

Dementia Dialogue; The System Journey, Episode 2

The Healing Conversation

Transcript of interview with Ron Roberts

David - Welcome to the second episode in our series, The System Journey, where we are talking about dementia and the health care system. We appreciate the support of the Geriatric Health Research System Group at the University of Waterloo for this series. Today, we are talking with Ron Roberts. Ron was diagnosed with dementia a few years ago and to maintain his health, among other things, he has enrolled at King's College at Western University in London, Ontario, and plans to finish his B.A. in 2021. Ron talks of his own experience and also touches a bit on the experience of Indigenous people. Ron himself is Métis. While a student at King's, Ron has also begun to give presentations to social work students, health science students and also away from the university to various health care worker training sessions.

So thank you very much for agreeing to be interviewed on our podcast series, Dementia Dialogue. What we're doing in this series is to explore people's experience with the health care system in terms of their experience with dementia. What I'd like to do is to kind of divide our interview into two parts: one is for you to talk a little bit about yourself and about your own experience with health care and your diagnosis.

And then also then in the second part, talk about your agreeing to give presentations to students at the medical school at Western University and to talk a little bit about what the content of your message is to them and also then what your reflection is on your experience with those students. Does it make you feel hopeful? Do you find it a little bit discouraging? Maybe we could start off then with you talking a little bit about who you are, what your current situation is, and then a little bit of your experience with health care.

Ron – Well I was diagnosed about five years ago with Alzheimer's. After I'd finished the test with a doctor from the province, I can't remember her name, all she said was, "It was nice talking to you, Ron. Hope we meet again".

And then two days later, I got a call from my family doctor, "I got bad news for you. You've lost your driver's license and you have Alzheimer's".
And that was it.

David - Wow.

Ron - I was in a bit of a shock over that one. I really didn't know what the hell to say or do. So we just hung up and that was the end of it. Just a little bit of encouragement and a little bit of guidance at the time of the diagnosis would have helped a lot. I didn't know about the Alzheimer Society of Canada or any of the other organizations. And so I just came home and started to look up Alzheimer's on the Internet. And what I found was a whole bunch of suggestions with no empirical background to them. It was just, well, try to learn a language, do puzzles, go to meetings and I thought, "I'd really like to know if any of these works before I start on". But there was no empirical evidence, as I said.

So I started by taking French and I did that for about a year. After about a year, I found it wasn't really doing much for me. I got bored with it, to be perfectly honest. Now, intuitively, I thought of university. It's always been a bucket wish for me. I dropped out of school in grade nine because we were a large family growing up in Halifax. And that was in the '40s. And there was just no way my family or I could afford university at that time. It was pretty elitist back then.

So I went to work. And fortunately I ended up in broadcasting. I went and did an interview at 16 at CFQC Radio and Television in Saskatoon and I'll be darned, I got the job and I started the next day. But all my time in broadcasting and in political reporting, which I've done, I've always felt a little inadequate.

So I've had this bucket wish since I was 16, to be honest; go to university. So university, by testing me almost on a daily basis because you have to do the readings, then you've got to go into class and participate in various discussions and try to follow the professors theme of that particular class, and that every day it's tested that way. But on top of that, what I found was, in addition to the testing, the social aspects of being on campus were tremendous. In fact, I think right now, because I'm in isolation, I'm missing the campus like you wouldn't believe. I think the social aspects of it are just as important. So the combination of the two have really helped me.

David - So, Ron, you kind of came to this realization of the importance of challenging your brain and developing your brain, you kind of came to that realization of making that decision pretty well on your own based on your own research.

Ron - Yes.

David – And your own kind of willpower to enroll at the university and start taking courses.

Ron - The other thing I did too, David, was when I decided to enroll in university, I decided I wanted to get into good physical shape as well because at our age, we sit around too much. So I started a walking regime and I walk every day and I found the walking was also helpful. What was good was it was also helpful with the university because as I'm walking, I'm thinking about courses I'm taking and the class maybe I had yesterday. I start writing papers in my mind while I'm walking.

David - I think you mentioned that your GP got these notes from whoever the physician was who did the testing. He took your license, told you you had Alzheimer's disease and that was it.

Ron – That was it. There was no literature in the office, no suggestion that I call the Alzheimer Society or Alzheimer's of Canada. Now I've been trying to talk to people for the last three or four years, that we've got to get that information into the family doctor's offices. But so far, nobody has sort of made a move that way. I know there's a lot of funding goes into Alzheimer's. Surely to God they can find a way of getting that information into the medical offices. Even if he had that in front of me and said "Here, Ron, here's a brochure on where you can go and what you can do" that would have been tremendous. But in fact, I just got sort of waved off.

David - Now, have you continued to use this physician as your family doctor?

Ron - Yeah. He's a nice young guy. I don't like knocking him because he really is. And overall, he's been quite good. But when it comes to the mental side of it, I'm afraid, that training just hasn't been gotten.

People I've spoken to in various meetings that I've gone to, and I've gone to a lot of meetings, I've heard this same story over and over again. It's like I say, it's more common than the other way. There are doctors, I'm sure, that are out there doing it, but they're a small percentage of the medical practice.

David - Now, Ron, when you say you've gone to meetings since diagnosis and since starting university, have you made connections then with other organizations or other groups regarding Alzheimer's?

Ron – Yeah, with Western University and of course, with King's. About two months ago, I did a conference in Chatham. That was the health care workers of that region. Was one of these educational healthcare things. They were tremendous. I really enjoyed that group.

I've got a real hang up now with the researchers. What I find with the research in the medical profession is that they're not doing enough research, if any, on how to live with these various things that we have. And that's really important. It seems all they're looking for are bloody pills. And I'm not a big believer in pills. I think the brain is the best weapon we have. And if the brain starts to go down, then we've got to get it to work. So look at ways to live with these things. I think that's not just Alzheimer's. That's almost any kind of a mental disturbance, if you will. But I find that that's lacking. It's like, "Okay, you've got this and you've got that. Take these pills. Go home". That's the way I look at it. No, I'm not happy with that.

David - I hope that message is beginning to sink in with researchers. I think there's a little bit more openness to hearing the message of people with lived experience about, the need to be able to live a satisfactory life while also contributing perhaps to seeking a cure. But you have to live in the moment.

Ron - But I'd like to see more of these medical associations, like they have meetings all over the place. Invite some of us to those meetings. I'd be pleased to go talk to a whole bunch of doctors and lay it on the line, how we feel as people living with this disability.

You know, the real experts are the ones living with it. So we should be out there in the front lines and we should be included in a heck of a lot more of the educational stuff outside of our universities. But we need to put that social aspect in with the doctors.

David - Now, Ron, you have given talks at King's to the social work students, I think you mentioned, and also to medical students.

Ron - Yes, I have.

David - Could you describe a little bit about the setting in which you give the talk and then some of the key messages that you try to get across to these young people going into these professions?

Ron - Well, the message is that they're the generation we've been waiting for. We have slipped so badly in the whole social justice area.

In the last few years, I've been talking about senior's homes, these warehouses for seniors. They're just a bloody nuisance and really a crime that we treat the seniors that way. The P.S.W.s are overworked and underpaid and we've been saying that for a damn 10 years, as far as I know and I've been on that bandwagon for a number of years.

And I volunteer at the long term care center at Oneida and they can do it. And I've come to the conclusion and I know some people are going to be really annoyed with me, get

business the hell out of social care. They don't believe in it. They don't belong in health care at all.

David - In terms of your advice to students about working with people with dementia or with their care partners, could you kind of give me a little bit of a sense of what the message you give to them?

Ron - Yeah. It's everybody's problem.

It's not just those of us that are living with dementia today. It's a problem that every family is touched by. And there are going to be even more so as we grow older as a society. And they really have to work with these people. And I tell my students, well not my students but the students, that success can't be measured in money because there's no secret to it. The real secret is contentment.

If you reach a stage in your life where you're content with what you're doing, you're successful. If you're not content, you're not successful.

And how to talk to seniors. They just don't take the time they should take with us sometimes. If they took two or three minutes at the beginning of a session, for example, that's not asking a lot. And that's sometimes is all the senior really wants. When I get pushed (and I think dementia has something to do with it) when I get pushed by a doctor, like, "What's your name? What's happening to you? What are you doing this? What are you doing that?" I start getting nervous and I get anxious and I get upset. I don't like being pushed, well I never did, but even more so at this age. So I tell our young people, be patient with our seniors. And it doesn't mean you have to sit there for an hour. Just take that two or three minutes to make them feel at ease and that the doctor's there to help you. But when they come at you, like, "Hurry up and tell me what it is, because I've got all kinds of other patients", I don't give a damn about the other patients at that time. I'm worried about what I'm going in that doctor's office for, and I want him to speak to me like he would speak to one of his own children or one of his own parents or whatever. Not to push me through like a number. And I find that's happening across the board too often. And again, I hear that from other elders, too.

There's a couple of things; there is one point that different cultures have different taboos, if you will. But I was reading the study that was done on the Indigenous peoples. And one of our people, and I think it was an Oneida lady, when the doctor or the student or whoever was interviewing her, he or she took out a book and started writing notes, and she just about panicked. They couldn't understand why. But if they knew our history properly, they would know why. This poor old lady had gone through the school system, the residential schools. She went through the sixties scoop. So as soon as they start taking their names, they are afraid you're going to send them away to one of these bloody institutions.

So you've got to really take time to get to know who you're speaking to and some of their background because that can make a big difference. And how you feel mentally makes such a difference. You know, if you walk away feeling good, you're going to heal when you feel good. If you're not feeling good, you're not going to heal.

We've got to do things that make them feel like we want them and we respect them. I think those are the key.

David - I think that's a really important message, Ron. You know, the simplicity of the human interaction of somebody asking a question and listening to the answer.

I think that healing conversation is critical and something that gets lost in so much of medicine and in health care in the moment.

Thanks, Ron. Our conversation was super. Ron's core message about encouragement and listening are key ingredients in a positive health care experience.

Check out our resource page for more information and tools for positive interactions with the health care system.

You can also visit us on Facebook. You may wish to comment on this or other episodes and please do so.

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In our next episode, we will be talking with Michelle Janisse, a First Link coordinator in Chatham, Kent, in southwestern Ontario.

Thanks for listening. My name is David Harvey.