

Our Dementia Journey Journal

A co-designed tool for strong partnerships between caregivers and care providers of persons living with dementia

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*. With funding from the Public Health Agency of Canada and SE Health, we have adapted the tool in response 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 type of care providers. We have also heard that there are changes over time in the roles of caregivers and care providers over time – and their respective roles in providing the “clinical” versus the 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 at all times, and particular in the times of change.

In response, over the course of more than a year, 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?

We have engaged, via in-person workshops, with persons living with dementia and their caregivers in three First Nations communities in northern Ontario, to get their feedback on the paper prototype *Journal*. We

also engaged with a community in rural British Columbia via a 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 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.

Since the workshops, we have revised the prototype *Journal* for these communities, translated them into French and created e-versions as an alternative to the paper format. We are currently delivering the adapted *Journals* (in both paper and e-version format) to the communities to see if they find it useful and if it improves relationships, resulting in improved quality of life and mental health. A mobile application version of the *Journal* is also currently under development with plans to start User Acceptance Testing in early June 2021. It is hoped that this version of the *Journal* will increase its reach across Canada.

What are we doing next?

We are now setting out to engage with people in additional communities across Canada to further improve *Our Dementia Journey Journal*. We are looking to engage additional rural, remote and isolated communities, as well as one or more communities with predominantly francophone residents.

With these communities, we will be holding online workshops with up to 15 participants (including people living with dementia, their caregivers and health care providers). Participants will be invited to provide recommendations to ensure cultural safety and increase usefulness. As with the earlier communities, we will provide *Our Dementia Journal Journey* to families and care providers, with changes suggested in the workshops, to be used in their community.

How is the research funded?

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

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

Researchers from the SE Research Centre

Dr. Paul Holyoke, Executive Director
Dr. Justine Giosa, Managing Director
Dr. Heather McNeil, Senior Research Associate
Dr. Anna Neely, Senior Research Associate
Karthika Yogaratnam, Research Associate

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.

Visit research.sehc.com Contact research@sehc.com