

Dementia Dialogue: Season 3, Episode 30

COVID-19: Being a Caregiver

Transcript of interview with Megan O'Connell and Claire Webster

David - Thanks for tuning into Dementia Dialogue and our episode on the experience of care partners during Covid-19.

Our guests today are Claire Webster, who was a care partner for her mother for many years. Subsequently, Claire has become a Dementia Care Consultant and operates Caregiver Crosswalks Inc. in Montreal. She has also initiated McGill Cares, an educational resource for families affected by dementia and for medical students at McGill.

Megan O'Connell is a professor and clinical psychologist at the University of Saskatchewan. Dr. O'Connell is also lead of team 15 of the Canadian Consortium on Neurodegeneration and Aging.

Let's listen in to our conversation.

Claire - Thank you for having me on your show.

I'm Claire Webster and I came into this space of dementia care education because of my own personal experience as a former caregiver to my late mother, who was diagnosed with Alzheimer's disease in September of 2006. I had absolutely, positively no prior knowledge about the illness, signs and symptoms.

I think one of my biggest challenges at the time, too, was with my mother she was showing like a really significant change in terms of her behavior. It wasn't really memory, it was a behavior. So one of my challenges, which I know a lot of families face, is that I didn't even know what type of doctor to take her to see. Was I supposed to take her to a family doctor or was it a psychologist?

First of all, again, I went to see a family doctor and then we went to see a neurologist. I was not prepared at all for the appointment. I had no idea what to expect. And basically, upon diagnosing her, the only, what I would call today, the only prescription of care or lack thereof was "Good luck, Mrs. Webster".

I ended up going through what I call a cyclone of caregiving and the lack of information and education, without a doubt led to I would say that if I would have been properly educated, my mother would have had a better quality of care. I ended up suffering a very, very severe nervous breakdown in 2011. Upon my healing, I decided to get on my own personal crusade and change the health care system. I was so frustrated at the lack of information, education provided I became a certified dementia care consultant. I work with families on a one to one basis and educating them. And I'm the founder of McGill University's Dementia Education Program. And we educate family caregivers and medical students at the university.

David - And Megan, how about yourself? What brings you to the table on our topic?

Megan - Well, I research dementia and dementia care, but part of the reason I do that is I also have a lived experience as a family caregiver, first for my grandfather, and saw how

the delays and diagnosis really impacted him. So you'll notice a lot of the work I do is in the diagnostic sphere, but also the diagnostic supports. It's another area where I do some research as well.

And so I'm a professor of psychology. I'm a clinical psychologist with specialty training and clinical neuropsychology, which is the part I use for the helping to diagnose dementia. I specialize in measuring cognition and aspects of thinking. I use those skills when I work in our rural and remote memory clinic, where we do interprofessional contacts, we diagnose dementia.

In addition to that, as well as my part as co-lead of the rural team in the Canadian Consortium on Neurodegeneration and Aging, I focus on using our knowledge about management and other types of non-pharmacological interventions, namely psychological interventions to provide post-diagnostic supports across the province of Saskatchewan at least that's what we're starting or in the process of starting for various parts of that project.

And because we are focusing on rural dementia care, we use technology to remotely provide these services. And the pandemic has really highlighted the need for a remote service delivery and the utility of remote service delivery and where it's quite feasible and quite acceptable for many people.

Claire - There's actually been a lot of advantages, like, for instance, the Zoom platform. First of all, I would say in my private practice and working with families, I've never done so many family consultations right now because prior to Covid, I would normally meet just one or two family members at one time because it was the norm was that other siblings would live outside of the country, outside of the province. But because of Zoom I'm doing a lot of family consultation. It doesn't matter where people are located across the world so that people could come together. They can all be educated and talk and be on the same page.

So that has been an advantage. And I think also with regard to the caregivers, McGill Cares, I started it in May of 2020 because we weren't able to have caregivers come into the university in to workshops. But if anything, we've never reached so many. We've never been able to educate and support so many caregivers.

David - Both of you have been involved with the Alzheimer Society and doing some early work on how to support people, given the isolation, the veil that came down and limited people from having access to services, having access to each other, having access to groups like the support groups of the Alzheimer Society. I'm wondering, given your early conversations and concerns in this area, I'm wondering if you might talk a little bit about how things have played out in terms of what you perceived as issues that would probably emerge and have those issues emerged? So what are some of the most pressing experiences of our partners in particular?

Megan - Well, we definitely because we were both on the Alzheimer Society Covid Task Force focusing on caregiver's experiences. The absolute cessation of complete no access to supports and services was profoundly distressing. And I think still is and Claire, I think, can talk to that even more so because of her work. But we did an early project looking at a scoping review of what these kind of experiences are and the impacts this had on caregivers early in the pandemic.

We also had a nice analysis of people tweeting about their experiences. This is a new world and some people use social media.

The other, as a researcher, the practical aspect to that was being able to quickly do it without needing to go through, because it's public data we don't have to go through ethics that can take months. So we were able to really describe the impacts of the complete loss of any supports and services on caregivers.

And then for those who are living with dementia and living either in a care facility or alone, the impact of that complete loss of socialization, stimulation and affection and access to their loved ones. And for some of them, they didn't understand why. So this could have profound impacts on them psychologically. And we saw some descriptions of that.

And also some descriptions both in the literature in our infodemic study or the Twitter study, and also my clinical work of exacerbation of problems and cognitive and psychiatric concerns due to this complete loss of any activities or stimulation.

Socialization is one of the most important things that we do for our mental health, our cognitive health. And to have that completely gone was pretty profound.

One of the things that our team did really early on is trying to help all the services get back online and I mean online on this platform. So we bought Zoom Health Care. We provided an account to the Alzheimer Society Saskatchewan so they were able to maintain their support groups, although I recognize they did have a few months where they closed it down, they were able to get up and running and give their support groups through this secured platform. And our team used our skills in training people with cognitive challenges or cognitive impairments to learn new skills, to use the telephone to train people who've never used Zoom how to get on Zoom.

So we spent the whole summer using the telephone and training and supporting people to get on and use the technology that they had in different ways, to maintain those social connections, to maintain their access to the remote services that were being offered by the Alzheimer Society Saskatchewan, for instance (they moved all of their programming online through video conferencing). So we did a lot of that, as well as a method to help people, because although I mean, we figured this out, I don't know about you guys, but I tell you at the beginning, even just doing Zoom and using Zoom, it was a really big challenge. And now you add to that your day to day caregiving challenges and/or your own cognitive impairment, you can imagine that just giving people the link to Zoom is not adequate. So we spent a lot of time doing that.

David - Coaching people.

Claire how have things played out in your experience?

Claire - It's been extremely challenging. I mean, so let's take a step back. As I had mentioned with my own story before Covid, families receiving a diagnosis, should they be lucky enough to get a diagnosis, were not provided, the majority are not provided with any information or education, not only about the disease itself, but then also about how do you access resources from the community.

So then let's add Covid into that mix. And here you have all of these families caring for a loved one at home who have dementia without understanding why they're doing what they're doing, okay? And so now you add isolation to that. So why are they repeating themselves? Why is all this challenging behavior coming along? So they don't understand why they're doing what they're doing.

Then for those people, for instance, who were getting some type of home care support when Covid happened, the majority of people that I'm working with stopped that, whether it was public support or even private support, because people were afraid Covid. They were told, don't let anybody into your home. If any home care support worker is seeing other families, don't let them in. So then the other thing that is happening is for those caregivers who have a loved one whose dementia is advancing where it was impacting their activities of daily living, meaning the dressing, the bathing, the toileting, all of a sudden the spouses or children had to start assuming these very intimate roles that they may have not done before, which was very difficult to do, to come to that realization that they have to do that. And so as a result of that we're adding a tremendous layer of stress onto the care partner. They're feeling isolated,

Like Megan mentioned, for those people with dementia who were getting some type of day centre activities, that had all stopped. So now you have people living at home 24 hours, seven days a week. There's nowhere to put their anger or their frustration except on themselves. Symptoms of dementia began increasing, but so did the coping mechanisms of not only the caregivers, but also the person with dementia. So people started drinking earlier or other coping mechanisms could be drugs, could be food, could be shopping online, et cetera. And what I have seen a lot is that these care partners feel like there's a lot of suffering in silence. So this feeling of anger or sadness or burden, they feel like, "I'm alone, like, is it me? I'm alone and no one to talk to". And that's been coming out I have to say a lot is this feeling of really suffering in silence.

And so what I'm trying to do is just let everybody know you're not alone in the lack of access to the health care. So then there are all these families, for instance, where their loved one is showing the early signs and symptoms of the illness. And people don't even know what the early signs and symptoms are because there is currently no public awareness campaign about it. So then it's like that question of, "Okay, who do I go see? I'm afraid to go take them to the doctor". Or they were told well their doctor is not seeing people by telemedicine. But it's like, who do I see? And then try to get on a waiting list or referral to see a geriatrician in many provinces, it could take months and months. It's so complex. But when you're dealing with a disease like dementia, you absolutely have to have an assessment.

David -Now, Megan, this is going back to some of your work in technology. This has been some of your work as to how to use technology to overcome this challenge of assessment. Could you talk a little bit about the progress that you've made in that regard?

Megan - Yeah, so one of the projects we had actually got funded before the pandemic was to use the telephone as the technology for accessing rural and remote and any urban people who needed access to diagnostic services and then using a telephone based cognitive assessment and a collaborative kind of diagnostic model. So that's one model that happened to be funded before the pandemic and fortuitously was able to continue during the pandemic.

The other thing, though, that we also did was we moved our inter-professional rural and remote memory clinic, which normally people travel into our center or urban center in the province and get an in-person assessment and then get a diagnosis, by the end of the day, they see multiple specialists. We moved that to Zoom Health Care as well. And we were able to, as much as possible, mimic the inter-professional nature of our assessment and do some remote cognitive testing and then also provide a diagnosis.

And I'm not going to lie. It wasn't quite the same quality. I think any of us who were working in the diagnostic context in the pandemic have definitely seen the limitations for some cases. But for some people, it made great sense and we felt very confident that we had a good picture and our diagnosis we felt much more comfortable about.

So I think there's a lot to be learned from that because there are some times where that is likely all that's needed. It really reduces the travel burden. It reduces barriers to diagnosis for those who can't travel or who don't want to travel. And also sometimes they don't want to see or they're rural or their primary care provider doesn't want to do that diagnosis because it has implications for things that can impact their relationship, like informing about driving and concerns about that license.

David - Yes. Claire, what is your experience of how families overcame this hurdle of access to primary care during the Covid period and then getting to some kind of specialist assessment? Was it just a barrier that was insurmountable?

Claire - It's a challenge. I mean I know that, for instance with the Alzheimer's Plan in Quebec, they're trying to now really encourage family doctors, give more power to the family doctor so that they will be able to make the assessments, so kind of like avoid not having to always refer to geriatricians and neurologists.

But what we do know is that unfortunately, depending on the family doctor, the age of the family doctor, what type of training has he received or she received at the university level? You know, a lot of the family members that I'm working with have family doctors who clearly have not been able to make proper assessments over the last two years and I end up being the one to insist to the family to try to get the referral to the geriatrician or neurologist.

There's also the Alzheimer Society of Canada has this First Link program across the country. Quebec is supposed to be rolling it out this summer. But I have to say it's a big challenge. And I think most importantly, again, it's the fact that the majority of people don't know how to navigate the health care system itself. So even if they do have a geriatrician, for example, they don't necessarily know that to make sure to get that assessment, because in order to get a social worker opening a file for you, you need that assessment.

So, what is the role of the public health care system? How do I if need be and it comes time to having to make a transition to long term care, they don't realize that the waiting list is two to three years and you need to start making those plans ahead of time.

There are so many roadblocks. And I just I really feel that it comes down to a lack of information and education for the public to really know how to access whether it's health care or the public health care system itself when they need it.

David - When one looks at the policy preparation as the story of Covid was unfolding, it's almost as if these populations were an afterthought. We started preparing for the impact of Covid on people with dementia sometime in mid-April, when the virus was already doing a lot of damage. I'm wondering what your kind of reaction is to those comments about the lack of preparation at a policy level; the fact that people might have been overlooked? Did people in your conversations with people, did they feel as if they had been abandoned by society in the sense?

Claire - I mean, I'm focusing completely on the dementia care and field of dementia care. We saw that in the long term care facilities, the majority of seniors who died had dementia. Very sadly, this is a population that cannot represent themselves, advocate for themselves, communicate.

So I think that what Covid has shown is for sure, this is an incredibly vulnerable population just because they cannot advocate for themselves. So if it's a senior who has dementia, living alone, who's advocating for them? And the conversations that I'm having right now with family members who are living abroad, with the sons and daughters that are not living in the same city or province or country as their parents, for me what I, what we've learned also from Covid is, "Who is advocating for your loved one?" You have to have an advocate.

So if a family member is not there, not living in town, who can be there for them? Somebody has to be there, has to be their voice, has to look out for their well-being. And I really think more than ever, you can go into life having a Plan A and this is the way things are going to go. But what Covid has shown us is that you have to have a Plan B at all times. There's got to be a Plan B moving forward.

David - Megan, your thoughts in terms of preparation or how we approached these populations of people in the early stages of Covid and how things have unfolded?

Megan - Yeah, I think it was really telling for me when we got together on that Covid task force, for instance, Claire is in Quebec and I'm in Saskatchewan, how different jurisdictions, for instance, the Alzheimer Society handled this.

Saskatchewan went online pretty quickly, resumed services pretty quickly, and had a 1-800 toll-free number to call for support, not 24/7, but still nevertheless, something. I think it really highlighted the disparities in even the Alzheimer Societies and the need for something more central, cohesive and combined so that it can adjust quickly and pivot fairly quickly.

An example would be as simple as what they have in the United States, which is a 24/7 crisis line for people living with dementia and their caregivers. And this is one of the things that our little sub-group spent a lot of time thinking about and advocating for, because that could have been very agile to the pandemic and could have been a major source of support.

And the second thing that was really highlighted and, like you said it nicely at the beginning too, but is the lack of respect for the human rights of those living with dementia and their caregivers. It was considered secondary and infection control procedures were primary. Which I understand in the context of the pandemic but human rights seemed to

really get lost. And we saw that particularly and acutely in long term care and in a multiple, multiple ways.

The Twitter study that I talked about where we describe people's reports of their experiences and loved ones who just kind of stopped eating because nobody was visiting them.

Claire - You know, I would just like to add to what Megan said. What happened in the long term care centers, I mean everybody heard what happened in Quebec, but preserving human rights and human dignity of people with dementia, that has been an issue for so long. And I think the pandemic just opened up the Pandora'sBox, exposed it all.

My mother was in both the private health care system and private residences as well as the public. And if I wasn't there, watching over especially during meal time, I mean, who was feeding her when she wasn't able to feed herself? Just the right to be able to have a meal and to eat was something that unless I was there or having to hire extra care to have somebody assist her to eat, who was helping them? Who was changing them when they were wet?

So, sadly it all came full-frontal when the pandemic hit. But this has been going on for such a long time and hopefully things will change. I think when you're caring for a loved one with dementia, the role of advocate really comes into play as soon as a person loses their ability to communicate and really understand what is going on.

I had to advocate. I wanted to ensure that my mother was happy, that she was safe and that she was clean. And when I was managing her care for the final five years of her life, every single decision that I did, every contact that I had with the health care system, everything that I did as her daughter, as her caregiver (which just understanding the fact that I was a caregiver was a whole new identity), was all about being her advocate. And it meant that when I was face to face or on the phone with anybody from the health care system or with the residences or with the home care agencies, I wanted to ensure that they were going to show up, that they were there.

I have a lot of family members say to me, "Well, I called that. I haven't heard back for weeks" and all that. Being an advocate means that it's your responsibility to call. You need to call. You need to follow up. It's those people that are going to take the action. You just can't wait at home and wait for the phone.

Being an advocate means that you are the one following up. What's important to know, too, is that the people that work in the health care system are under a tremendous amount of pressure, tremendous amount of stress. They clearly have not received the training that they deserve to care for this population. So when you do approach them, you be respectful and be polite, because getting frustrated and screaming and yelling isn't going to change things, right? But being an advocate is probably the most important role that a caregiver is going to have for the final years of a loved one's life. It truly is.

David - Megan your thoughts?

Megan - To me it's a sign of a failure of our health care system, really. That, you're quite right, families and people living with dementia need to even advocate to get diagnosis. You need to advocate to get someone to hear that there are concerns. You need to advocate

that you need to get certain services and supports. And the caregivers who are more successful are the ones who are able to do this and know the system. The ones who don't are the ones that are falling through the cracks. And to me, it's a sign that the health care system is underfunded.

I guess that's a pretty obvious statement. But it's underfunded for dementia care, particularly. I think the fact that families have to fill in those gaps, including in advocacy, including in a lot of the care needs, even when you are receiving formal care, just speaks to the fact that we need much more funding. We need much more funding focused on dementia care, whether it be post-diagnostic or pre-diagnostic.

David - Okay, well, thanks very much. It's been a dynamic conversation. I've enjoyed it very much.

There's so many issues and the sadness, the great sadness that has pervaded over the last many months. So thank you.

Thanks very much, Claire, for your work. And thanks to the leadership that you're providing in Quebec and in Montreal.

And Megan, I'm very intrigued and I'll be interested in following your research work. And Saskatchewan is a very, I get a very nice feeling about the collaboration that's going on there and the advances that are being made.

Claire - Thank you.

Megan - Thank you.

David – Our note today for this episode contains links to recent research conducted by Dr. O'Connell and Miss Webster, including a paper they co-authored with other members of the Task Force of the Alzheimer Society on Covid-19.

There are also links to Claire's service and to the McGill Cares program.

Please join us for our next episode, the last in our series on spirituality. This episode features a discussion with two caregivers about how spirituality has been a valuable resource in their life.

A second episode on Covid will be released later in July.

Let us know what you think, share your ideas for new topics or just give us some of your advice. Write to us at dementiadialogue@lakeheadu.ca

Thanks to the Center for Education and Research on Aging and Health for its support and to the Public Health Agency of Canada.

My name is David Harvey.