

Our Dementia Journey Journal: Frequently Asked Questions (FAQs)

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General Questions about the Our Dementia Journey Journal (ODJJ)

1. What is the Our Dementia Journey Journal (ODJJ)?

The ODJJ is an interactive tool that aims to strengthen relationships between caregivers, and their care providers as they support people living with dementia. It exists as a paper version and a mobile application available for download on Android or Apple phones or tablets.

2. Who can use the ODJJ?

The ODJJ can be used by anyone involved in a person living with dementia's Circle of Care from family and friends in caregiving roles to health care providers. There is no limit to the number of members that the Circle of Care can contain.

3. Is there a cost to access/use the ODJJ?

No, the ODJJ is a free resource which you can use at your convenience.

4. Can multiple caregivers/ care providers contribute to the ODJJ for the same person living with dementia?

Yes, the ODJJ offers space for different members of the Circle of Care to connect, share information about yourselves and reflect along the journey together.

5. What kind of information can be shared in the ODJJ?

The ODJJ offers a safe space to record the following kind of information to keep to yourself or share with the Circle of Care:

- Questions about dementia — symptoms, feelings, or who's responsible for what.
- Personal information to get to know the rest of the Circle of Care and what they experience and expect throughout the dementia journey.
- Well-being tracking including symptoms, mood, and concerns.
- Personal reflections you may have along the journey.
- Resources that you find useful to refer to later.
- Photos and videos — there are multiple areas within the tool which you can add photos and videos.

The ODJJ is intended to support relationship building. Any information you choose to include in the tool is accessible to the members of your Circle of Care.

6. Is the ODJJ customizable to my unique needs or the unique needs of my Circle of Care?

There is no single way to use the ODJJ, feel free to use it however would best help you and your Circle of Care.

The ODJJ can be customized in various ways to meet the specific needs and preferences of any member of the Circle of Care. In the paper version, pages can be added or removed according to need or preference. In the app, images, symptoms, prompts, and tools are all adjustable.

7. I've run out of pages in my ODJJ, is there a way to print out more?

Yes, you may print out any of the ODJJ pages from any language and version you would like on the SE Research Centre webpage. Visit the "Download the Paper-Based ODJJ" available on our website: <https://research.sehc.com/resources/aging-in-society/our-dementia-journey-journal>.

8. Can I use more than one format of the ODJJ simultaneously (e.g., paper and the app)?

Yes, you can use both formats of the ODJJ if that helps you and your Circle of Care. For instance, you may use the app's questions or chat features and then visit the website <https://research.sehc.com/resources/aging-in-society/our-dementia-journey-journal> to print off pages such as the monthly dementia symptom tracker or bi-weekly check-in to fill out manually.

Questions about Cultural Relevancy

9. Is the ODJJ customizable to my unique needs or the unique needs of my Circle of Care?

The ODJJ paper version is available in English, French, Hindi and Punjabi.

The ODJJ app is currently available in English and French and will be available in Hindi and Punjabi by March 2024.

10. What different versions of the ODJJ exist?

There are three adaptations of the ODJJ: the Generic Version, the First Nations Version, and the South Asian Version.

The paper edition is available in all three versions. The app is available in the Generic Version and the First Nations Version.

11. How does the ODJJ address cultural practices and preferences in caregiving?

The First Nations Version and South Asian Version of the ODJJ were co-designed with people living with dementia, their caregivers and their care providers from First Nations, urban Indigenous and South Asian communities across the country through community-based consultations and workshops to ensure that the tool is culturally safe and useful.

Furthermore, the tool can be customized to meet the specific needs and preferences of a care partner or Circle of Care. In the paper version, pages can be added or removed according to need or preference. In the app, images, symptoms, prompts, and tools are all adjustable.

Questions about the ODJJ Mobile Application

12. What devices is the ODJJ app available on?

The ODJJ is available for Android and Apple devices. Please contact us at PaigeFernandes@sehc.com to download the app onto your phone or tablet.

13. Someone in my Circle of Care does not have an email address. Can they still sign up for the ODJJ app?

No, unfortunately the app requires an email address to create an account. If you do not have an email address and still wish to use the ODJJ tool, please consider using the paper version.

14. Who has access to my data on the ODJJ app?

Only you and members of your Circle of Care have access to your personal information, photos, and entries that you input into the app.

15. If I no longer want to use the ODJJ app, is there a way my data can be deleted?

You can request to delete your information from the application which includes your profile and all information which you have input into the application. Please contact research@sehc.com to delete your data from the ODJJ application.

16. What technological support is available for ODJJ app users?

There are video tutorials linked throughout the app that walk users through the basic functions and commands of each section. These videos are accessible from the information page of each section of the app at any time.

Feedback & Questions

17. Who can I reach out to if I have questions?

If you have any questions, please feel free to contact Paige Fernandes at PaigeFernandes@sehc.com or call 416-355-5901.

18. How can I provide feedback?

We would love to hear any feedback you have. Please reach out to Paige Fernandes at PaigeFernandes@sehc.com or call 416-355-5901 to get in touch.

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