

Our Dementia Journey Journal: Frequently Asked Questions (FAQs)

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Table of contents

General Questions about the Our Dementia Journey Journal (ODJJ) 4

1. What is the Our Dementia Journey Journal (ODJJ)?..... 4
2. What is a Circle of Care?..... 4
3. Who can use the ODJJ? 4
4. Is there a cost to access/use the ODJJ?..... 4
5. Can multiple caregivers/ care providers use the ODJJ for the same person living with dementia? 4
6. What kind of information can be shared in the ODJJ?..... 4
7. Can the ODJJ be adjusted to fit my needs??5
8. I’ve run out of pages in my ODJJ, is there a way to print out more?.....5
9. Can I use different formats of the ODJJ, like the paper version and the app, at the same time?5

Questions about Cultural Relevancy..... 5

10. What languages is the ODJJ available in?.....5
11. What different versions of the ODJJ exist?.....5
12. How were the cultural changes for the ODJJ decided and made?..... 6

Questions about the ODJJ Mobile Application 6

13. What devices is the ODJJ app available on?..... 6
14. Can someone in my Circle of Care who doesn’t have an email address still sign up for the ODJJ app? 6
15. Who can see my data on the ODJJ app?..... 6
16. If I decide to stop using the ODJJ app, can my data be deleted?..... 6
17. What support is available for ODJJ app users? 6

Feedback & Questions..... 7

18. Who can I reach out to if I have questions?.....7
19. How can I provide feedback?.....7

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 support relationships and communication between caregivers, and health care providers as they support persons living with dementia. It is available as a paper version and a mobile application on Android or Apple phones or tablets.

2. What is a Circle of Care?

In the ODJJ, we use the term Circle of Care to describe the connections between a person living with dementia, their family/friend caregivers, and their healthcare providers.

3. Who can use the ODJJ?

The ODJJ can be used by a person living with dementia, their family/ friends in caregiving roles, and their health care providers.

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

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

5. Can multiple caregivers/ care providers use the ODJJ for the same person living with dementia?

Yes, the ODJJ offers space for all members of a Circle of Care to complete activities and reflect on the dementia journey together.

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

The ODJJ offers a safe space to record the following information with the Circle of Care:

- Questions about dementia — symptoms, feelings, role and responsibilities
- Personal information to get to know the rest of the Circle of Care
- Well-being tracking including symptoms, mood, and concerns
- Personal reflections you may have along the journey
- Resources that you can collect along the dementia journey
- Photos and videos — there are multiple areas within the ODJJ where you can add photos.

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.

7. Can the ODJJ be adjusted to fit my needs??

There is no single way to use the ODJJ, feel free to use the activities that you find most helpful or meaningful.

The ODJJ can be customized to meet your needs and preferences. In the paper version, pages can be added or removed according to your preference. In the app, features, images, font size, prompts, and tools can be adjusted.

8. 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 from 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>.

9. Can I use different formats of the ODJJ, like the paper version and the app, at the same time?

Yes, you can use both formats of the ODJJ if you prefer. 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 by hand.

Questions about Cultural Relevancy

10. What languages is the ODJJ available in?

The ODJJ paper version and app are both available in English, French, Hindi and Punjabi.

11. 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 and app versions are available in all three versions.

12. How were the cultural changes for the ODJJ decided and made?

The First Nations Version and South Asian Version of the ODJJ were created with feedback from people living with dementia, their caregivers, and care providers from First Nations, Urban Indigenous, and South Asian communities across Canada. We did this through consultations and workshops to make sure the tool is culturally safe and relevant. Now, we're looking for more feedback to see if there are other ways to improve the ODJJ and better serve different cultural communities.

Questions about the ODJJ Mobile Application

13. What devices is the ODJJ app available on?

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

14. Can someone in my Circle of Care who doesn't have an email address still sign up for the ODJJ app?

No, the app needs an email address to create an account. If you don't have an email address, you can still use the paper version of the ODJJ tool.

15. Who can see my data on the ODJJ app?

Only you and members of your Circle of Care can see your personal information, photos, and entries in the app.

16. If I decide to stop using the ODJJ app, can my data be deleted?

Yes, you can ask to delete your information from the app, including your profile and all your entries. Just contact odjj@sehc.com to request data deletion.

17. What support is available for ODJJ app users?

The app has video tutorials that show you how to use each section. You can access these videos from the information page of each section at any time. If you have any additional questions, please reach out to odjj@sehc.com.

Feedback & Questions

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

If you have any questions, please contact odjj@sehc.com. You will receive a response within 1-3 business days.

19. How can I provide feedback?

We would love to hear any feedback you have. Please contact odjj@sehc.com. You will receive a response within 1-3 business days.

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. Visit research.sehc.com or contact us at research@sehc.com.