

Dementia Dialogue; The System Journey, Episode 5

Transitions: Doing Our Best Part 2

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

David - Welcome to Dementia Dialogue.

My name is David Harvey. This episode is the second part of a conversation with Rachel Hofstetter, Monica Wood and Cara Dowhaniuk . Our focus is the experience of Rachel and her parents, Chris and Dorothy Quick.

At the end of part one, Rachel's mom was finally admitted into a long term care home while her dad continued to live in their apartment before eventually moving in to the same long term care home as his wife.

We joined the conversation when Rachel's dad begins to live on his own.

Your dad is at home now and your P.S.W. support is going in to provide him with some time.

Rachel – He has refused it in the same way that he did with Mom. Ultimately, I can probably count on one hand the number of times the P.S.W.s were allowed into their apartment. He just felt it was a real intrusion. But again, that was one of those transitions that was really hard because I didn't feel in his particular case with his G.P. that we were working, rowing in the same direction. I believe he had Dad's best interests and wanted to be his ally as well.

David - I'm going to ask Monica or Cara just on that point, if you might have observed this in other (not to point the finger at G.P.s but what we're talking about is primary care) that desire on the part of G.P.s to be loyal and supportive of their patient. Perhaps they've had them for a long time and at the same time to realistically address the current circumstances and that tension that must be within some practitioners.

Cara - Absolutely. I think there is that longstanding relationship in history and trust that G.P.s have built with their patients over the years. And so I think we're fortunate as a team because we can kind of facilitate these tough discussions and make these tough decisions alongside the patient and their families and hopefully maintain that relationship, allow the patient to maintain that positive trusting relationship.

Monica - And certainly, the transition and the loss of a license, I think is one of the trickiest transitions that we see in memory clinics. I think it's so challenging because there are so many different pieces to that puzzle. You know, in terms of the technical pieces, then there is also these very personal pieces where people really identify with their ability to drive and it's devastating for them to lose that independence and lose that piece of your self-esteem. There are so many different nuances to everybody's journey with dementia, that you really have to keep assessing things. And I think for our clinic, the more effort that we put into working alongside a patient and a family as well as their other care partners, whether it's family physicians, the specialists, the other community partners like the LHIN and the Alzheimer Society, the more we try to work together in the interests of the patient and their individual needs, the more successful that transition can be.

Rachel - And Monica's comments just spark a memory for me. In that time of transition, there was a portion, so once he passed that driving test and we still had this really deep gut sense and even some of the testing that was done on coming out of the memory clinic,

we kind of knew but legally, he had checked the boxes, but there was these continued little micro incidents that happened in that time. And it was up to me, the main caregiver now, when do I have to escalate this? Who do I escalate to? What's bad enough that changes the situation? And then the tremendous risks and responsibilities that I felt for just the public in general.

Cara - I think you highlighted a few transitions, Rachel, those really tough transitions around like license and long term care. And we see time and time again, the idea about role reversal, like caring for parents. And when do you step in and what's that like? And it's really tough because you want to honour your parents and you want to respect their decisions and their privacy, and it's almost like it's a real dance because you want to trust that they're making the right decisions but how do you really know? It's kind of a grey area. And when do you step in? When are those cues?

David - You mentioned earlier on, Rachel, after the diagnosis of your mom and then you began to have some interaction with the LHIN and you found that very confusing. And then you were talking with, I would assume, somebody like Cara at the memory clinic, who used this kind of motif of a flower, which is one way of describing the LHIN, the various support services that shoot off of that flower. I wonder what thoughts you might have about how your situation might have been ameliorated earlier.

Rachel - It's interesting. So in the line of work that I'm in, we often will interview others about their experience. What it reminds me of is folks who have been dealing with mental health services for children and they have these navigators that kind of help parents know who to call when for what type of thing. And I thought something like that would be really interesting for caring for older adults as a child; knowing who are the supports? How do they match together? What's the priority? So almost like a network map, a system map of what's out there and how did those different nodes kind of relate to one another, is one of the things I thought of. Or a peer-to-peer. Maybe somebody who has been through this and knows how to navigate it and maybe somebody who's a little further along.

David - Cara, do you have any thoughts on that question about how we might help families understand and manage the support system better than we do at the moment?

Cara - What I've kind of learned is that over time, I mean, the nice thing about the memory clinic is we see people every three to six months. So I say what I learned is the importance of the development of the therapeutic relationship that develops over time. Throughout the visits, I get an opportunity to be able to talk about dementia, understand where things are at in terms of how people are coping. What are the challenges? Give people a sense of confidence in their caregiving to be able to support them and encourage them. And weaving in those conversations, of course, what's available. But I think dementia is challenging, and that is as the disease progresses, it's a constantly moving target.

So it's equipping family members with the skills and then also to understand the system and how to access it and when to access it. I think we kind of weaving in those conversations as time goes on around understanding, for example, the importance of self care or communication challenges and where you can go for more help around those pieces.

So it's having those conversations over time and really building that therapeutic relationship and then making those referrals.

Rachel - And as the recipient of those kinds of conversations, I would just like to amplify how valuable they are. I know I would make an appointment and then I would have somebody else check in and say, "Oh, has this appointment been made?" And I was like, in the back of my mind I thought all of these network resources talk to each other. I didn't realize I was the conduit in some cases to be able to transfer that.

So, after that, just understanding. Another thing that comes up for me is something visual. I had a lot, in the beginning, of people telling me a lot of information and I think not processing it all and seeing how it connects together. Different people describe different services differently, sometimes even just the language they used to describe those services. So something visual that would be a little more concrete would be helpful.

David - Monica, what are your thoughts on these issues of navigation, as Rachel called it, or helping families understand more easily how support systems interact, helping them understand that it may be on their shoulders to ensure that information flows one from the other, that that's not necessarily inherent in the way the system works?

Monica - Well, I think one of the things that memory clinic in particular tries to keep in mind is how important communication lines are. And I think there is always a balance that we're trying to walk between.

When do we sort of coach families on how to advocate for themselves? And when do we need to step in and advocate on their behalf? And that's something that I see our nurses and our social workers doing quite often. And again, like I said before, there's not really one right way because there are so many variables in everybody's situation. And even for one particular patient using one strategy might work in one situation. But come the next challenge, you've really got to change your approach on how to problem solve.

David - Cara or Monica, do you sense that people wrestle with these issues of communication and trying to kind of understand the pressures that family members are under? Do you get that sense that people are sincerely wrestling with those challenges in their practice?

Cara - Well, absolutely. Dementia is so complicated and all the players involved, there's so many of us and we all do similar things; who's doing what and what kind of conversation have you had? What challenge are you talking about? What were the strategies that you discussed? Advance care planning to a communication breakdown to brief discussion around grief. So we all try to work together as best we can to provide support in our realm.

David - Rachel, I'm just wondering if there's any tips or lessons learned or a last message that you would like to get across to our listener.

Rachel - I don't know if I have any nuggets of wisdom. I feel like I'm up my neck in alligators in the moment.

But I would say that it has to start with that self care piece, if you are a supporter or a caregiver. And one of the things that I think I've been able to reflect on on my journey is I had a lot of expectations around how my parents would react, how the system would react, what I would expect the system to do. And there has been many wonderful surprises, like I didn't know about the memory clinic beforehand. And I think that is the absolute gem in our community.

I think letting go of expectations and having a real sense of curiosity, nimbleness. You know what worked one day is not going to work the next day. Your own emotions are

going to change from day to day. And I think that resilience, that having a really bad episode or a transition or an experience, doesn't mean all of the rest of the experiences are going to follow that way. So knowing today was one of those crummy ones, tomorrow's a new opportunity.

David - Monica, do you have any last thoughts about what are the critical things that people can do to help families out in these transition moments?

Monica – Well just kind of going back to the memory clinics overall goals; it's not only to improve care for persons living with dementia and their caregivers, but it's improving access to care and just those key ideas of communication and collaboration. We really try to focus on that in our own clinic. And providing a patient centered approach.

And so I think the more that all of these different organizations keep that in mind, and I know that that's everybody's goal, the more that we can work cohesively, I think the more we can create that comprehensive support system and that soft place to land.

And we just kind of have to keep focusing on the patient and that really does include the care partners, the spouses, the children, that sort of thing. Their needs are really important as well.

David - Cara, you mentioned a little while ago about the privilege that you have to be able to develop a relationship with the folk that you provide support to over the course of time. And I think a lot of people in some other primary care settings might be envious of the time that you've got to be able to foster that type of relationship. Given the business of primary care in lots of settings, are there any tips that you might be able to help out in that fostering of a relationship?

Cara - Like you had mentioned, I am very fortunate to have the gift of time but I also think in the work that I do as a social worker, really giving the opportunity for families or patients to share their story. Even though you might not have time, I think it's so valuable to hear, "How are you doing? What are your goals and how do we go from there to work through a challenging problem and go from there?"

So I think I'm fortunate to have the time. But I think if you invest that time to really listen and walk with the person, you're going to get all the information you need to move forward.

I wanted to add too, I think Rachel made a few really good points around the idea of expectations, and that's huge. I mean, it's a real personal journey to take a step back and reflect on what are my expectations of myself, of the care for my parents and just reflecting on that.

And then the idea of self compassion in this, too, because dementia at times expects us to be superhuman (and our family members). So to be compassionate to oneself and recognizing that we're all doing the best we can and to give ourselves credit for what we're doing and how much we are caring and working together.

David - Okay, well, thanks very much, everybody.

Monica – We so appreciate that from you, Rachel and we really are thankful for the opportunity, David, for us all to participate in this conversation. Thank you so much.

David - Through this reflection on Rachel's experience of managing transitions and the lives of her parents, Chris and Dorothy, and in her own life, we have been able to uncover some important learnings, some of which are deeply personal, such as having compassion for oneself, as well as practical things like the idea of a simple graphic to help care partners understand key services and how they are intended to work together.

I think our series is achieving our goal to capture some of the critical elements in helping people and practitioners manage transitions in the experience of people with dementia.

In this episode, Rachel mentioned resilience and it makes me think of Ngozi's highlighting the importance of taking care of oneself as a care partner.

Today, Cara mentioned listening as a key message, one that also is shared strongly by Ron Roberts in a previous episode in this series.

Our next episode is based in a family care practice in rural Saskatchewan that also operates a memory clinic periodically. In it, we talked to Leanne Lawrence about her and her mom, Marjorie Toppings, and also with Jean Daku, who a nurse practitioner at the clinic. Please join us for those conversations.

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Until the next time, take care. My name is David Harvey.