Dementia Dialogue; Season 3, Episode 23

A Pioneering Partnership
Transcript of interview with Brenda Hounman and Dr. Sherry Dupuis

David - Welcome to Dementia Dialogue. Our episode today is the second of two exploring the relationship between research participants and researchers and the evolution of that relationship in the research process. We hear from Brendan Hounman, a woman living with dementia for the past 20 years. Brenda has collaborated with Dr. Sherry Dupuis, professor of Recreation and Leisure Studies at the University of Waterloo, and the two join me in conversation.

Brenda - My name is Brenda Hounman and I live in Paris (Ontario) and I was diagnosed in the year 2000. I'm the single mother of two children, one of whom was still in school at the time. And the reason I got involved was I volunteered my whole life in one way or another. And my dream was when I retired was to really fill up my retirement years with being able to volunteer and I found out very quickly that with the diagnosis of dementia that I wasn't accepted as a volunteer anywhere. But there was a small ad that was been posted by MAREP (Murray Alzheimer Research and Education Program) looking for volunteers. And I applied to that, and that was in 2002.

Sherry - I'm Sherry Dupuis. I'm a researcher and professor in the Department of Recreation and Leisure Studies and also co-lead a culture change program called the Partnerships in Dementia Care Alliance.

I got my job at the University of Waterloo in 2001 (so right before Brenda joined us) and was part of my job when I was hired was to be the at that time Associate Director of Research for the Murray Alzheimer's Research and Education Program. And we very quickly determined, I think, that in order for our work to be relevant to people with dementia, we needed to ensure that they were included in what we are doing, whether it was research or education.

David - Brenda, you mentioned the Changing Melody project as being the first one that you got involved with. Could you just describe that a little bit for our listeners?

Brenda - Well, that was the forum that there were persons with dementia sitting on the committee and their care partners sitting on the committee and as well as staff from MAREP and other professionals. But it was a forum for and geared for persons with dementia and their partners in care and was very unique at the time.

It was quite unique to be able to go into a learning experience where you felt totally comfortable as a person with dementia. There was always a quiet room made available for them. When we were sitting on the committees, we were always listened to and our expertise was respected, but not only our expertise as a person with dementia, but our expertise that we had just gained in life. We were still valued as a whole. And that was huge.

Sherry - I had a lot of learning to do in the beginning days, as she said, this was really charting new territory. There wasn't really… we looked worldwide for a forum that was basically engaging with people with dementia as co-creators, co-researchers in everything that we were doing. And it was very new at the time. And so as a researcher, I had learned how to do research in a particular way and always needed to be in control of things.

David - The first Changing Melody had to be canceled because of the low registration of people living with dementia and care partners.

Sherry - And I had to learn, actually a really important lesson, it was a difficult one, that people with dementia that we were working with taught me; that I needed to have faith in the process and the people that we had brought together in that process to and particularly with people with dementia, to be able to lead the process.

So I went to people living with dementia who were on the committee and said, “My goodness, what went wrong? What did we do wrong?”
And I was very fortunate that people like Brenda and the other people with dementia on the committee were very honest with me. And they said, “You weren't listening. You weren't hearing us.” And I think it's because people with dementia knew what they needed and we were able to communicate that to other people with dementia.

Brenda - I would like to add to that, because this is a very important part, I think of this partnership is the reason that I still stayed there was the fact that we were able to come back together again and do that.

That was large steps taken that other people and other professionals at the time were not willing to take. I can remember coming up against brick walls when I was trying to approach on different ideas that we might do, and as did other persons with dementia that I was talking with. And that was huge at that time to be able to sit down and have those discussions.

And there's nothing wrong in making mistakes. It’s that you learn from those mistakes that's important. And that was all we wanted to hear was a willingness to keep trying. Because that's how you come across this great idea, is the perseverance to do that, to admit you made a mistake and now what can we do working together to fix that and move forward? And that was for the first time that we were having that sense. We were having a feeling that we were being treated the same as we would have been without dementia, and that that was a remarkable step. And even after all these years, we don't always get that. And there's only pockets of that kind of thinking around.

David - Could you maybe describe another project that you've been involved with, apart from Changing Melody where you've brought some of these learnings and principles that you felt engaged in the same kind of way?

Brenda - Well, I can't help but bring the one forward that is the closest and dearest to my heart and that’s the By Us For Us guides. And this is another unique thing that Sherry had the foresight to see. A group of us were working on these guides, and we had established that we wanted to do this and we were working on our own on it as a group.

David - Brenda recalls the group approaching Sherry and other professionals for an endorsement of the guide that they were working on. When asked, Sherry went further and offered to help out with printing and distribution, while leaving the project in the hands of people living with dementia.

Brenda - What's unique about those guides is there's different layers to it. So people with dementia can be involved at different levels and be comfortable. And no matter what, whatever level, they feel comfortable in. So they can do it totally anonymously. They can do it through written, just answering surveys and questions. They could do it by telephone. They could do it by one-on-one interviews. We have some groups that came back, guide after guide, and those people read some of the first guides and were so ecstatic to think that they were now involved in participating in one of the newer guides.

Sherry - I think what was so remarkable about the By Us For Us guide too, because it really was led by people with dementia and they actually were the researchers. And so they would go out and facilitate the focus groups or do the interviews and the MAREP staff would just support them in doing that. So they were actually the researchers facilitating those qualitative research methods, while the MAREP staff supported them in that. So there's so much stigma and assumption around what people with dementia are capable of doing. But we watched them be researchers.

Brenda - But I learned a lot from that. And then when I started to work with Sherry and that through these projects and Lisa on these projects, the knowledge that was gained and formulated just became much more solid on the actual researching. And we became quite comfortable in doing that, mainly because we knew we had that the support person sitting right next to us.

David - Yeah, kind of a consultant.

Brenda - Yes. Yes. It was really a win/win for both sides.

David - I made a connection between this approach to research and participatory action research. While agreeing, Sherry went on to say,

Sherry - We also wanted to develop our own sort of methodology. And so we actually worked with Brenda and other people with dementia who had been partners with this, as well as care partners and professionals. We did a lot of research with them. We had a number of all day or half day workshops where we really explored what were the things that really supported people with dementia as co-researchers in the process and what were things that were really challenging. And we were able to work together to develop the authentic partnership approach.

So it draws a lot on the principles of participatory action research, but also I think adds some very specific things that we need to be thinking about in order to support people with dementia in being co-researchers and being valued for the expertise they bring to the table.

The authentic partnership process really emphasizes that if this is going to work, all diverse perspectives have to be valued and then we need to work together to figure out how we address conflict. And so we've had a number of issues where care partners, they have experiences with dementia as well, right? And so they would often bring their experiences together. And we had to find ways to say, “Okay, how can we balance ensuring that the voices of people with dementia are privileged, but also not forget that family members also are experiencing them alongside?”

But how do we make sure that that happens in a respectful way? Because the stigma is taken up by everyone; people with dementia, family members, professionals, researchers. So how do we make sure that what we're bringing forth does not perpetuate that stigma.

Anyone in our process can choose how they want to participate. And it's all valued.

And so, like she said, we would spend a lot of time exploring people's strengths and abilities and talents and how they want to support the project and then try to include them in that way and not be concerned if they didn't want to participate in other areas.

So some of our people with dementia would participate in analysis processes and data collection, in designing data collection strategies, in writing. Other people would not. They would say, “No, I want to come to these meetings and I'll help with designing the plan and making decisions about the plan.”

David - The By Us For Us guides have been very popular and the group is now working on the fifteenth guide.

Sherry said that over time they learned to offer participants different levels of involvement. Also, more time is needed to get tasks done. Communication, especially non-verbal communication, always needs to be recognized and valued, and there is a need for critical reflection all along the way.

Brenda added that each new guide brings a new group with the mix of old and new members. Cuing is important to help people remain focused on the item at hand. Guide 15 is created entirely online –a new experience for everyone. While it has had its challenges, it does facilitate participation, especially from people in other regions of the country.

Brenda - There was always something with each guide, and the great thing about this partnership is that we have that support person sitting there to assist us with those situations. We lose track of what's happening or we're rambling. And sometimes time schedules don't work well for persons with dementia. So that's another thing that has very important to have that support person there is to try to keep us on track. But they also have to appreciate the time schedule for what would have been done under normal circumstances in business, don't work with persons with dementia. You have to have a longer time schedule for the time. So time schedules are very important as well.

David - I asked Sherry about other research projects where the principles of authentic partnership have been applied.

Sherry - Well, there is the Living Well with Dementia project that work together on using authentic partnership to guide that. We've just published a paper on that that we're all very proud of.

So that's one project where we did some strategic planning at MAREP and worked really closely with very diverse stakeholders to sort of identify where the key gaps were. And what kept coming out from all key stakeholders was there wasn't enough sort of information in an accessible way for people with dementia and their care partners to help them with self-management. So we brought a bunch of people together and committed to creating that resource. And we worked over I think a couple of years on that project.

But the other thing that I've always been really interested in as well is because people with dementia don't only live in the community, they live in long term care. So we wanted to see whether or not the authentic partnership model would work in long term care. And we worked with about five or six different long term care homes and brought the authentic partnership approach to those homes.

It’s extremely, much more challenging in those settings. But we learned a lot in that process as well in terms of how to engage people with dementia in different ways, but also the importance of having those champions within those homes to support people with dementia in participating and the leadership to do that.

And that's where those processes don't go so well, when those supports and champions aren't there. The beauty about MAREP and I think was that we could champion that, but we wanted to see what happens when we try to teach this to others and have them champion it.

David - What are the hurdles that are still out there that prevent the kind of collaboration or perhaps not prevent it, but don't nurture the kind of collaboration that we might be wanting to achieve in the development of new ways of supporting people, the development of new knowledge about how to do that.

Sherry - There are so many hurdles enduring in this type of work. I mean, I still get reviews back from grants where reviewers tell me that people with dementia can't be researchers.

I know from my colleagues trying to do this in other universities and from people with dementia who really want to be involved in this, that they're often shut out because there’s still stigma.

I think stigma still is alive and well in society. And that's really been brought to the forefront, both in terms of ageism and the stigma associated with dementia with the pandemic. That's really come out for me.

And so I think until people realize that people with dementia at all phases along the journey, have the capacity to share their experiences and engage in different ways, and that's going to look very different for every person. But they can contribute. And until people understand that and then are willing to do the work to support that, I think this doesn't happen.

I think our whole academic system doesn't really support this kind of work because it takes a lot more time to do this kind of work.

David - Brenda, what are your thoughts on, your observations of obstacles that have yet to be overcome or may reappear when you think you've resolved them?

Brenda - I think the obstacles are very broad. If you take dementia and put it aside, the obstacles in trying to get something and work together with a group of people are compounded with each marginal thing that you add to it.

So it's out there. And when you're working as a specific group, groups especially that don't have a visual. So when you don't see dementia visually -like mental health is in that same category, you don't see that visually- I think are more difficult. But it's the root of how we've evolved as a group of people. It really is root based.

David - So that social exclusion or stigma is a word that's often associated.

Brenda - Yeah, but you just think like as I said, I come from a business background and you just find sometimes people are like minded and they can come together and they can have great success working together. The more people can work together and the larger number we have on that same wavelength, the more we're going to make changes.

David - So what advice, Brenda, would you give to a person with dementia or perhaps a care partner who might be wanting to become involved?

Brenda - I think what has to happen with people that want to get involved in these things, they have to have a level of acceptance and be comfortable with themselves just as anybody would. So I don't think it's any different for people with dementia. We have to get to that point where we have to be accepting of who we are and know that we have this expertise and voice.

And that's easier said than done. But the more we can encourage people to feel good about what they still can do, the more people we’re going to have that are going to be willing to step forward. And the more comfort that they see in the situations and that they're accepted for exactly who they are and that they are unique individuals, the better chance we have of making bigger changes.

Sherry - One of the principles in the authentic partnership model that we learned from Brenda and the people who participated in that first one, is we thought we were listening, but we weren't actually acting on what they were asking for. And so there was no accountability. And so in an authentic partnership, it's not just about listening. It's about every single decision that's made coming back to it and being accountable and showing how have we addressed that.

Brenda - You know how you vet employees when you're hiring them? But when you're doing a situation like this, you should be basically doing that same thing. Both parties should be having a discussion and to see if you can fit together or not.

David - That kind of goes back to your earlier comment, Brenda, about people feeling confident that they've got something to contribute and to check out the situation to see whether the other person feels the same way.

Brenda - And yes, when you have a disability, you lose that confidence. And you know why we lose that confidence? Because everybody around us is telling us we can’t. So that just adds to.

David - Sherry reinforced the way that stigma undermines the confidence of people with dementia and the sense that they have nothing to contribute.

Sherry - So in those spaces, in these research spaces, we can continue to tell people that and show people that they still have value in our world and they still have so much to contribute.

Brenda - I think it's really important not just to have one single person -to invite more than one person. I've heard my peers and I am one of the first ones to say it myself, that we feed off each other. We feel motivated when we're working on a project together.

David - So I want to thank you both very much for your time today, but I also want to thank you just as people for the pioneering work that you did. I learned a lot from you two.
So I thank you.

The collaboration between Brenda and Sherry has been fruitful. The By Us For Us guides are now in reprint. You could find out more about the guides on our website.

The authentic partnership approach has influenced researchers and practitioners in many fields. An article about it is also on our website.

The Research Institute on Aging at the University of Waterloo, of which the Murray Alzheimer's Research and Education Program is a part, is donating a set of all 15 guides to one of our lucky listeners. To win this set, write to dementia.dialogue@lakeheadu.ca and put a "*Guide"* in the subject line.

Thank you to our partners at the Center for Education and Research on Aging and Health at Lakehead University and to the Public Health Agency of Canada.

Thank you for listening and if you have any thoughts or ideas on this or other episodes, please write to us at dementia.dialogue@lakeheadu.ca

My name is David Harvey.