

Our Dementia Journey Journal: A co-designed tool to support partnerships among persons living with dementia, their caregivers and care providers

Unpaid caregivers and care providers of persons living with dementia (PLWD) told us they want a tool to help them communicate with each other and support their individual and joint roles for working together in dementia care.

18 months of co-design work led to the development of a prototype tool for supporting unpaid caregivers and care providers of PLWD. We call it *Our Dementia Journey Journal*. With funding from the Public Health Agency of Canada and SE Health, we have spent the last 3 years adapting the tool to reflect the diverse needs of people in a variety of communities across Canada.

Project Overview

As of 2020, there were approximately 597,000 Canadians living with dementia, with numbers expected to rise to almost a million by the year 2030.¹ In turn, Canada's 2022 Dementia Strategy calls for increased capacity to care for persons living with dementia (PLWD) with an emphasis on integrated, person-centred, quality care.²

Person- and family-centred care (PFCC) means actively involving PLWD in their own care throughout the dementia journey³ and has been described by PLWD, their unpaid caregivers and care providers as “promoting a continuation of self and normality”.⁴

In a collaborative project exploring PFCC in dementia care with the Alzheimer's Society of Canada we heard from unpaid caregivers and care providers of PLWD 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 the roles of unpaid caregivers and care providers change over time, including their roles in providing “clinical” versus more “emotional, relational” care. They told us they would like to have a tool to help them communicate with each other and support their individual and joint roles for working together in dementia care.

In response, over the course of 18 months, we held 6 co-design workshops with 26 unpaid caregivers and care providers of PLWD in an Ontario long-term care home community to develop a prototype paper-based tool for unpaid caregivers and care providers to be active, informed, collaborative caregivers of PWLD. We call this tool *Our Dementia Journey Journal* (ODJJ).

Considering the diverse experiences of PLWD, their unpaid caregivers, and care providers there remained questions about whether the content,

focus and structure of the ODJJ would be relevant to other communities who differ based on their access to health resources (e.g., geographic location), culture, race and/or language.

What have we done?

We completed community-based consultations and workshops with PLWD, their unpaid caregivers and care providers with two First Nations and one urban Indigenous community in Northern Ontario (n=34), a group in British Columbia (n=5) and members of South Asian communities in Ontario and Alberta (n=10). Participants were invited to review the paper prototype of the ODJJ and provide commentary and suggestions for ensuring cultural safety and for its usefulness in their relationships especially during changes along the dementia journey.

Through these consultations and workshops, we received considerable feedback on the look and content of the prototype. Feedback included the need for culturally relevant imagery as depicted by the medicine wheel in Figure 1 which is part of the Northern Ontario First Nations version of the ODJJ; the request for a digital version of tool; and changes to layout like including more room for writing questions. At the same time, we heard from participants that they believed the core components of the *Journal* would be helpful to improve the care of PLWD.

Since then, we have revised the prototype and developed community-specific versions of the ODJJ. Furthermore, we have translated these adapted versions into French, Punjabi, and Hindi and have also created e-versions that offer an alternative to the paper format.

Following adaptation, we provided revised versions of the ODJJ (in both paper and e-version format) to 10 members from the British Columbia and First Nations communities involved. Participants were asked to complete a survey before and after using the *Journal* for a minimum period of three months. Participants found the ODJJ useful in different ways

including to connect with others in the circle of care and to reflect through journaling.

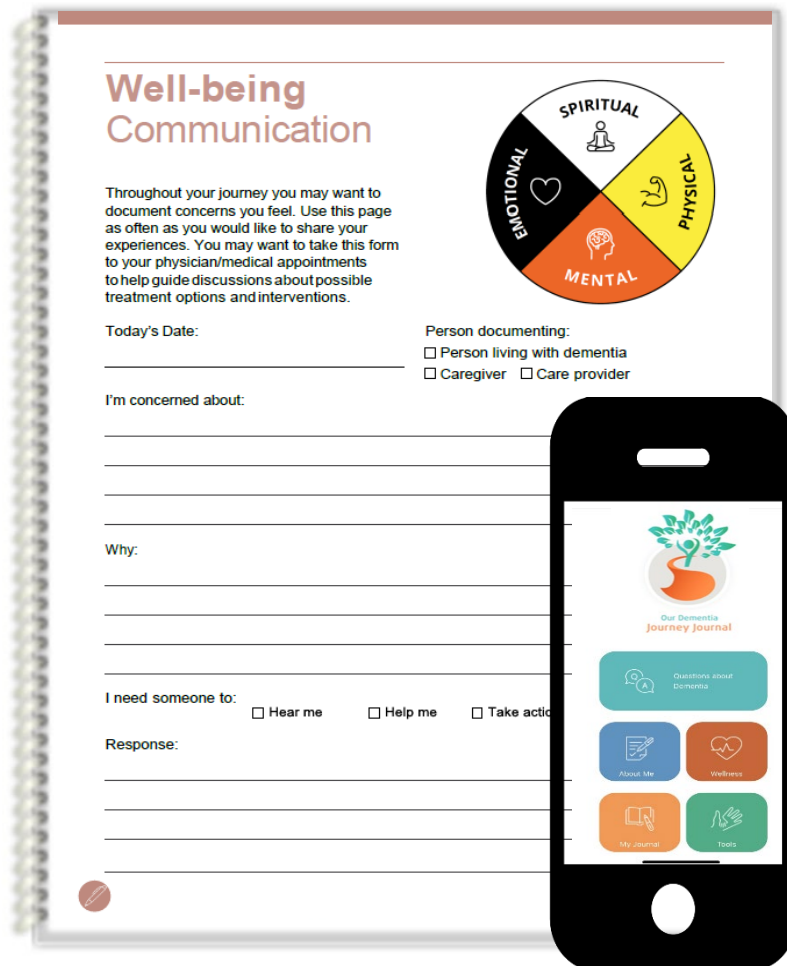


Figure 1. The image above, is an excerpt of one of the pages of *Our Dementia Journey Journal*, adapted for the Northern Ontario First Nations communities. The image on the right, is a screenshot of the home screen of *Our Dementia Journey Journal* mobile

What are we doing?

We are currently working on optimizing the South Asian version of the ODJJ through further co-design with community members. This version will be made available in English, Punjabi, and Hindi.

In addition, we have been developing a mobile application 'generic' version of the ODJJ, as requested by participants. It is hoped that the mobile application will increase the tool's reach across Canada.

Lastly, as a part of new Public Health Agency of Canada (PHAC) funding, we began the deployment of the ODJJ paper, e-version and app in facility-based continuing care in Alberta, First Nations communities across Canada, and South Asian communities in Southern Ontario in the fall of 2023. This project will focus on the evaluation and sustainability planning of the tool so that it can be used more widely and beyond the funding by PHAC.

What is the intended impact?

We hope that our work on *Our Dementia Journey Journal* will strengthen relationships among the dementia circle of care enhancing the quality of dementia care in different settings across Canada.

How is the research funded?

This research was and is funded by the Public Health Agency of Canada under its Dementia Community Investment Program, and by SE Health, one of Canada's largest social enterprises.

For more information, contact:

Paul Holyoke LLB MSc(Econ) PhD

Vice President, Research & Innovation, SE Health

Justine Giosa PhD

Scientific Director, SE Research Centre

Valentina Cardozo MSc

Research Associate, SE Research Centre

Paige Fernanes MSc

ODJJ Project Manager, SE Research Centre

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