

Dementia Dialogue Grassroots Changemakers

Transcript of Interview with Jim Berry and Bill Heibein

David - Welcome to Dementia Dialogue. Our episode today takes us to Northwestern Ontario to talk with Jim Berry and Bill Heibein by members of the Northwest Dementia Working Group. I first met Bill about ten years ago when we worked together through the Ontario Dementia Advisory Group.

Jim and Bill's group is a partner in the Building Capacity Project funded by the Dementia Community Initiative of the Public Health Agency of Canada. Their co-partner is a senior's agency network in West Vancouver. Researchers from UBC and Lakehead University are involved.

I'd like to welcome Jim Berry and Bill Heibein to our interview, where we're going to be talking about the Northwest Dementia Working Group that Bill and Jim are involved with.

And before we get talking about the group, Jim, I'm wondering whether you might just introduce yourself to our listeners and tell them, you know who you are. Are you married, Jim?

Jim - Yes, we have two children that are grown up, we have six grandchildren, two great grandchildren, some of them live out in the country and some of them live in Thunder Bay.

David - Oh, excellent. So they're nearby either way. And how about yourself, Bill? You're married and you have got some other occupations.

Bill - Well, since I met you last, actually David, I'm now a widower.

David - Oh, I'm sorry to hear that.

Bill - No problem. No problem. I continue to live by myself about forty-five kilometers outside of Thunder Bay. I continue to own and operate a one-hundred and fifty acre farm under the name of Amethyst Farms under which we have bred, trained and show and registered quarter horses for many years.

I am involved with a number of research projects, Lakehead University, a number of research projects in the University of Waterloo. And I also sit on the advisory committee for the Alzheimer Society of Canada.

I have a daughter and her family who live in Saskatoon, Saskatchewan, and my son and his family live in Arlington, Virginia.

David - The reason that we're talking today is to talk a little bit about the Northwest Dementia Working Group and also its connection to the Building Capacity Project that you're partnering with some folks from Vancouver.

So I'm wondering if you might talk and you guys can decide who wants to go first. But if you could describe a little bit about the Northwest Dementia Working Group in terms of who are its members, when did it start and what are some of the activities that you've been involved with? So maybe we could start first with the simple question of when did it start? How long has the working group been in existence? Do you want to take that Bill?

Bill - The Northwest Dementia Working Group actually started in 2014, and it's more or less a spinoff from other projects, which Dr. Elaine Wiersma at Lakehead University had started a group of us working with her on. And this seemed to be the next logical step, because at the end of the first session that she had done, we all wanted to continue on to do something.

And the main thing about the Northwest Dementia Working Group, it is basically it consists of people who have been diagnosed with a form of dementia. We have direct input through this organization into a lot of what we hope to see happen that will affect us in the future.

David - Now, Jim, if I can ask you, of the twelve or the fifteen people that are involved in the working group, some of you are people with a diagnosis of dementia and some of the members are care partners. And do you meet on a (apart from Covid, which has caused a lot of changes) would you be meeting on a monthly basis, more or less?

Jim - Yeah, pretty much, David, up until Covid, we actually met in person at university.

David – Yeah okay, and now you've been using Zoom to have some meetings.

Jim - Yeah. And we'll probably be using Zoom now until we get rid of the pandemic.

David - Yes. Yes. Okay, now what kind of projects have you been involved with? Jim, I think you were instrumental in putting forward the idea of having a conference.

Jim - Yeah, that was quite a while back that I thought it would be best to get people from outside of Thunder Bay and bring them in and have conferences with them.

We had people coming in and talking about places and others had opportunity to talk and things like that and discuss how you were progressing and how we were integrating further out into the interior of Northwestern Ontario and trying to get them more get them more involved with the group.

David - Okay, I think if I recall from my reading, the conference was called Living Well with Dementia.

Jim – Yes, that's right.

David – So that was the basic idea was to bring people together and get them to describe how they are living with dementia and to encourage others to live maybe a little bit more actively and fully.

Jim - Yes.

David - And I think there were like over one-hundred people attended, as I recall. So you must have been, as one of the organizers, Jim, you must have been pretty satisfied with the audience.

Jim - Yes, it went well. Yeah really went well.

David - We're going to post some of the information about the working group on our website. So we'll be certain to give people some more information about the conference because perhaps some people might want to organize a similar kind of thing in their community and maybe they could get in touch with you to find out more information about how you did it.

Bill, could you describe a little bit of some of the other activities that the working group has been involved with?

Bill - I think, David, the one that stands out most in my mind and I think most in the minds of the people associated with it, would be the establishment and assistance in running Dementia Café.

Now dementia café basically, it started out it was going to be once a month, then it went to twice a month. And at one point we got up three times a month. Now it's Sunday afternoons. And it is at the Urban Abbey, which is a church in downtown Port Arthur, Thunder Bay.

It's also been run in conjunction with the university and the Urban Abbey Church, but it has been very successful. We've had busloads of people coming from the seniors homes. It's basically the concept behind it is, number one, a place for people to come out, feel safe, feel secure, sit and have a coffee and talk with people in the same position they're in without any threat whatsoever.

Plus, in addition to the talk sessions, we have people come in and do a little guest speaker portion at times and every so often, maybe once a month, depending, it would be live music, which is just a case of sit back, enjoy your coffee and listen for two hours.

I think we had at least two full years before Covid really whacked us on this one.

David - Okay I'm going to talk a little bit about this Building Capacity Project that you're involved with.

As I understand it, one of the ideas of Building Capacity is to work with organizations like the Art Gallery or other kind of community groups to help them become more capable of involving people with dementia and creating an atmosphere where people with dementia feel welcome in a setting compared to otherwise, where people can be made uncomfortable or maybe embarrassed, for example.

So the Art Gallery might be an example of an organization that's already keen to be welcoming of people with dementia. And the Dementia Cafe might be a model of how an organization could become more welcoming. Is that kind of part of the thinking of your working group at this point in terms of the Building capacity Project?

Bill - Yeah, I think you're right. I think one of the key things, though, too, about Dementia Cafe or getting together is the location is so important.

We tried the Dementia Cafe about a year or so before the successful one. It was held at a library and it, in all honesty, bombed. It was just the wrong place.

But the Building Capacity we're involved with groups in B.C. (Vancouver) with this project. And one, again, of the key factors here is that we're trying to build it from the bottom up. Built from people who are living with dementia, expressing what they feel they need.

The Vancouver crew have come in from the other end of it. They've come in from the view of experts saying what they think individuals should have. And it's been an interesting combination to put these two together.

David - Yeah, yeah, it would be.

Well, I hope people have got listening to each other. Everybody's got something to learn. So by listening to the people in Vancouver, you might learn about some of the things that might be on the minds of people in decision-making capacities in Thunder Bay. And you can tailor your conversation with them.

I want to ask each of you guys why you think it's important to be involved in an organization like the Northwest Dementia Working Group? Why do you think it's important both to yourself and maybe to the broader community? What do you get out of it, Jim?

Jim - Well, what I get out of it, I have friends, none of them that I associate frequently, they don't have Alzheimer's. But anyway, we collectively come together as a group that have Alzheimer's and dementia and talk about what we should be doing and how can we develop our involvement in the community and things of that nature.

So I've been involved in a number of activities and we've been in the newspaper, (Chronical paper) and those kind of things that we've been trying to associate with people in the outer area of Thunder Bay.

David - So being together with other people that have got a dementia is a positive thing and then doing something for the community?

Jim - And we went out to Dryden. It was a two day conference there.

David - How about yourself, Bill? You've been a long time member now what do you derive from it as a person and also then what as a community member?

Bill - Well, as a person and having earned a good living in Thunder Bay, I've always been overly active and giving back to the community. I spent years on the board of directors and the Thunder Bay Symphony, years on the board of directors of Magnus. I was a Northwest representative for the Old Fort William here.

So I've always been active in the community. Eighteen years as a Rotarian. But the big factor with this group is I think the more those of us who have received a diagnosis can be seen still active and out in public, the more it tends to fight the stigma that goes along with the diagnosis of this disease.

I know a lot of people, people that I do know that have been recently diagnosed, the fact that they know that I'm continuing to be involved, the same as Jim's continuing to be involved, we're trying to get across to a lot of these people that the diagnosis of dementia or early onset Alzheimer's, whatever, is not necessarily a death sentence at that moment. And you simply do not stop living.

Jim - We've gone to Lakehead College and also to the Lakehead University to speak with the students at the college and also at the university.

David – Okay. What if I said, “Gee, you know, I'm interested in maybe joining your Northwest Dementia Working Group and becoming more active in supporting your efforts”. What advice would you give to me in that case, then?

Bill - Actually, I'm looking for more people and we're hoping to try and get people from the outskirts more involved.

David - So any last thoughts you'd like to share with anybody who might be listening who's got dementia?

Bill - The only thing I think that I would like to say is if you receive a diagnosis, don't sit in a chair and figure that life is over. If there's something you enjoy doing, get out and carry on as long as you can do it.

Jim - Yeah, and that my motto is keep physically active.

David - Jim and Bill's conversation describes a grassroots effort to promote opportunities for people living with dementia to become more involved in their community. It is said that change often occurs either from the bottom up or from the top down. In the Building Capacity Project, the Northwest Dementia Working Group might be considered a “bottoms-up” group, a grassroots partner.

Later in the spring, we'll be talking with the Vancouver team that might be considered, on the other hand, as a top level partner.

Our website has more information about the Northwest Dementia Working Group and the Building Capacity Project. We acknowledge the support of the project in providing today's episode.

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Thanks to our sponsor, the Center for Education and Research on Aging and Health at Lakehead University. My name is David Harvey.