

# *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*. With funding from the Public Health Agency of Canada and SE Health, we are now testing to make sure it responds to 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. We call it *Our Dementia Journey Journal*. It is in paper format, and soon will be a prototype app.

### **What have we done?**

We have engaged with persons living with dementia and their caregivers in three First Nations communities in northern Ontario, to get their feedback on the paper prototype. We received considerable feedback on the

look and feel of the prototype with a goal of making the *Journal* more culturally relevant. We also heard that the essential components of the *Journal* would be helpful to improve the care of persons living with dementia. We are revising the prototype for these communities, and will return the revised prototype (along with a prototype electronic version) to them to try out to see if they find it useful, if it improves relationships, resulting in improved quality of life and mental health.

### **What are we doing next?**

We are now setting out to engage with people in additional communities across Canada to let us know about the prototype *Our Dementia Journey Journal* so we can improve it and make it useful. We are looking to engage additional urban, rural, remote and isolated communities to get a variety of perspectives. We will also be engaging with one or more communities with predominantly francophone residents.

With these communities, we will be holding online workshops with up to 15 participants (people living with

dementia, caregivers and health care providers). Participants will be invited to review the *Our Dementia Journey Journal* and provide commentary and suggestions for ensuring cultural safety and for its usefulness in their relationships especially during changes.

In a later stage, as with the first three First Nations, communities, if these additional communities would like to participate, we will provide *Our Dementia Journey Journal* to families and care providers, with changes suggested in the workshops, to be used in their community. Again, we will monitor whether *Our Dementia Journey Journal* makes a difference in people's lives – improved relationships, better quality of life and mental health.

### **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.

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### **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.

### **Researchers**

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### **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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