

Dementia Dialogue – Dementia Friendly Communities

Transcript of Interview with Phyllis Fehr, Debbie Keay and Roger Marple

David - Welcome to Dementia Dialogue. Today, we are achieving a couple of firsts. This is the first episode in a series that we will be producing over the next while about dementia friendly communities, a growing movement in Canada and around the world. We thought it is especially important to begin this series by talking with people with dementia about why the dementia friendly community movement is important and how they are contributing as individuals.

As well, this is the first time that an episode of Dementia Dialogue is hosted exclusively by a person with dementia. Phyllis Fehr, a member of our editorial board, interviews Debbie Keay, who is involved in a Dementia Friendly project in Hamilton Haldimand and Roger Marple, a dementia advocate who is involved in a Calgary based project.

Phyllis - Good morning. I want to welcome you to Dementia Friendly Dialogues, and today we're talking about Dementia Friendly Community's work. And I have two of my close associates here with me today. We have Roger Marple from Medicine Hat, Alberta, and Debbie Keay from Hamilton, Ontario. And they're both helping on Dementia Friendly projects across Canada. So I think we want to have a good discussion with them. So can you tell us a little bit about yourself and the Dementia Friendly project you're involved in? And, Roger, I'm going to go ladies first.

Roger – Yes, by all means.

Debbie - Hi, my name is Debbie. Thank you, Phyllis, for the introduction.

I became involved with the Alzheimer Society and I became involved because I had a 40 year history of working and caring for seven family members. And then unbeknownst to me two years ago, I myself was diagnosed with early onset Alzheimer's. And I thought that I pretty much had a handle here on taking care of people with Alzheimer's except for myself and fell into crisis. And I looked at medically assisted death quite seriously. And at the urging of many medical professionals that I was seeing it was suggested I contact the Alzheimer Society.

When I did, they engaged me in a survey and I was really interested in what you were trying to get across from this project. So I asked if there was any kind of volunteer opportunity, I was thinking maybe telephone opportunities, but they asked me to be part of a working group.

So I'm part of the group for Empowering Dementia Friendly Communities. And I am not just a token visitor. I am totally engaged. I am respected as anyone else on the team. I am able to voice my thoughts, my feelings on what it's like to live with dementia because I am early onset so I have my faculties about me.

So that's how I became involved with the project and how I'm still evolving, I'm at the infancy stage and learning a lot more. But the disability that I have and the fear that I have has done a complete 180 (degree turn) and I'm no longer seeking medically assisted death. I am actually looking forward to having a very abundant life since joining the Alzheimer Society.

Roger - My name is Roger Marple been living with I call it Alzheimer's with vascular component. So I would say that it's a mixed dementia. But I was diagnosed five years ago and I'm still quite functional regardless of challenges. So I'm living a full and meaningful life.

The project I'm involved with, it's called Dementia Lives Here. And what caught my eye and why I was excited to support it, I thought they were thinking outside of the box a bit and they got funding for this Dementia Lives Here project. And their whole way of approaching it is I did six short videos on how I see my life in our community, right? And they recorded these videos and they made a website www.DementiaLivesHere.ca And it's got a lot of really great information.

But what they want to do, what they're trying to achieve is reaching out to two communities, in particular in Calgary, and just paint a picture on how the community can interact with people and the idea is take a look at the videos. This is how the guy sees his journey within the community and then they go on to meaningful discussions, right? With the community organization they're working with. So I thought that was out of the box thinking. I liked where they were going and that's why I got involved with them.

Phyllis - Can you tell the listeners what made you want to get involved?

Debbie - What made me decide to be part of the project was that they were looking at the issues that people with dementia were facing in the community. What they had done was contacted about three hundred people through a survey and interviews with people who were living with dementia and their caregivers. And what they wanted to do was to educate the community and educate me. The education that I have received is phenomenal regarding getting rid of the stigma.

I mean, I'm not going to die tomorrow and I'm fully capable of doing everything that I was pretty much doing before because my thought process and my memory's gone. So I saw them looking proactively at helping individuals with the Alzheimer's or the dementia and then helping individuals who were the primary care givers and then taking all that information out into the community and saying, "Look, this is what needs to happen. We need to change how people think about dementia. We need to have services provided for people with dementia who take a little bit more time to do things". And that involves educating other social groups and agencies, physicians, you name it, just educating the population.

And then what really got to me is that they did it not from their perspective, but from a person who's living with the dementia and taking that person and having that person take the lead in where the growth and the vision and the strategies should be.

And so that's what really prompted me, is this total group of people who are caregivers beyond and maybe not personally had experience with dementia, but the people who really care about the community and making it a lot easier for us and the caregivers to just live a quality of life that is led by them.

So that's why I joined the group

Phyllis - Wonderful, Debbie. Roger?

Roger - Why I joined this project, you mean?

Phyllis - Yeah. Why did you want to get involved in it?

Roger – I'll tell you, I was going to say, "Yeah. What Debbie said. I'm going to build on that because they were all good points.

Okay, here's my philosophy. With dementia in the big picture, stigma is the number one issue with dementia worldwide. It's not so much living with the condition, it's more the stigma related issues. So I have a hatred for stigma and the effects that it has on people. Real time repercussions. And I've had times where it brought me to tears and it all goes back to stigma, right? So I have a particular hate.

So I, like Debbie, want to change the culture. So here's the thing, we have a culture of silence, especially in Canada. There's only a handful of people speaking openly with their condition, comparatively speaking, to how many people are living with the diagnosis or loved ones who live with this condition as much as we do, right? So very few people speak openly.

So here's what happens. I see reoccurring issues decade after decade, people saying stigma drives people underground. Well, by God, that's true. But why aren't we changing the culture to change that? I think we spend way too much time talking about how stigma affects us and not near enough time on how to make stigma go away in our discussions.

So here's my philosophy. If we're to expect better funding for research, dementia research in Canada or if we're to expect a hot point issue is in care facilities. That's a hot point issue right now. Have you ever noticed that things that we advocate for, we've been advocating for 40 years and little or no change? Well, the reason this is happening is because we're not speaking openly in mass. We don't see the benefits of speaking openly. And in that website, I pepper it with why you should speak openly and there's an advantage to speaking openly, here's the benefits.

But if we're to expect meaningful change in a very short period of time rather than decades, it can only be done by the voice of the many. And the reason I did those videos is I want other people living with dementia to feel comfortable speaking about their journey without reservation and comfortably. I want to change the culture that we all speak comfortably and then things move ahead in an expedited way. Change happens.

Phyllis - I agree with you there, Roger. That's so important. So what changes do you hope your Dementia Friendly Community project will achieve?

Roger - So I'm seeing the changes now. Like right now. I had the Calgary Alzheimer Society share with me that they're getting people with dementia reaching out to them, that they had no idea these people live in the community and they had a diagnosis of dementia and all of a sudden they're calling them up, right?

That's the end goal, is to have people comfortable and reach out and get the support you need. And the other thing is, the reason I support Dementia Friendly Community efforts is, if you walk to a building and you see these automatic doors that automatically open and you see ramp's to help people with mobility issues get into a building that's already incorporated into our society for people with mobility issues.

So our wheelchair access, our automatic doors, what we need in society is understanding. And the reason I support Dementia Friendly Community projects is because they're fostering that understanding.

Phyllis - Thanks, Roger. That was great. Debbie?

Debbie - I agree with Roger.

What I'm seeing is, in the small community that I've become a part of, is a new awareness of what's happening. Like Roger, I don't commit to anything unless I am spreading my spirit to do something about it.

My big thing is that I would like to have seen or am seeing is less fear. I don't want people to have to go through what I went through when I was first diagnosed. And I can see that the Dementia Friendly Community project that I'm part of is helping to look at those feelings and thoughts that people with dementia have that prevent them from becoming involved.

Dementia is a very scary word. You're told that it's life threatening, nobody can give you answers of when or where. But through the education, what we're learning is for me is dissipation of the fear. My fear is almost totally alleviated. I'm still intimidated by certain things and certain people because that's part of my makeup I think. I've always been a fight person. I've never been flight person. This is the first time I've been a flight person. And I was running away from things and I was scared. All I saw was what was in the media. All I saw was what my aunts and uncles and my mom went through and it was horrible.

So I'd like to see and I am seeing the participation of partners within the community that are coming on board and asking for support and asking us to do speaking engagements. And that's flowering as far as I'm concerned.

And then what I'd like to see further is the community opening up their capacity to look outside the box of who I am, even my own family. I just started sharing with my family about a year ago and not everybody in my family knows and friends don't know that I have early onset Alzheimer's. And so it is, like Roger said, it's just speaking forward and engaging other people. And so that's what I'm trying to do right now.

Phyllis - Do you have any advice for people with lived experience who might want to get involved with Dementia Friendly Communities? Roger?

Roger - Well, that's a no brainer. Here's the thing, I don't care if you're an advocate or not, I really don't. What I try to encourage people, especially living with dementia, loved ones who support us, my big recommendation is you don't have to be an advocate. You really don't. There's a lot of people that don't have that kind of personality, the personalities that we have, that we enjoy advocating. It's a big part of living, a meaningful life for us. So we enjoy it. But not everybody's wired that way.

So the advice I give is if there is a program in your community and you think it might work for you, what I encourage you to do is reach out to that program, that initiative, whatever the heck they're trying to get out there to make life easier for people with dementia and latch on to it, take advantage, cherry pick what works for you, right?

And the big advice that I give is if you do want to get into advocacy, I'm telling you, there is a crap ton of people that want to hear what you have to say. I understand that. I encourage, going back to my previous comment where to make meaningful change in society and change perceptions and all of the things we want, it's going to require a lot of voices.

And my goal is to have my voice drowned out, that's my goal. I want to have so many people speaking, I can't get a word in edgewise. That's what I want to see in society.

So there's three things for people, I'm talking to you people living with dementia. There's three things to remember:

Get out, live life, whatever way it may look for you. If you like golf then go play golf. If you like traveling, go travel. If you like hanging with family, hang with family. Whatever it is that floats your boat. I don't care if you're advocate or not, but live your life because everyone lives in the sea of despair and Debbie's story here, contemplating suicide, that's a common story. So we're taught to look at dementia from an end-of-days point of view. And we tend to look at our lives from an end-of-day point of view.

But what we're having here, this conversation right here right now is representing the eighty percent of people that live in our community that aren't sitting in care homes, unable to communicate. That's the reality with dementia. Eighty percent of the people living with it, living in our communities right here, right now, it's that person who's right behind you in a grocery store line. You don't know they have dementia. So I always encourage it from a community point of view, you don't have to know a lot about dementia. And I mention this in the videos I did. And hopefully you'll share the website. But my perception is that people are decent human beings. But the reality is most people in the community aren't going to reach out to an Alzheimer's website to learn more. That's the reality unless you've been touched by it.

So what I try to foster is you don't have to know a lot about dementia because people naturally are kind by nature and they figure out the most amazing solutions and they don't know a damn thing about dementia.

Here's my point and I'll shut up. The problem with perceptions that we have in society, I'm starting to wonder if it's not us who has the problem. My experience in the community, people are cool with dementia and they just naturally want to help and learn more. And that's how I see dementia in our community. And I find the communities really cool. I'm starting to think the problem is with us and reaching out and being comfortable speaking about dementia and understanding the benefits of that.

Phyllis - Yeah, and Roger, I really think you've hit the nail on the head there about people in communities wanting to help. But I think part of it is some of us don't identify as having a problem and then people don't know how to help us. Debbie, can you answer our question now?

Debbie - Yeah. What I would say to individuals who have a dementia is and was recently diagnosed is to not focus on what you've seen in the media and focus on all of the other things that you might have known or heard about, because there are so many different stages of dementia and it's so important to understand where you are. And I could be at this stage for the next 15 years, we don't know. And I'm quite comfortable and at peace with what's happening with me right now.

So I would say try not to be pulled into the overall view that most of society has about people who have dementia.

And the other thing I would say is, like Roger, don't be afraid to reach out. I was in crisis because I knew something was wrong for many years, the denial and trying to compensate and overlook and ignore. If you're not feeling well, care enough about yourself to get some help, it could be your family physician. It could be a support help line. It could be call to your local Alzheimer Society. They have incredible information.

And as Roger said, you don't have to be an advocate, but you do need to learn how to adapt to certain situations in your life as you grow with this dementia.

So I'm not dying with dementia right now. I'm living with dementia. I am not demented. I am a person who has a disability like anybody else who has a disability and has to learn to adapt. And so I would just say reach out to those that care about you, that might have some information that could provide you with a better understanding of what's going on with you.

And I think everybody is going to experience feelings, but I think we can lessen the intensity of those feelings and those crisis thoughts when you have a little bit more knowledge behind what's happening to you.

So that's that would be my suggestion and offering. Just to seek the help. And that says to me that you care enough about yourself and by caring about yourself you're going to ease up that will allow for other people to come alongside you, because they won't be afraid as you are not afraid.

Phyllis - Thank you, Debbie. That was amazing.

Talking to you two is so enlightening. I live with dementia, too, so I've been there, I've gone through it. I'm at a totally different stage than both of you are. But I'm still living life to its fullest. I'm still moving ahead. And I think that's what we really want people to know is Dementia Friendly Communities is not about locking people away. It's about learning and expanding and embracing your life as it is. Learning what you're still able to do, you may have to do it differently, but you can still do it.

So I want to thank you both for being such great guests today. And I like to leave always with some food for thought. And, you know, COVID's going around and nobody's getting together. And I will tell you, this is a bit of personal story that just after Christmas, you know I didn't get to see the kids or the grandkids or anything. And I was a little down and I was a little blah. And I'm sitting here and I'm thinking and I'm thinking. And in my thinking, I realized that people, every person in this world needs love. L-O-V-E.

When I was thinking about it, I realized what people living with dementia really do need, and right now I've written it down. We're starting to use it here in Hamilton, but it's in the process of going out to be copyrighted. People living with dementia need love: L-U-V-E. They need listening, understanding, validating and empowering because you get a diagnosis and all of that is taken away from you immediately. So if you think of that love, L-U-V-E.

But thank you so much for being here today and we may connect back with you in a while, because we're doing multiple episodes on Dementia Friendly Communities, so just keep your ears open, because our next episode is we are going to be talking with the leaders of some of the Dementia Friendly Communities and how they're doing it and in their communities. Thank you.

David - Thanks very much, Roger, Debbie and most importantly, thanks to Phyllis for organizing and conducting this interview.

Our notes for this episode are on our website at www.DementiaDialogue.ca
Here you can find more information about Phyllis and Debbie's project, as well as a link to Roger Marple's videos, along with several links to other Dementia Friendly Community projects across Canada.

Feel free to comment on this or other episodes on Facebook, Twitter or via our email dementia.dialogue@lakeheadu.ca
Your suggestions and feedback are always welcome.

Thanks to our partner at the Center for Education and Research on Aging and Health at Lakehead University and to the Public Health Agency of Canada who provided funding for this episode.

Thank you, our listeners. My name is David Harvey.