

Dementia Dialogue; The System Journey, Episode 6

Transitions – A Rural Dementia Resource for rural communities

Transcript of interview with Leanne Lawrence and Jean Daku.

David - Welcome to Dementia Dialogue and today's episode, where we return to our series, The System Journey and the theme of transitions.

Kipling is a small community in southern Saskatchewan which is fortunate to have a primary care clinic which has partnered with the RaDAR program led by Dr. Debra Morgan from the University of Saskatchewan.

Leanne Lawrence's mom, Marjory Topping, was a patient of Jean Daku, a nurse practitioner at the clinic. We will learn in this conversation about how Marjory and her family were supported by Jean and others in Marjory's final years.

Leanne, if you might just describe a little bit about who you are, your mom, the place where you live and some of the background in terms of who she was as a woman, as a mother and wife and how to dementia entered into her life.

Leanne - OK. Her name is Marjory Toppings, and she was eighty-five years old. She was a widow for twenty years, was a farmer's wife, worked very hard on the farm. She was one of twelve siblings growing up and was the only one that was still living around here, which is where she grew up. She was a very kind, gentle woman who never complained about anything, was always grateful for what she had, had a good sense of humour, enjoyed the community. She was a very loving, kind of mother. Yes, someone that I aspired to be.

So everybody was kind of aware that there were some subtle changes in her. I talked to my brothers and said, "You know, I think something's going on". That just wasn't her and she just seemed so lost. And whenever we left town, she would just get very confused and not be able to make her mind up, just became very unsettled.

And as time went by, it got worse and worse to the point that I just didn't take her to Regina anymore to see her other two sons. It was just too hard on her. So that's when we started doctoring with Jeanie here. I wanted to get some testing done or find out what we could do to find out if she did have dementia. And that's where Jeanie came in.

David – Okay so ,Jean, could you just describe a little bit about your practice, I suppose, in general, and then what your role would have been with Marjory in this particular situation?

Jean - So I'm a nurse practitioner in a primary health clinic and I work with three other physicians. We're very team based and so we try to be engaged in all aspects of team based care. We serve the Kipling community and surrounding area. The population of Kipling it changes. It goes up and down but I would say it's about twelve-hundred, so a very small community. But we have a large farming community and as well as oil community around. So a lot of the people I see are from outside of Kipling.

I noticed that we were seeing more and more people with cognitive concerns and quite often they come to us with mild cognitive impairment and, of course, as you know, that that does often progressed to dementia or Alzheimer's. So I always wondered. I felt like I wasn't doing enough. You know, the testing, we had that little bit of testing and then (I think as you saw on the video) we had been working with the RaDAR group from

Saskatoon. So a big project to bring in more education and ways of dealing with dementia in our small rural communities.

So we started a memory clinic and we have a team based approach. So we have many different practitioners. We have the physicians, we have home care nurses, we have physical therapists, we have occupational therapists, we have social workers (if it's applicable in the area), we have the Alzheimer Society First Link coordinator, that are all involved in assessment and meeting as the team following the assessment piece that we do.

We really need to focus on that early diagnostic piece, especially in our rural communities, because we're two hours from Regina. There is an assessment clinic in Saskatoon, which is four and a half hours away. So that is a lot for people to have to wait probably a year or two for an assessment and then (especially if you had your mom in Saskatoon) that would have been really difficult to navigate through that process, too. So I guess we have really found this just really important for the people of our communities and our rural areas to be able to have a diagnosis and have a plan for them and for the family.

David – Leanne, I'm wondering if you might describe a little bit of what you and your brothers decided to have your mom go to the memory clinic and to have this assessment. What were you hoping would be the result of that kind of process?

Leanne - Well, first, I want to find out if she did have dementia. If not, what else was causing these differences in her being, right? I wanted to be able to say, "Okay, so this is what it is. How do we best deal with this so that you have the best quality of life that you can have? What can we do to slow this down or at least be able to live with it comfortably and safely in your own home?"
Because she didn't want to leave her home.

David - Jean, you had mentioned the treatment plan in your mind to benefit the patient and benefit you as a practitioner.

Jean - Well, our goal for any of our patients, but specifically for people with cognitive impairment, our goal is to improve the quality of life or keep their quality life status quo, for the patients and also for the caregivers. Through our assessment piece, we were able to (I'm just trying to pick an example)
Okay so in the beginning, Leanne's mom did not have any home care services. That was maybe something lacking. So we looked at that piece and we said, "Okay, does your mom need Meals on Wheels? Does she need someone coming in frequently to see if she's taking her medication? To see if she is eating?" Like all those different kinds of things. Leanne checked on her mom a lot. But she had a job, too, so she was not always able to do that follow up. So that home care piece was huge for her mom.

Leanne - Yeah. Oh, it was definitely beneficial for quite a while. And then we actually increased it to two days a week. So it was the socializing, her being able to converse and speak with somebody else. They assessed her every time they went there. And if they noticed something, then they would let Jeanie and myself both know.

David - Now, as your mom's condition began to change, Leanne, and as her capacities became more limited, how did you feel that kind of change in her condition was recognized or communicated to people that were involved in providing her support?

Leanne - Everybody was aware that she was declining. They all just became more supportive, were willing to do more and more emotionally as well as mentally and physically. Quite often the home care nurse would text me even, "I just saw your mom today. She's looking well. She's still eating okay. I noticed there was food in the fridge and she's done more Afghans" because she was always crocheting (which is a blanket, right?). So they kept on top of that at all times, which made me feel good because it took some of the onus off of me trying to watch and assess her every time I went. They were my extra set of eyes, I guess. And as her dementia got worse, it was becoming more and more apparent that sooner than later, I was going to have to make some kind of a decision as to move her somewhere else where she could get more care.

David - Now, did that decision point materialize? Did it come to a point where your mom was no longer able to stay at home?

Leanne - Before we got to that, she had a fall at home and broke her hip, which was kind of the beginning of the end.

David - Jean, what kind of role would your primary care clinic have then at that point in Marjory's life and in her care?

Jean - I do want to mention a little project that we had been working on in the past year, and this is when Leanne's mom was still at home. Our team decided that we needed to try and offer something for people with cognitive impairment or dementia. We do the assessment. We say, "Okay, maybe these medications will help. Maybe we'll give that a try. And you go home and you keep doing what you're doing".

To me, that's just kind of bleak. And so we got together and we decided we were going to start an active living program, specifically for people struggling with cognitive concerns or dementia. So they would meet once a week for two hours a day and they would do mind games, they would have dancing, they would do baking, they would be doing exercising. All those things (singing!). All those things that stimulate that mind, that stimulate the mobility and actually...

Leanne – she loved it.

Jean – Leanne's mom did so amazing. And I think the social aspect was so wonderful too.

Leanne – Oh, she was so happy. Yes.

David – Leanne, you mentioned your mom fractured her hip and the surgery was done in Regina and then she came back home after that to her own home and lived alone again?

Leanne- No, we came back to the Kipling Hospital.

David - Oh, I see. Okay.

Leanne - And then I applied for long term care because she was using a walker but there was no way she would be able to go home and look after herself without help. And I wasn't able to kind of live with her. So we applied for long term care.

David - Now, was that long term care provided in the facility associated with the hospital then?

Leanne - Actually it was a nearby town about forty minutes away that has level three and four people at it. So she was there for three weeks and then she got a permanent bed in the Kipling facility, the Kipling long term care facility. So I moved her back here.

David - How did you find that transition to the place forty miles away and then back again? Did you feel that you were able to provide the receiving facility with adequate information and she was well received there?

Leanne - The one nice thing about being rural and being small town is everybody knows everybody.

Jean - Everybody knows your name.

David - That's the good side and the downside.

Leanne - So there was actually people that worked in Wawota that knew her. So it made the transition much easier.

Early detection is very, very important. The sooner you find out what it is, then you can learn to help her in any way you can. But if you don't get the diagnosis or if you don't enquire and get the help that you need to find out, then it's quite a struggle.

So I would definitely say that the earlier the better, because there's so many things that you can do to increase a better quality of life right from the start.

Education is very important. I think the more you can read and learn about it, the more easier it is for you to implement different ways to make a quality of life better. Definitely socialization is very important. Very important. As is exercise. I think both of those things are definitely key. The longer you can keep them active, it's better for them physically, mentally, emotionally. I think those have to be my main points.

David - Jean, what are some of the things that you think work well in your practice setting and what are the things that you need to kind of protect or ensure are in place so that a person like Marjory or Leanne and her brothers can be well supported in the way they care for their mom?

Jean - Well, I think it's always important to remember that patients and families are feeling very vulnerable. And it's a very vulnerable time for them because things are changing. The patient isn't driving their car anymore. Making a grocery list may look different to them. Following a recipe may look different to them. So there's so many changes that take place in these patients lives. And we as a team, I think, are very aware of that. And we really keep that in mind when we're dealing with our patients and their families. They're not just a number coming through. We're looking at their whole life. We're trying to look at the patient as a whole and try and help them that way.

I guess we hope that families and patients will have a better understanding of dementia and the symptoms surrounding memory loss. And we're hoping that they will, as Leanne was saying, learn how to manage some of those things.

And they're very difficult because one day your mom may totally know exactly what's going on. And other days she wasn't so sure, right? Depending on the day. So I think it's really important that our team, at our memory clinic, really is aware of those things.

And families are in need of that support as well as a patient. You know, we always talk about the patient, the patient, the patient needs this, the patient needs that. But it's the families that are dealing with those things and dealing with all these different symptoms. So they are also needing a lot of support. And that's where our First Link Coordinators from the Alzheimer Society, I think are very helpful as well.

And I think, and maybe Leanne can attest to this, I think that whole team approach of everybody doing an assessment, coming together and bringing their findings and helping to come to diagnosis.

David - Thank you very much for your time this afternoon to be able to do this.

Marjory was indeed fortunate to have a team like the one led by Jean to support her after a long life in her home town.

RaDAR is an initiative to bring better services to people in rural communities. You can learn more about RaDAR on our resource page, including a video of Leanne and her mom.

Thanks to those of you who have been in touch. You can also subscribe to our newsletter by writing us at dementiadiologue@lakeheadu.ca

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Take care. My name is David Harvey.