

Dementia Dialogue; Changing and Adapting Series, Episode 7

Transcript of interview Ron Posno

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 our sponsor and partner, the Centre for Education and Research on Ageing and Health at Lakehead University, Thunder Bay, Ontario.

Our guest today is Ron Posno, a retired educator who lives in London, Ontario. Ron is living with a diagnosis of mild cognitive impairment. He shares with us some of his experiences, coming to terms with his condition and continuing to live a full life. Most of all, I was struck by Ron's forward looking approach to life. For me, his key messages that emerged were know where you are and ask for help and plan ahead.

Thanks, Ron, for joining us this afternoon and for sharing a little bit of your story of developing some cognitive impairment and for your willingness to share your story with other people. I wonder if you might just talk a little bit about yourself, who you are, what you've done in your life so far, and then we'll kind of get going from there.

Ron - Well, my ideal life role I describe as a teacher. I love teaching. One of the things I really feel has to be addressed today is the people who have cognitive problems leading to dementia, whatever stages they are at, but so many people have never really accepted that. They deny it. They even deny it with their spouses, let alone the rest of their family or their friends. And it's a shame because it's that group around you who are going to carry you through that rest of your life. And if you can't talk about it, you can't share, then you have a problem.

But it gets right into the business of the initial acceptance of it. So we do need to talk about it. This is this is not a sexually transmitted disease. There's no shame about it. It's a problem we all have.

David - I wonder, Ron, if you might just describe to us when you first became aware that there was something going on in your body or in your life that wasn't right from your perspective?

Ron - Well, I've got to make a joke. I tend to make jokes out of those things. You mentioned body...One of the things I did in retirement, was took up golf,

David - and that's not an uncommon thing.

Ron - No no. And what I found out was that after the first few years, the game just got worse. So that's not an uncommon reaction either. But then you get to the point where you can't keep score either. But now I make fun of it. But the reality is that I don't know how much of the body stuff, but I do know and then I was aware because I did some reading and checking on the stuff of some of the problems with cognitive behaviour as it gets into memory functioning, on recall and all that stuff. So I was worried about it. I was concerned about it.

I went deliberately to my GP, explained my problems, and she gave me the classic test that Montreal test, MoCA test and I passed it very well. So anyway, a year later, I went back at her again because I said no and I insisted on a referral to a specialist and thank goodness I did, I got that, because with my push to get a proper appraisal, a thorough appraisal by somebody who knows something about, it gave me, let's say, an affirmation of where I'm at. And once I know where I am and I can start planning, working on where I got to go, because I live on the basis of the fact that I got a plan for tomorrow.

David - Now, how about the response of people that were around you when you would have come home from the clinic or wherever.

Ron - Well, I made a point. My wife was involved right from the beginning, so it was not the issue. But I was determined to share it with family and close friends. Friendships are very important to me. In taking it to my friends, once I had the assessment, I explained that I'm at the beginning stage here and of course, they're all shocked and horrified and all those kinds of things. Some people have had similar experiences with their family, so they bring them to me, but almost ninety-nine percent of them said I don't believe it.

David - So you're continuing to function at a level that your friends would not observe any particular difference.

Ron - No I don't stop. Now I know there are things I can't do and there are times I tell them I can't do that. So I can't join in that kind of activity. But for the most part, I do. And they recognize, too, that if I screw things up, I've got a valid excuse. So, "I forgot to come". Well, big deal.

David - Okay, so you have a diagnosis of mild cognitive impairment.

Ron - That's right.

David - I'm just trying to get a sense of where you think this is heading in a sense, because as I understand it, not everyone with a diagnosis of mild cognitive impairment necessarily progresses to dementia.

Ron - Seventy-five percent of us do, twenty-five percent don't.

David - Yes. So what's your kind of approach to those odds?

Ron - Well, my approach is I'm more likely in the seventy-five percent than twenty-five percent. If I'm in the twenty-five percent, great bonus. But I'm more likely the seventy-five percent.

David - Are you making a periodic, annual visits?

Ron - Oh, yeah. That's part of the program we have here in London is that we get that annual visit. Here in London, they offer an annual MRI of your head. Well, see there's where I already know they show me, I can see the parts of my brain that are beginning to be plaque incrustated, develop those cavities. So that's where I think I'm going to be in seventy five percent. So I have that advantage to it, if you consider that an advantage, that I just know more that's all.

And by knowing more, it's great.

David - The kind of the testing and the diagnostic process itself, did you find that, were you comfortable with that? Did you find that burdensome?

Ron – No no.

David - Probably too, I mean the sense that I have is that you entered into it, you know you asked the question of a specialist in a sense, “Can you tell me what's wrong with me?” So that you could figure out how you were going to deal with it.

Ron - Oh, absolutely.

David - It's a different kind of thing when people might ask that same question, but is really fearful of the consequences.

Ron - Or anger like my sister was, “The doctor thinks I'm crazy”. Yeah and there are people who are going to deny what the doctor said, just like that happens all the time with different diagnosis other than dementia.

But dementia is a very difficult thing for people to handle because they're absolutely terrified of it.

So I like to cook. I've always been the cook in our home. My wife and I, we have kids, so I cook; he cleans up, I cook. So I have enjoyed it, I have always enjoy cooking but now I'm having problems. Fundamental recipes are always in my head. They're not there anymore. I've got to refer to a written note recipe. And as you can realize, at our age, most recipes are for four, six or eight or twelve people. So when you're a cook, you make your adjustments to the recipe because you can't prepare twelve or at least I don't. So we got to make adjustments. Well, that simplistic kind of math is very difficult for me. Now I can't figure out a recipe for two out of a recipe for six. So, yeah, I have to accept some of these realities but you make adjustments for it.

David - How do you feel about that when you face that kind of realization of the limitation?

Ron - I suppose there's some frustration or disappointment but also there is I guess it's a reaffirmation of my status. And okay well, I got to go on from here, and I do go on. It's more, I take it on as a challenge, I guess, a personal challenge and I don't mind that. I don't mind trying to do things a different way. And if I can't do things that I've always done, I'll set that aside and go do something different. And that's my whole attitude.

David - Yeah. Try a different recipe.

Ron – Yeah or go get takeout.

David - Ron has become active in his local Alzheimer Society and spoke of some of his involvement with them.

Ron - You're not going to live with dementia without care providers. And the more you move along, the more your care provider is involved and whether it's a paid professional care provider or whether it's your spouse, whether it's a family friend, that's the reality that you're no longer alone in this. You can't do this alone. You have to have help.

So the Society recognized that. So you're brought in, you deal with it together. And the alumni, we meet once a month, just an informal thing for a couple hours or so. It's people who have taken the Learning the Ropes session and it provides them with an opportunity to meet with other people who have taken that Learning the Ropes session. And we just talk about personal issues or problems, how we're dealing with it. Sometimes people bring their worst fears forward and other times they just hear worst fears from other people and learn from that. But it's a very positive, constructive, mutually supportive kind of environment. I can't think of a better support means.

David - I wonder if you might think about adapting to a new kind of identity as maybe some of the strengths and that area might become more diminished should the condition progress. Have you given any thought to your changing identity or how you would see yourself in the future?

Ron - When I get to the point where I can't communicate with people, where I feel that I've got something to say and I can't say it right now, it's very hard for me to imagine that, but I know something like that will happen. I prefer to think that I will seek and provide another means by which I can show people, explain to people what I'm thinking or feeling. But yeah, there will be a time when I can't do that. And I accept that. I will accept that because I know what's going to come and I'm not going to duck it or run from it, it's part of it. When you see the clouds outside, you know the rain's going to fall so you carry the umbrella, don't you?

David - So it's part of that adaptability and trying to anticipate what something that might happen and what your strategy might be at that point in time.

Ron - And I'll give you an example and again, we're talking about communication, really. I have a great deal of difficulty now remembering names, even people that were very close to me but I still recognize them from all the recognition factors. But in communicating with them, like there are little things that you do, like I tell them my name and hopefully they'll give me their name. And if they don't, then and I say, "Well, you know, I think I remember you best..." and I'll try to share that. Well, that gets them talking and then it gives me a little bit of a clue. And so those kinds of things I do now. But I've stopped worrying about the fact I don't recognize names. I've stopped worrying about the fact that I can't remember words. And because I've told the people that I'm with usually that I've got a problem, so when I stumble in a sense because I can't remember the damn word, I'll ask or I'll just simply say, well, I can't remember that.

David - I'm wondering, Ron, if you've got any thoughts around lessons learnt or any kind of critical teaching points that you would like to kind of leave with people that might be listening to this conversation before we go.

Ron - Well there are a number of things, because it could we could really extend this if we got going on it, but once I knew that I have dementia or MCI, I started going to the computer. Google and company are just tremendous and getting information. So the doctor did the assessment referred me to the London Alzheimer's Group.

To go back to my basic theme for everybody that's in this dementia mode, whatever stage you're at, it's important to want to accept the fact that you've got it.
Number two: accept that there are a lot of people willing and anxious to help you out.
And number three: start working out your plan. Work out a plan. You're at the mild stage. You still got lots of ability to do things so do it now. Don't put it off.

And when I say do it now, find out what are the different stages of development of dementia. And how do you handle it? What are you going to do with it? It still blows my mind to think that somebody gets into even the moderate stage of dementia and they haven't got a will worked out, haven't got powers of attorney for this or that. Well, come on. This is well into the Twenty-first century. We're past that. There are people fifty years ago that didn't do that, but not today. But unfortunately, they do. They don't have wills ready. They don't get involved.

So financial planning and wills are strong part of it. Well get it done and get it worked out. And there are lots of resources w with it. And yeah, you're going to lose your driver's license. For me, that's going to be a fundamental turn of my life. Well I'm psychologically ready for when it's going to happen and I keep checking the different things that they've got on these websites for signs of when they're going to need it. I'll likely even take a test long before the doctor even thinks about it or like I know she thought about it, but before she threatens to pull my license, I'll likely turn it in because I realize I've got problems that I can't otherwise deal with.

So I look at it in terms of just how I've always functioned. I have enjoyed a life of being able to work with people, whether it's in a classroom or outside the classroom or where ever it is, I just enjoy being and working with people. In this case, it's much more personal; I'm directly and personally involved. So what does it mean to me? It gives me a personal sense of accomplishment and fulfilment. It gives me a reason to live.

David – Okay, well thanks very much, Ron.

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

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 Ageing and Health, at Lakehead University, Thunder Bay, Ontario.

I would also like to thank Bruce Ray, who hosted us at the Alzheimer Society of London and Middlesex in Ontario and who recorded our conversation.

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.