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Living with and caring for those with dementia

Edmonton – According to the Alzheimer Society of Canada, more than 540,000 people in Canada are living with dementia – and an almost equal number are impacted indirectly – many as family caregivers.

“Dementia is complex and doesn’t typically fit with the traditional ways we provide health care,” says Holly Symonds-Brown, assistant professor, Bachelor of Science in Nursing, MacEwan University. “We know hospitals aren’t good places for people with dementia but keeping people at home for as long as possible has its own set of challenges.”

Day programs provide opportunities for older adults with dementia to stay active and socialize – and offer respite for family caregivers. But the reality is that not a lot is known about whether these programs work, and how they impact the quality of life for people with dementia and their caregivers.

“The research on day programs tends to focus on the programs themselves and doesn’t acknowledge that there are a lot of ways that families need to work to make those services fit their lives,” says Symonds-Brown. “If we’re trying to keep people with dementia at home for as long as possible, we need to look at the things that make life easier or harder.”

This summer, Symonds-Brown is beginning a study that she hopes will help us rethink the way we look at care and space. Working directly with five families, she is exploring the back-and-forth connection between a person’s experience at home and their experience in a day program.

“I’m asking families to let me be a part of their daily practices,” she explains. “To observe what happens at home before and after they attend a day program, to look at spaces, to see how they get to the program, what they do when they get there and the paperwork that materializes in different places along the way.”

It’s a long study and slow research – Symonds-Brown anticipates that field work alone will take at least nine months – but it will offer a different perspective on quality of life than the biomedical approach to dementia research.

Ultimately, her research aims to identify innovative ways to help people with dementia live the best life possible.

“We really haven’t had access to this type of information before, and that means we might see things that we haven’t been able to pay attention to because of the methods that were used,” she adds.

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