

Dementia Dialogue; Season 3, Episode 28

Up Next

Transcript of interview with Dr. Elaine Weirsma, Dr. Arne Stinchcombe, Kathy Hickman, and Lisa Loiselle

David - Welcome to Dementia Dialogue. This episode entitled Up Next is a bit different than what you would normally hear from us. As we're just about halfway through our third season of Dementia Dialogue, we thought we would take a moment and give you an outline of some of the episodes and series that we will be presenting over the next few months.

We will also be featuring some more guest producers in the future and we want to introduce them to you.

Dr. Elaine Weirsma has collaborated and co-founded Dementia Dialogue. Elaine is a professor at Lakehead University and she is hosting two episodes, one on women and dementia and one of dementia as a family affair. And she gives us a taste of what we are likely to hear.

Elaine - So the first one is an episode on women living with dementia, where I had the opportunity to speak with three women who have been diagnosed with dementia and to have them share their experiences and stories and reflect a little bit on what it's like to be a woman and to have this diagnosis of dementia and aspects around identity and roles and that kind of thing.

And then the second episode is an episode with a family. One of the reasons why we decided to do this is because often we tend to look at the person with dementia perspective or we look at the care partner's perspective and really any kind of situation, chronic condition, diagnosis of dementia happens to a family. It doesn't just happen to individuals. And so we really wanted to have the opportunity to speak with a family and get kind of a family's perspective on dementia. So in this with the Mersereau family, Clara has been diagnosed with dementia. And then we had her husband, Bill, and her two daughters, Patty and Jo-Ann, who joined us.

David - One of the questions when I think of families and dementia is the age of people that are involved because depending on the age, the impact can be quite different. So what would be the age group we're talking about in this episode?

Elaine - So Clara was diagnosed in her seventies with dementia. And her daughters are adults, adult daughters. So, yes, a very different experience than when somebody is diagnosed younger, but still really, really wonderful insights on what happens with a family, especially as children are older and move away.

David - Now, going back to the first episode you spoke about in women and dementia, why do you think it's important that we kind of put a particular focus on gender and the experience of women?

Elaine - More women are diagnosed with dementia than men, and so we know that there is a gendered component to dementia. I think the other reason why it's so important is what we tend to have done through kind of our research and our focus on people living

with dementia is see the diagnosis of dementia first and foremost and every other aspect of somebody's identity is secondary.

And from doing some research on women living with dementia, that's in fact not the case, right? When people get a diagnosis of dementia, that doesn't supersede everything else. It doesn't erase their history. It doesn't erase their identity. It does not erase their gender.

And so we have to understand better how people are as individuals and those different aspects of their identity. And then what happens when a diagnosis of dementia comes layered on top of that?

And I guess that's probably the third reason is I have been so incredibly inspired by so many women living with dementia. And these three women in the podcast, Clara, Myrna and Brenda, are just so incredibly inspiring. I think anybody who listens to this episode and walks away, I would hope that they would be inspired because there are just some of the strongest women who I know with immense amounts of wisdom. And I think that we as a society can really benefit from that.

David - Dr. Arne Stinchcombe recently was awarded a Young Researcher Grant from the Alzheimer Society of Canada. Arne's research project is on the experience of LGBTQ2S folks with dementia or as care partners. And this is the focus of his four part series that he's going to speak about just now.

Arne - For the four episodes of the podcast, we'll be chatting about the intersection between LGBTQ people and dementia. So these are folks who are members of lesbian, gay, bisexual, transgender and queer communities. And when we think about members of these communities, we often think of these rich life courses, life course experiences of things like community and resilience.

But we also tend to think of the experiences of minority stress. So these are things like stigma and discrimination. So important things to consider when we're thinking about caregiver supports and dementia care.

So in these four episodes, we'll be talking to LGBTQ people who are caring for persons with dementia. We'll hear from their experiences, including some of the challenges, but also some of the positives about caregiving experiences for those folks.

We'll hear about the importance of specific supports for LGBTQ caregivers and persons living with dementia.

We'll also hear from LGBTQ folks living with dementia and how their life course experiences and their identities are influencing their dementia experience.

And then finally, we'll hear from some researchers who are working in the field looking at the risk of dementia for LGBTQ folks and who are identifying ways to promote LGBTQ2 inclusion and safety within dementia care.

David - I'm interested in the idea of incidence. Do you think the incidence of dementia might be higher in this population?

Arne - Yeah, that's a really great question. We suspect that the incidence and prevalence is indeed higher as a result of some of these minority stress experiences that accumulate across the life course.

But I'll be honest with you, especially in Canada, we don't have very good data that would support that. When we look at some of the risk factors, yes, indeed, the risk factors are there, which leads us to suspect that this may be an at risk group, but certainly we need more data on that front.

David - Kathy Hickman is with the BrainXchange and the Alzheimer Society of Ontario. Kathy joins us to talk about the four part series that she and her colleague, Jillian McConnell will produce concerning young onset dementia and the impact on families.

Kathy - So at the BrainXchange, we often hear all kinds of different issues that are of importance to a variety of different stakeholders. And one of the things that often comes up is, is the experience of early onset dementia, which we know has a lot of similarities with other types of dementia in that experience.

And also at the same time, some unique characteristics, unique experiences, just because of the point in life that the person may be at. And so one of the areas that we'd like to explore through the podcast is looking at the perspectives and experience of caregivers of people with early onset dementia. It's an area that hasn't been explored in a lot of detail. And so we want to speak to both young folks who have had the experience of caring for a parent who is living with early onset dementia, as well as potentially a spouse with early onset dementia.

We want to look at also some different perspectives, like, for example, from a research perspective, what do we know about early onset dementia and some of the issues and concerns and perhaps from a service provider's perspective as well.

One of the things that there aren't always a lot of services out there. Again, there's the needs of people with early onset. So the services need to be customized a little bit. And so there are some services that exist and we'd like to be able to share some of those.

One of the young women we're going to be talking to in the series had the experience of being a teenager and her mum having early onset dementia in her forties. So looking at her experience of caregiving for her mum at such a young age. Also her own concerns and thoughts and perspectives on her future. Because there is a genetic component to the familial Alzheimer's disease that her mum had, she has made the decision to go through genetic testing.

So we're going to talk to her about her experiences with that, her decision to do that genetic testing and what that experience has been like for her.

David - Reverend Faye Forbes and Lisa Loiselle were our first guest producers for the series on spirituality. Lisa is going to continue with us and is producing a series on arts and dementia, something many of our listeners are keenly interested in.

So, Lisa, there's a lot of people excited about the upcoming series on arts and dementia. And I'm wondering if you might be able to outline some of the topics that you're going to be covering and maybe talk about some of the types of people that we'll be listening to.

Lisa - Well, I'm really excited about this special series on arts and dementia that's coming up, and it's going to be an eight episode series, which is great because it provided me with a lot of opportunity to speak with so many individuals who are in the field, in the arts field.

So some of the topics that I'll be going in to are going to include visual arts, so speaking about dimension, visual, the importance of visual arts in their lives. Also on music. Music was huge. We've all heard about how important music is in the lives of people living with dementia. So that was a really exciting conversation.

We're going to be talking about expressive arts. So some really lovely artists and individuals who are experts with experience. So people who have been diagnosed, who are talking about their experience working with different mediums of art.

I'm also going to be speaking with somebody about dementia in the media. There's been a ton of new movies that have come out in the last little while. So we'll be going into that dementia in the media as well.

And so really excited to dive into all of these different modes of art and a variety of individuals, and the one thing I want to say is I'm really excited that I have a co-host for a number of these episodes, Cynthia Huling Hummel.

So I'm really excited about this in having a co-host, Cynthia Huling Hummel, to speak with me specifically on the expressive arts and dementia.

David - You did a fabulous job on the spirituality series, so we're really looking forward to hearing this.

We will soon be finishing our very popular series on spirituality. And after that, we are picking up on the issue of Covid-19 and talking with some researchers, advocates and people with lived experience and care partners.

There is even more: Visiting Dementia Friendly Places with our co-host Phyllis Fehr and talking about new exercise resources for people with dementia and care partners with Professor Middleton from the University of Waterloo.

We are also working on co-producing a series of episodes in the French language. All of this could not be done without the stimulating advice and unending ideas of our editorial board. The members of our editorial board are listed on our website, www.dementiadiologue.ca

I also want to mention a recent addition of Dementia Connection, which you can pick up at www.dementiaconnection.ca

And we appreciate the support of Dementia Connection in offering us an advertisement in that issue.

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My name is David Harvey.