

## **Dementia Dialogue; The System Journey, Episode 4**

Transitions: Doing Our Best Part 1

Transcript of interview with Rachel Hofstetter, Monica Wood and Cara Dowhaniuk

**David** - Welcome to another episode of Dementia Dialogue.

I'd like to thank all of our listeners who were in touch over the last while. Your interest helps us reach more listeners.

Our episode today is another in our series, The System Journey. In this episode, we have three guests. And to be fair to them and to our listeners, we are presenting it in two parts.

In this episode, we talk with Rachel Hofstetter about her experience as a daughter of Chris and Dorothy Quick. We are joined in conversation by Monica Wood and Cara Dowhaniuk, who work the Kitchener Family Medical Center, which operates a MINT Memory Clinic. Indeed, their clinic director, Dr. Linda Lee, is the originator of the MINT Memory Clinic concept.

Please note that since our recording, Mr. Quick has moved into the same long term care facility as his wife.

Thank you very much, Rachel, Monica and Cara, for joining us for this discussion about dementia care and especially trying to uncover some of the themes related to transitions.

Now, Rachel, as I understand it, you've had an experience as a daughter supporting both your parents and in the process of providing that support, you did make use of multiple services and experienced some of these matters related to transitions.

**Rachel** – Sure, thanks, David.

Yes. So both my parents are currently living with dementia. It started off with my mom's diagnosis about six years ago. Then my dad followed about two years ago. Who they were before were outgoing, warm, loving people who had a very full life and a deep circle of friends, a deep faith community that they were very connected with. My dad a salesman and then moved into his own business in mechanics and he was a real entrepreneur at heart and loved solving problems, loved his independence and being able to make decisions for travel and all of those things.

My mom, to this day, even with dementia, remains the sweetest person that I know on the face of the earth. She is just a loving soul and that has not changed at all in this journey with her. She is very sociable. Her cognitive skills are very, very low right now but her ability to still communicate and be relational with people is a big part of who she is and continues to this day. It's been hard. You know, the whole journey. They call it the long goodbye for a reason.

**David** - What are their living circumstances now, Rachel? Are they still at home or in a residential setting?

**Rachel** - Yeah. So my mom has transferred to long term care and Dad is in an apartment on a list waiting to get in to long term care. And he's at the second level of crisis so there's a lot of challenges at this current time with his living situation.

**David** - Right. So your mom has had dementia for six years. She's now been in long term care. Can you maybe describe how the system supported your mom in that interval between diagnosis and her admission into long term care?

**Rachel** - In the early days of getting the diagnosis (which I believe came from her GP) of course, as kids, as the daughters, we weren't really involved in that. It was mom and dad going to the doctor. We were noticing some things and really prompting them to go. And there was a lot of secrecy around it in the beginning. And so there wasn't much information at the beginning, but we were starting to see an increase, just in odd behavior and forgetfulness and weird responses to things.

We started to talk to mom and dad about getting supports in and being able to care. And there was a real kind of shut down on their part, and I think it was in part due to their age and their pride and not wanting other people to know that this was happening. It would have been interesting to have ways to bring family members into that early stage of diagnosis, to really start to set ourselves up as a family, as the care team around them.

Eventually, they got referred to the memory clinic and that was amazing.

So that was one of the first positives in that journey and I felt very, very fortunate to have my mom in that case put into a situation where she was seen by a number of clinicians, different practitioners, who came around and gave a really well-rounded view of Mom's experience. And for the first time, outside of her GP who hadn't really communicated much, I got a sense of what I could start to expect and what was available.

There was also some connections with our Local Health Integration Network (LHIN). Although the people were incredibly nice, sometimes it was overwhelming for information and what I felt was I felt paralyzed. I didn't know how to move forward. I knew there was a lot of things that were available. I knew there was a lot of things that could potentially help. And I didn't really understand my role in the beginning. You know, Mom and Dad were together. Dad was kind of taking on that caregiver role. And you have to remember, unbeknownst to me at the time or any of us, he was also starting to wrestle with dementia. That didn't even enter into my head. So that was another complicating factor. And I just found knowing who to call for what; so, for example, getting P.S.W.s support in, which was recommended for her. We would make arrangements as to the time P.S.W.s would be showing up but then they didn't arrive at that time. They'd show up at another time and I didn't know exactly who to call. I'd call somebody and they'd say, "Oh no, you need to talk to the coordinator". Well, this was the original person who had referred me and it kind of felt like it was bounced around a lot.

Each time I went to the memory clinic, I felt like I got reoriented. And one thing that was described to me by someone at the memory clinic, was to start to think of a flower. The center of the flower would be where the LHIN was and then there was petals coming off for the different services. And that picture was really, really helpful. That was probably a couple of years into this journey before I had that and once I had that, everything else started to make sense for me.

So the next stage for us getting Mom in to long term care was complicated by the fact that my dad did not want her to go. He felt that he wanted to look after her. Anybody who's supporting folks with dementia, the emotional complication of trying to do everything for your loved one and then wrestling with your own physical capabilities, complicate that with my dad's dementia, there was a real battle and a real power struggle.

Again, every time I would come to the memory clinic, I would find allies. Where I did not find allyship was with their G.P. It ended up that the G.P. really put a lot of faith in my dad's abilities, which confounded our abilities to get Mom into long term care. I had to wait for a LHIN person to kind of step in and really kind of move some of those decisions.

Dad's journey is also filled with many transitions.

**David** – So in terms of the G.P. experience, at the beginning, at the point of your Mom's diagnosis, and it was mostly managed by your parents (and you weren't that involved, so there was kind of a lack of information that you experience and a little bit of uncertainty as to what were the implications of this kind of diagnosis) and the G.P. wasn't too interested in talking with you, I guess.

**Rachel** - Yeah, we didn't get that sense.

And they share a G.P. so that has been validated, that sense has been validated in our experience with Dad's care as well.

I think my hope would be that we could come around Mom or come around Dad as a care team. And that's really kind of what I experience at the memory clinic, that I was included in that care team.

**David** - So that might have been a positive gesture on the part of the G.P.

I think one of the contributions of a memory clinic is often G.P.s feel themselves limited in terms of what more they can offer to a person or a family where dementia is in existence. And so having the ability to call upon another resource like a memory clinic can be a really positive contribution on their part.

**Monica** - I'm really glad you mentioned that, David, because I think in every healthcare model, there's always going to be limitations to care. This particular issue of general practitioners not having the time or the scope of their practice to fully investigate a complex disease like dementia, that is really what inspired the creation of the memory clinic.

You know, our clinic was designed specifically to carve out space, to investigate, to assess more fully. It's important for our team to remember, too, that every clinician is here to help and to do their best. And our goal is to replace the valuable work that they do. But the goal is for each team to enhance the work of the other in a way that serves patients and their family compassionately and comprehensively.

**David** - Rachel, you mentioned that you have sisters in your family that you're working along with as well.

**Rachel** - I have a sister in Ontario and then two sisters in the U.K. So having that distance is a complicating factor here for sure. So Mom and Dad are closest to me so I ended up being the primary one.

**David** - You've referenced your father being resistant to having your mother go to long term care. How did that get worked through, apart from kind of the technical issues, maybe about power of attorney and substitute decision makers?

**Rachel** - I have many examples of how these little micro decisions were actually showing me that he really wasn't ready to have Mom leave or kind of wasn't really dealing with the diagnosis. And the next kind of level of that, the evolution of having the P.S.Ws coming in

to support Mom with personal care and make sure she was showered and that kind of thing, and he'd send them home.

So, it was having these little battles with him of, "This is what she needs".

And so all of these trends to finally get to the point where he would let her go into a nursing home. It came down to that power of attorney and having a bit of an interview with him where an R.N., actually from the LHIN, went through a checklist of questions that assess his fitness to be her caregiver.

And then there was one other kind of pivotal incident. I remember being in bed sound asleep, getting a call at about eleven thirty at night from my dad saying, "She's leaving, she's leaving. I can't keep her in". And I could hear my very sweet, laidback mom screaming at him that she wanted to go home. And we don't know what home meant for her at that point. So he's trying to rationalize with her, "You're in your apartment". And I called my sister, who lives in Ontario who's also an R.N., and she said the only thing he could do at that point, in the state they were both in, is just walk with her in the apartment, left the door open and just walk with her and ask where she wants to go and just try. And that's what they did. They walked the halls of their apartment for about ninety minutes before she tired and went back. And he finally in that moment could see that he couldn't handle it.

So we had the technical or the piece of paper that said we can make that decision but then that was finally where he did allow it.

**David** – In part two of this episode, we will pick up on Chris, Dorothy and Rachel's experience with dementia.

We will also hear more from Monica and Cara about the memory clinic and how it supports its patients and collaborates with referring physicians and others.

More information about memory clinics can be found on our resource page on our website.

Thanks to the Geriatric Health System Research Group at the University of Waterloo for their support for this series.

Please join us next time for part two of our episode on The System Journey.