

Our Dementia Journey Journal

A co-designed tool for strong partnerships among persons living with dementia, their caregivers and their care providers

Through previous research, we have heard from people living with dementia, their caregivers and care providers that they would like to have a tool to help them communicate better so they are working even better together.

We co-designed with people for over 18 months to develop a prototype of such a tool. We call it *Our Dementia Journey Journal*. Following this work and with funding from the Public Health Agency of Canada and SE Health, we have spent the last 2 years adapting the tool to respond to the needs of people in different kinds of communities across Canada.

Project Overview

The growth in the aging population, alongside the growth in consumer advocacy, have contributed to a growing emphasis on person- and family-centred care in both home care and long-term care homes. Becoming more person- and family-centred is therefore a widely held goal in the care for older adults.

However, we have heard from people living with dementia, their caregivers and care providers that the dementia journey is full of changes – in mental and physical function, in care settings, and in the number and types of care providers. We have also heard that there are changes in the roles of caregivers and care providers over time – and their respective roles in providing “clinical” versus more “emotional, relational” care. They told us they would like to have a tool to help them communicate better, so they are working even better together, particularly in times of change.

In response, over the course of 18 months, we held 6 co-design workshops with caregivers and care providers in home care and long-term care homes to develop a prototype tool: *Our Dementia Journey Journal*.

What have we done?

Since the development of the initial prototype, we have engaged, via in-person workshops, with people living with dementia and their caregivers in two First Nations and one urban Indigenous community in northern Ontario. Participants were invited to review the paper prototype of *Our Dementia Journey Journal* and provide commentary and suggestions for ensuring cultural safety and for its usefulness in their relationships especially during changes. We also engaged with a community in British Columbia via virtual workshop.

Through these four workshops, we received considerable feedback on the look and feel of the prototype with a goal of making the *Journal* more culturally safe and geographically relevant. We heard from workshop participants that they believed the core components of the *Journal* would be helpful to improve the care of persons living with dementia and we received feedback about how to make the *Journal* more culturally safe. Since then, we have revised the prototype *Journal* for these communities, resulting in two adapted versions of the *Journal*. Furthermore, we have translated these adapted versions into French and have also created e-

versions that offer an alternative to the paper format *Journal*.

What are we doing?

We are currently in the process of delivering the adapted *Journals* (in both paper and e-version format) to the communities involved to see if they find it useful and if it improves relationships, resulting in improved quality of life and mental health.

We have also been seeking to engage people in additional communities across Canada to provide their feedback about *Our Dementia Journey Journal* so we can improve it and make it more useful. In particular, we have been looking to engage rural, remote and isolated communities to get a variety of perspectives. We also plan to engage with one or more communities with predominantly francophone residents.

In addition, we have been developing a mobile application 'generic' version of the *Journal*, as requested by participants; with plans to start user acceptance testing in early May 2022. It is hoped that this version of the *Journal* will increase the tool's reach across Canada.

What is the intended impact?

We hope that our work on *Our Dementia Journey Journal* will make lives better for people living with dementia, their caregivers and their care providers.

How is the research funded?

This research was funded by the Public Health Agency of Canada under its Dementia Community Investment Program, and by SE Health.

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Well-being Communication

Throughout your journey you may want to document concerns you feel. Use this page as often as you would like to share your experiences. You may want to take this form to your physician/medical appointments to help guide discussions about possible treatment options and interventions.

Today's Date: _____

Person documenting:
 Person living with dementia
 Caregiver Care provider

I'm concerned about:

Why:

I need someone to: Hear me Help me Take action

Response:

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An excerpt of one of the pages of *Our Dementia Journey Journal*, Adapted for the northern Ontario First Nations communities

About the SE Research Centre

The SE Research Centre is funded by SE Health to conduct impact-oriented health services research and evaluation for the benefit of Canadians. We study the needs of people, their caregivers, and health care providers, to develop evidence-based solutions to tough health and social care problems. Our researchers collaborate with a wide variety of community and academic partners across Canada.

In the SE Research Centre there are four fields of research and evaluation: Aging in Society; Dying, Death and Grief; Health and Care Experiences; and Models of Care Delivery.

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