

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

A variety of tools and care models exist to support person- and family-centred care for persons living with dementia (PLWD). Family/friend caregivers and care providers of PLWD told us that they want a tool to help them communicate better with each other and support their individual and joint roles in dementia care.

Eighteen months of co-design work led to the development of a prototype tool for supporting family/friend 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 3 additional years adapting the prototype tool to reflect the diverse needs of people in a variety of communities across Canada. Now, we are in a position to deploy the refined tool to various communities across Canada, and to develop concrete plans for the longer-term vision of scale and spread of *Our Dementia Journey Journal*.

Project Overview

It is expected that the number of Canadians living with dementia will reach almost a million by the year 2030.¹ 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 care throughout the dementia journey³ and has been described by PLWD, their caregivers and care providers as "*promoting a continuation of self and normality*".⁴

In a collaborative project in 2017-18 exploring PFCC in dementia care with the Alzheimer's Society of Canada, we worked with caregivers and care providers of PLWD. They told us 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 caregivers and care providers change over time, including their roles in providing "clinical" versus more "emotional, relational" care. They expressed

interest in a tool to help them communicate with each other and support their relationship as well as individual and joint roles in working together in the journey.

In response, over the course of 18 months, we held 6 co-design workshops with 26 caregivers and care providers of PLWD in an Ontario long-term care home community to develop a prototype paper-based tool to enable caregivers and care providers to be more active, informed and collaborative in their care for PLWD. We called this tool **Our Dementia Journey Journal (ODJJ)**, and it is designed to be able to be used by the entire "circle of care" – caregivers, care providers and PLWD.

Considering the diverse experiences of members in the circle of care, we had questions about whether the content, focus and structure of the ODJJ would be relevant to other communities that differ in various ways (e.g., their access to health resources, geographic location, culture, ethnicity and language).

What have we done?

We completed community-based consultations and workshops with PLWD, their 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 (n=16). Participants were invited to review the paper prototype of the ODJJ and provide commentary and suggestions for ensuring cultural safety and 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 the tool; and changes to layout like including more room for writing questions. We also heard from participants that they believed the core components of the ODJJ would be helpful to improve the care of PLWD and to improve the relationships between caregivers and care providers.

Since then, we have revised the prototype and developed community-specific versions of the ODJJ. 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 ODJJ 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.

We have developed a mobile application based on the paper-based ODJJ, as requested by participants. The mobile application is available on both Android and iOS platforms in English, French, Hindi, and Punjabi. We have also adapted a version for First Nation and Urban Indigenous communities. The mobile application will be available for public release on Google Play and the Apple Store later in 2024. Revised paper-based versions of the ODJJ in

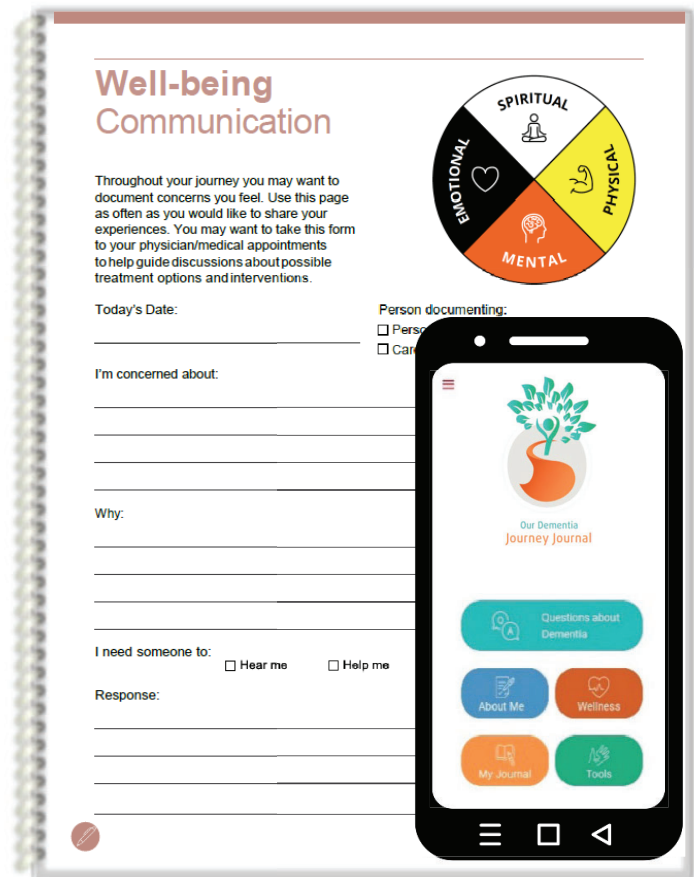


Figure 1. This is an excerpt of one of the pages of Our Dementia Journey Journal, adapted for the Northern Ontario First Nations communities. The image on the right is the home screen of the mobile app.

English, French, Punjabi and Hindi have been developed as well.

What are we doing now?

With new Public Health Agency of Canada (PHAC) funding, we began the deployment of the ODJJ paper and app in two facility-based continuing care homes in Alberta in the spring of 2024. In the summer of 2024, we will make the ODJJ available in South Asian communities in Ontario and First Nations and urban Indigenous communities across Canada. We will focus on developing successful deployment approaches and planning for sustainability of the ODJJ so that it can be made widely available to all Canadians 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 circle of care and enhance the experiences for caregivers, care providers and PLWD along the dementia care journey in different settings across Canada.

How is the research funded?

This project 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.



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References

1. Alzheimer's Society of Canada (2022). *Navigating the path forward for dementia in Canada*. <https://alzheimer.ca/en/research/reports-dementia/navigating-path-forward-landmark-report-1>
2. Public Health Agency of Canada (2022). A *Dementia Strategy for Canada: 2022 Annual Report*. <https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/dementia-strategy-annual-report-parliament-2022/dementia-strategy-annual-report-parliament-2022-en.pdf>
3. Alzheimer's Society of Canada (2011). *Guidelines for Care: Person-centred care of people with dementia living in care homes*. https://alzheimer.ca/sites/default/files/documents/Guidelines-for-Care_Alzheimer-Society-Canada.pdf
4. Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *J Clin Nurs*, 19(17-18), 2611-2618.