is any history of this, say, you know that your mother-in-law's family you know there might have been her mother or father had dementia. Was there any discussion of that?

Penny: No, not that we know of. It was interesting, we attended a workshop or conference I guess. There was a doctor speaking at, I guess it was at Sunnyside, and I did ask him about the familial relationship between mother and son getting Alzheimer's. And he said that there was no data to say that it was hereditary, and he was rather abrupt about it. We were kind of surprised at the time. And then, since then, of course you know there has been more of a relationship.

David: Yes, that's right. There is there is a small but significant population of people where there's a genetic tracer from within a family. And then there is an understanding that if you have a parent with dementia, then you're likely at higher risk. But it's not inevitable in that in that situation. It's just a risk factor, which is the same for heart disease or lots of other conditions.

Could you speak a little bit about your brother-in-law's situation then and your observations of his experience?

Penny: Yes, he was diagnosed about six years ago. My sister-in-law said that she noticed changes probably ten years ago. He was between jobs when he was around 60 and decided to go back to school. And he was taking a fiberglass course at Fanshawe, and he couldn't remember any of the formula or the calculations that knew in his job as a tool maker. And I think that's when he became aware of the fact that there was something seriously wrong. My sister-in-law had noticed other subtle things like, he worked from home, and she would leave him a list of things to do, and things wouldn't get done. And she was concerned about him being home alone, and that's not really good for anybody to be isolated like that.

David: So then your sister-in-law had some observations and was concerned about his ability to perform tasks. And, what happened then from there?

Penny: Well they decided to move back to Kitchener. He was still driving until just a year ago. And when they were planning to move, Lynn was having a difficult time getting him to pack and decide what they were going to keep and what they weren't going to keep. And he kept going through the garage. Things would get moved around, but nothing seemed to become accomplished. So Brian and his other brother helped quite a bit and Lynn's other brother-in-law. The family's been very supportive all the way around, and, you know, trying to keep him active and busy and to feel useful. And that was the hardest part for him. He's very aware of the fact that he has Alzheimer's, and he was very angry initially. He seems more accepting of it now. When he was first diagnosed and even now he still calls himself a sufferer of Alzheimer's.

David: I see. He sees it as an affliction or a burden.

Penny: And of course he didn't want anybody to know initially. It was okay for a family to know, but he didn't want his friends [to know]. And they were quite active, and they still are quite active in their church. And it was about two or three years ago, I guess, he was interviewed for the KW record. And there was an article in the paper about him.

David: So that would have been an interesting process to become involved more in advocacy work or in some of the public activity to advance the understanding of Alzheimer's disease. How did you get involved in it?

Penny: When they moved to Waterloo, my sister-in-law was still working in London, and Al was asked to participate in this program. So they asked me if I would like to go along with them. And I found it very interesting, and because of what we were going through with his mother as well, it just seemed to be a good fit and volunteer [activity].

David: Yes. Now that was what the Murray Alzheimer's Research and Education program.

Penny: Yes. So there were about seven or eight couples in Waterloo. We were one of three hubs, and we helped to develop a new program for people newly diagnosed and their care partners.

David: And that's Taking Control of Our Lives.

Penny: Yes. So we found that very interesting.

David: Yes. Now, one of the comments that have been made by a couple of our people that we've interviewed speak to the issue of stigma and a lack of understanding, that a person with dementia might experience from other people in the community. Any thought on that?

Penny: I do. Al is very aware of that. And, he said, when he did start to feel more comfortable about letting people know, quite often if he and Lynn were together talking to someone, as soon as they found out he had dementia, they didn't direct their comments to him anymore. They just talked to her, and he found that very upsetting. Yes and I think that was part of the reason why he didn't want people to know, because he didn't want to treat him any differently. And they have lost some friends along the way. I think a lot of people feel uncomfortable when they really don't know what it is and they don't want to see their friend change. It's difficult.

David: Now, Al and Lynn and yourself are involved in a group in Kitchener Waterloo, I think.

Penny: Yes, Al has actually joined the YODA group, which is the young onset dementia program. It's a group of, I think they're all men at this point, but they meet once a week, and they go on little trips. You know they do various things of interest, like whether they go on a hike or to a different place. They get together once a week for that. He's also active, I didn't mention to you, he was also part of a research study with Dr. Borrie in London, and he felt really good about that. He researched dementia and Alzheimer's online quite a bit, and he he's always been an avid reader. And he was on this research drug for, I think it was two years. It was an infusion. He had to go once a month and was followed quite closely. He found out that he was actually on the drug. Lynn says that since he's come off of it, she has seen an increase in his symptoms. It seemed to keep him level for the time he was on it.

David: It's interesting that you mention that he's kind of, you know, sought out a deeper understanding. Getting information about Alzheimer's as a way of understanding.

Penny: And it has been perhaps more difficult for Al as well because he saw what happened to his mother and her progression. Now she was much older when she was diagnosed. But you know to see what happens as the disease progresses. It is difficult to know, to realize that that could be me someday. You know my brother and Albert started going to a kind of an exercise program for people with dementia and their care partners. And Al found that very distressing because there were people there who were much further along in their journey. And Al said that like that just made him feel bad. You know like "That's me in however many years".

David: Is that the Minds in Motion program?

Penny: Yes. That's what it was. Minds in Motion. Yes. And he really found that it wasn't helpful for him.

David: Yes, I could understand that situation where you might be looking at somebody, you know, who is perhaps 10 years down the road and find that to be a bit disturbing.

Penny: I mean he functions quite well you know. And to see everybody else in that advanced state was very distressing. We've also started working on, and it's kind of stalled a bit, but the Blue Umbrella project. Al has been involved with that. He goes out and speaks, with a social worker from the Alzheimer's Society, to various groups. We had really hoped to get it going in the Stanley Park area of Kitchener, but it's hard to get businesses involved especially at the ground level. You know, they're saying that you have to go to the corporate level to get permission for us to do that. But for businesspeople to recognize when somebody is having difficulty and what to do. Al loves Home Hardware, and he goes to Home Hardware quite frequently, and he might only buy a few nails or a board, but go back three or four times. I'm sure the people there, they know him now, but you know just to see someone wandering around the store and coming back and forth. A lot of the employees, I would think, would wonder about that.

David: Yes. So the idea of a blue umbrella program is then to train employees to be more...

Penny: Yes, to recognize people with, not necessarily just dementia, but any kind of difficulty. You can wear a Blue Umbrella pin, and then the employees would recognize that, and say OK this fellow may have trouble paying at the cash register. You know he may not remember his PIN on his credit card or, you know, they would learn how to help them with that kind of thing. And if a business gets the training, the idea is to put a Blue Umbrella logo in their window so that people with dementia and their care partners would say, "OK, you know, we can shop here and we won't feel uncomfortable." For example, when my mother-in-law was dying, the family got together and went out for lunch, and the waitress came to him first for his bill. And she was talking to him, and I wasn't really sure what the conversation was, but my sister-in-law and brother-in-law and his other brother and sister were right there and weren't even aware. But Al wasn't sure about the tip. So he gave a ten dollar tip for lunch, and I spoke to Lynn about that afterwards, and she said, "Oh, he does that because it's a it's a nice easy number." But if the waitress knew that, like if she had seen a pin, she could say, "Well you know three dollars would be great for a tip, thank you."

David: Yes. But it's interesting now he's developed a mechanism to solve that problem, that, you know, he knows it's important that he give a tip. He wants to be doing that, and it's an easy solution for him.

I'm wondering, the role that you now see yourself playing in Al's situation, I wonder if you could talk about that a little bit. How do we interact with a person with dementia? How do you kind of adjust your particular form of communication, maybe behavior, sense of acceptance. Can you maybe talk a little bit about how you do that?

Penny: Okay. I try, I've tried not to change how I how I react to him. You know we have a pretty good relationship. Like I say he's three years older than my husband, so we don't do a lot socially anymore. We did when we were younger. I like Al's sense of humor. He's a very well read man. And so we talk about the research that he's read about, that kind of thing. I pick him up, and we go to our meetings once a month.

David: So that's something that, it's kind of you two together.

Penny: Yes, just the two of us. And that's been good. Since we've moved this year, we're not as close, and I have to I have to remind myself, like if I'm going into KW for the day, that I should give him a call and go for coffee or something like that. And it's not just me, like you know there are other family members as well who are quite involved with their lives.

David: Yes. So it's so it's a supportive family.

Penny: And support for the caregiver is a very important element, too. And I think realizing that more and more all the time. But, you know, it's hard to deal with somebody all the time who doesn't have much energy or who doesn't want to participate in things. And you know how essential it is that they do get up and belong to an exercise group and be active and be involved, especially with your grandchildren, you know, because it's making memories.

David: A sense of apathy can be a negative exchange.

Penny:] Yes. And Lynn does find that that Al tries very hard to participate in conversations. And like when he is together with family or friends or whatever, he doesn't want people to think that he's different, and he tries very hard to carry on a conversation and be part of it and be normal. And then afterwards, he just kind of deflates and is angry at her about little things, and then he'll sleep the next day.

David: To muster all of that energy to participate must be a very tiring process. And I could see that it might require a day of recovery afterwards, as all of us that have to exert ourselves need some time to recover. On the other hand, it could be stressful for the other person involved in the close relationship.

Okay, I wonder Penny if you've got any thoughts, as we come to the end of our interview, of things that you've learned that you might want our listeners to have in mind as they might be interacting with a person with whom they have a relationship.

Penny: One of the big things is that if you are a friend or whatever, you know, just to remember that it's still the same person that you're dealing with, and treat them the way you always have. And as the disease progresses, I realize that some people just can't cope with it, and you're bound to lose friendships along the way. But that support is the biggest thing. And, just be there if you can. And to support the caregiver, too. And even if you're not comfortable being with them, you know, if you can call and just check in and let them know that you're still there, that you still care.

David: Thanks, Penny.

If you would like more information about our series and the research underlying it, please go to our website, dementiadialogue.ca.

Penny mentioned some community resources, including Taking Control of Our Lives, Minds in Motion, and Blue Umbrella. You can find more information about these on our website. You will also find other useful resources to help you learn more about living the dementia journey.

Please join us also 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 today's episode, The Centre for Education and Research on Aging & Health at Lakehead University, Thunder Bay, Ontario.

Please join us for our next episode on Dementia Dialogue, as we continue our conversation on changing and adapting, as part of the Dementia Journey. My name is David Harvey.

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