# Dementia Dialogue; The System Journey, Episode 3

Navigating the System
Transcript of interview with Michelle Janisse

**David -** Welcome to Dementia Dialogue. My name is David Harvey. In this third episode in our series, The System Journey, we will talk with Michelle Janisse. Michelle is a First Link coordinator in Chatham Kent, a mixed urban rural community in Southwestern Ontario. One of the challenges in primary care service to people with dementia is the practitioner's availability, in terms of time, to understand the support services that are available to help people with dementia and to learn how these services can be accessed. First Link is a program that has been designed to help primary care practitioners with this particular challenge. Michelle describes how First Link fills that gap.

Well, thanks very much, Michelle Janisse, for joining our conversation on Dementia Dialogue. We're exploring in this series the experience of people as they interact with the health care system to support themselves as a person living with dementia or perhaps as a care partner or other person that cares for a person with dementia. I'm wondering whether you might just tell us a little bit about yourself, about the kind of work that you do and the length of time that you've been in this position.

**Michelle -** All right. Well, thank you for having me. So I've been with the Alzheimer's Society of Chatham Kent, for over eight years now. Currently, my role is First Link Care Navigator and I also manage the social work departments. In the navigator role, we work closely with clients and care partners. We do a lot of navigation, counseling, education, a whole myriad of different supports that we offer.

**David -** Now, how do people find out about you, Michelle? How do people come to use your services?

**Michelle -** So through the First Link program, which I think you're quite familiar with. It's a program to help people link with the Alzheimer Society and the different supports. It's meant to be from point of diagnosis and sometimes even before, for people that we meet with, and to stay with them throughout the continuum of the journey. A good portion come from physicians and the Chatham Kent area, as well as other primary care providers. We also have people that consult here first. You don't need a doctor's referral to come and get support from us. This way you don't even need a confirmed diagnosis.

**David -** I'm wondering what would be some of the rationale or background reasons why a physician might refer somebody to the First Link program?

**Michelle -** One of the biggest things that we do that we get referrals from physicians for, is we administer cognitive assessments, whether that be the Clock Draw, the MoCa. We don't diagnose. We do administer the assessments and send them off to primary care providers in order to interpret. Even if the referral just says a cognitive assessment, we're able to meet with that person, do a fuller assessment, let them know about our different supports and services. And if they maybe don't need our supports now, they may need them in a few years down the line. So, for instance, last year I had a lady contact me and say, "I found your card. I think it's from about six years ago but you met with my mom and we need help". So I tell people, hold on to that card and we're able to sometimes meet with people even before that diagnosis is given to that person.

**David -** What are some of the common challenges that you observe people facing in terms of their interaction with the health care system or support services?

**Michelle -** Some of the challenge is actually just even receiving that initial diagnosis, whether that's because of hesitation from a primary care provider to give that diagnosis or maybe not having the training they feel is necessary. Maybe there's not the availability of a specialist to diagnose. For some of our clients, they might not have a primary care provider. So navigating that system, even at the first point of trying to get a diagnosis, can be challenging. So a big part of our role is advocating for that test and not just through cognitive assessments, but also we do those scores but then we also look at activities of daily living; how are they functioning, day-to-day? Are they having trouble or are they having concerns that might not be addressed in an assessment?

**David -** So once a person is assessed and receives a diagnosis and perhaps live relatively normal lives for a period of time, depending on the progress of the condition, what are some of the challenges that people might encounter as their condition changes? You know, there's kind of a shortfall in their ability to manage their lives in a normal fashion. What are some of the challenges that people face at that stage?

**Michelle -** You know, there's different challenges, not only for the individual diagnosed with Alzheimer's disease or related dementia, but also for the care partners, whether that's a spouse or a child, a friend or family member. Some of the challenges might be that changes in functioning, whether that's making your own meals or adhering to their medications appropriately.

So we do offer one-on-one counseling and education, both for the individual with a diagnosis as well as the care partner. We offer that however it's most convenient for the person. So, including the person with dementia and their family is extraordinarily important at making sure this is customized care for that individual.

**David -** You mentioned collaboration being one of your core elements of your practice. I'm wondering whether you might be able to unpack that word a little bit. What are some of the ingredients of that collaboration?

**Michelle -** We try to start from day one. We want to work collaboratively with the family or the primary care provider. What that might look like is if an individual is receiving home supports through the LHIN. We want to work with the LHIN if we're looking at putting in our own respite supports or if we're exploring an adult day program.
We don't want to be silos where we all have the same information, but we're getting it from the same person over and over and over again. We have an individual who comes to our day program and utilizes in-home respite support and we know they're having some responsive behavior; so Behavior Supports Ontario is involved. We know this person is now going to be transitioning to long term care; we work collaboratively with the BSO Care Coordinator and the team. We will get information from day program; what does this person like in the day program? What kind of music do they enjoy? Do they enjoy art projects?
When that person moves over to a new living arrangement in long term care; so we're able to get that information to them and they can go, "John Smith, you enjoy Johnny Cash and you love to do art. Well, let's start that out right away".
So we really want to work with all our partners at every stage.

**David -** You've mentioned a few of the different support services that might be involved in a person's life. And that's one of, I think, the unique challenges of supporting a person with dementia and their care partner; in the community is a multiplicity of services that might be involved.

I'm wondering in that constellation of services, where you see primary care fitting? Are there some times where there's active engagement with primary care or are there times where they’re kind of, from your perspective, on the back burner in terms of services that are engaged with the family on a regular basis?

**Michelle** - Primary care for a lot of individuals who we work with, for us are a lot of our involvement is in that cognitive assessment piece.
In addition to, if we're able to keep the primary care provider as best we can up to date; if that person is attending our day program, or are we making a referral to a geriatric mental health outreach team or BSO support? Certainly we encourage people, if they're having concerns with the individual, to follow up with that primary care provider. In our day program, the nurse may reach out to their primary care or pharmacy. The BSO team might reach out to primary care as well about concerns or changes.

So, absolutely, primary care is an integral part of a team that we want to keep involved and have family involved with.

**David -** Not an uncommon condition, for example, might be a urinary tract infection that might contribute to a person's change in their attitude. So that would be an example where you might contact the family physician about that.

**Michelle -** Absolutely. And that's not terribly uncommon, and especially can be scary for someone if they haven't had a family member with dementia present with a urinary tract infection, a UTI,

We might get a call saying,”Something's wrong with dad. He’s very confused. He's very forgetful. His behavior has changed. And this has been very sudden”. And that's kind of a red flag for us. But when we hear there’re sudden changes, we say get to the doctor. Rule out something that could be underlying, like a UTI, an infection, delirium, whatever that may be, we say get your doctor to rule it out.

**David -** Now, how about something like depression, which is another phenomenon that may be part of the experience of a person with the condition and sometimes the caregiver, depending on the circumstances. Would that be another example where you might contact the primary care provider again?

**Michelle -** So this is something. An example might be we received a referral for a cognitive assessment with an individual we haven't met with before. And when we do a cognitive assessment, we don't just do the assessment in 10-15 minutes, you're out of here, here's a number for the doctor.
We sit with that person usually for roughly about an hour in total and do a full biopsychosocial assessment. Say,”You know what? We really encourage this person to speak with you about this”. So it might be a referral out not only for the person with Alzheimer's disease or related dementia, but for a care partner. If they're reporting some changes in mood, anxiety and things like that. If they're hesitant, we'll offer to make a referral.

**David -** But are there any recommendations or thoughts that you might want our listeners to consider in terms of their family members or persons with the condition; what are some of the things that they might be able to do themselves to enable a more successful experience with the health care system?

**Michelle -** We want to help people know from point of diagnosis or like I said, sometimes before diagnosis, if they're having concerns. You know, we find that people linked with the Alzheimer Society through the First Link program were really able to optimize supports when we get people right at the start.

You don't have to have a doctor's referral. Call yourself. And we really want that customized care plan. We want to treat the person like the individual they are.

**David -** Any thoughts for practitioners, for your colleagues?

**Michelle -** Again, that collaborative approach, working together. We definitely want to work together with the families as well as our community partners.

**David -** Thanks very much, Michelle.

Listeners might want to check out our resource page to learn more about the First Link program and how you can access it in the place where you live.

Dementia Dialogue has some good news to share. Last Thursday, Health Minister Patty Hajdu announced twelve new projects to be funded through the Dementia Community Investment of the Public Health Agency of Canada. These projects are designed to help advance Canada's dementia strategy. We are pleased to let you know that our project was one of the twelve included in this funding announcement. You can learn more about this announcement and the other projects by visiting our resource page.

Over the next several episodes, we will be sharing with you some of the information about the other projects that form part of the Dementia Community Investment.

Dementia Dialogue is producing a monthly newsletter that you can sign up for at our website, www.dementiadialogue.ca

Also, liking us on Facebook helps us reach more people. So if you have a moment, go to our Facebook page and like us.

Our next two episodes will feature a conversation with Rachel Hofstetter, Monica Wood and Cara Dowhaniuk. They will be talking about how Rachel and her sisters have supported Rachel's parents in their journey with dementia.

Thanks very much to the Geriatric Health Systems Research Group at the University of Waterloo for continuing to support our System Journey series

Until the next time, my name is David Harvey.