

Alzheimer's researcher puts focus on the role of caregivers

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HALIFAX, N.S. - Better understanding the challenges facing those caring for a spouse with memory loss, dementia or Alzheimer's is the goal of a research project spearheaded by Kinkora native Dr. Janice Keefe.

Keefe, a professor of gerontology at Mount Saint Vincent University, leads a team of nurse trainees currently interviewing caregivers 65 and older who are looking after spouses with various cognitive impairments.

"People are living longer. Because the gap between men and women is narrowing it's more likely that with two old and frail individuals co-residing one will have dementia," said Keefe.

To date, 35 spouses with loved ones in the early stages of cognitive impairment or memory loss or in the late stages of Alzheimer's or dementia have been interviewed. All are from Nova Scotia and P.E.I.

"One of the critical people in the care-giving group is the spouse yet they are the least likely to seek out help," said Keefe. "Spouses may be less likely to seek out support because, in many cases, they think 'I'm their spouse, I am supposed to take care of them.'"

Five third-year students from the UPEI School of Nursing are conducting interviews on the Island. The goal is to have 100 interviews completed.

"Getting the perspective of the caregiver is really important while you are also treating the patient," said nursing student Brandi Martin. "It's interesting to see the varying perspectives because we had some caregivers that are thrilled to look after their spouse and would have it no other way. We have others that feel guilty because they feel they have to be there versus wanting to be there."

It's been an invaluable and eye-opening experience for the Kensington native.

"We don't necessarily focus on every disease in the nursing program. It's first hand and not from a textbook. You're learning from their experience," added Martin. "In nursing you are caring for a patient, but it's becoming more apparent now that we need to do more family-centered care. Getting the perspective of the caregiver is really important while you are also treating the patient."

The students are using the CARE (Caregivers' Aspirations, Realities and Expectations) tool, developed by Keefe, to interview caregivers.

"It is a 10-part questionnaire. We go through literally every aspect of these people's lives. It is completely up to them if they want to answer some of the questions," explained Martin. "Most people I have spoken to have been thrilled to discuss their situation. A lot of times it is the first time they had the chance to talk about it with someone that's coming into the situation and not trying to necessarily find a solution but just be a sounding board."

She can't discuss specific cases or reveal whom she has interviewed, but Martin said there is a common theme she's hearing from caregivers.

"It's to just have support. A lot of them do know of different support groups that are available, but a lot of times they are very much focused on their spouse who is ill and aren't necessarily focusing on themselves or their own health."

Project funding ends in March 2012. Keefe and her project partners are looking for spousal caregivers interested in telling their stories.

A report will go to the project's advisory board next year. Keefe hopes the information gathered and recommendations will result in more support services.

"Ultimately we hope that it's going to inform practice in terms of putting caregivers' needs on that agenda in helping to keep people in their home," she added. "We hope, broadly, that education around caregivers can go into the health-care professional field so that all health-care professionals become a bit more aware of the challenges and the positives associated with caregiving."

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About the project

- Project team consists of Janice Keefe and Pamela Fancey from Mount Saint Vincent University, Nancy Guberman from L'Université du Québec à Montréal and Catherine Ward-Griffin from the University of Western Ontario.

- Funded by the CIHR Institute of Aging, the Canadian Nurses Foundation and the Parkinson Society of Canada.

- Caregivers interested in taking part in the project can contact their local home care office, the Alzheimer Society of P.E.I., email caretool@msvu.ca or call 902-457-6573 or 1-877-302-4440.

- The team is looking for people aged 65 and over who are supporting their spouse/partner living at home with memory problems, cognitive impairment or dementia.

- To learn more visit the project website at www.msvu.ca/nsca/caregiverassessment.