

Our Dementia Journey Journal

“Share more. Care together. Stay connected”

An Overview of ODJJ for caregivers and care providers



ODJJ
Our Dementia
Journey Journal

Agenda

ABOUT OUR DEMENTIA JOURNEY JOURNAL

KEY MESSAGE & TESTIMONIALS

NEXT STEPS

Q&A



THE OUR DEMENTIA JOURNEY JOURNAL



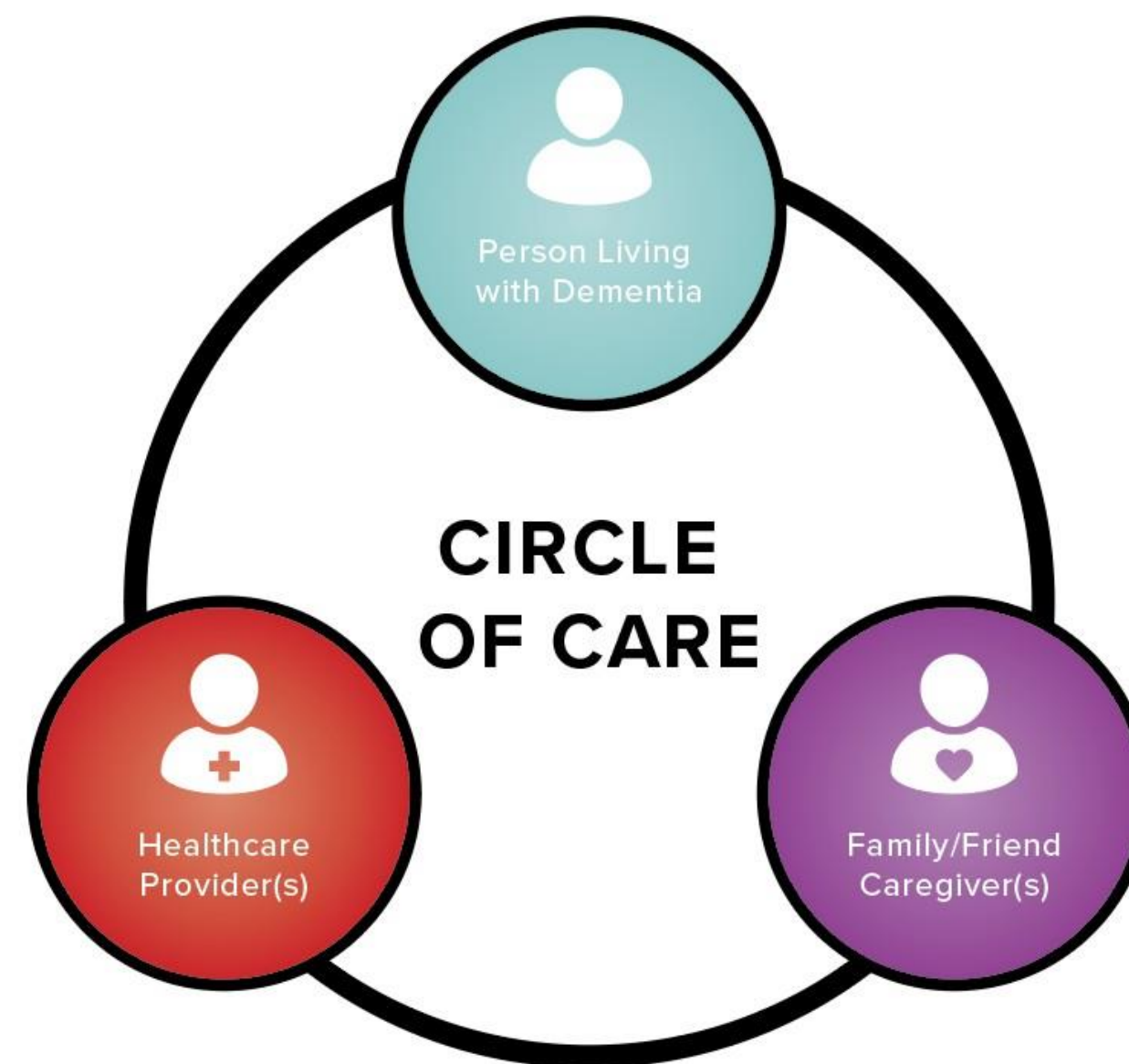
An interactive resource
Co-designed, tested and refined
with and for people living with
dementia, family/friend
caregivers, and healthcare
providers



The Circle Of Care

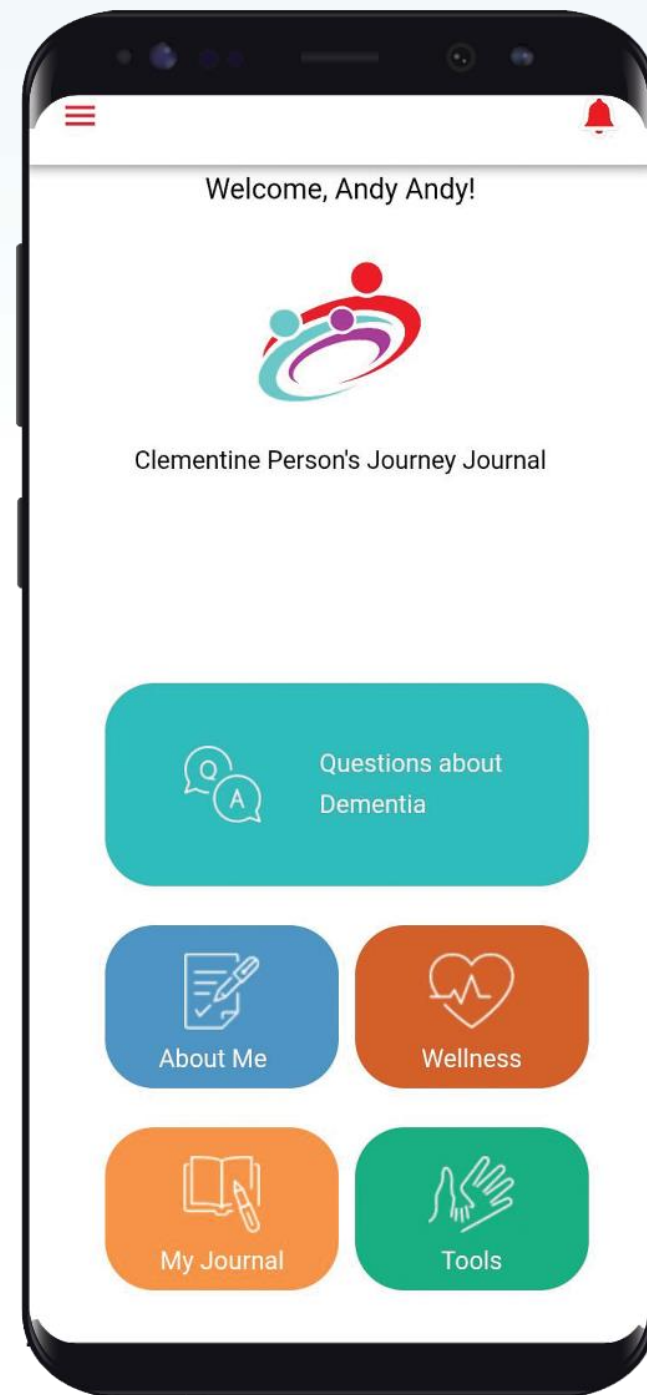
A Circle of Care is made of the relationships between family and friends in caregiving roles, health care providers and a person living with dementia.

The ODJJ aims to strengthen the relationships specifically between caregivers and health care providers as they support a person living with dementia.



ODJJ VERSIONS & LANGUAGES

Formats – App (Apple & Android), Paper Based
Versions - Generic, First Nations, South Asian
Languages - English, French, Hindi, Punjabi



ODJJ Our Dementia Journey Journal
 This journal is adapted by and for the general public

Blue Pages: for sharing information to support relationship building
Pink Pages: a place to document your journey and well-being
Peach Pages: for diary keeping and noting your reflections
Green Pages: resources for when you are feeling overwhelmed

This is your journal, use it however you like!

ODJJ Our Dementia Journey Journal
 This journal is adapted by and for First Nations people

Blue Pages: for sharing information to support relationship building
Pink Pages: a place to document your journey and well-being
Peach Pages: for diary keeping and noting your reflections
Green Pages: resources for when you are feeling overwhelmed

This is your journal, use it however you like!

Notre journal de bord avec la démence
 Ce journal a été adapté par et pour un publique francophone

Pages Bleues: pour partager de l'information à fin d'établir de bonnes relations.
Pages Roses: un endroit où documenter votre parcours et votre bien être.
Pages Pêches: pour noter vos réflexions et tenir un carnet intime.
Pages Vertes: des ressources pour quand vous vous sentez dépassé.

Ceci est votre journal. Utilisez-le comme bon vous semble!

ODJJ Our Dementia Journey Journal
 This journal is adapted by and for South Asian communities in Canada

Purple Pages: an introduction to this journal
Blue Pages: for sharing information to support relationship building
Pink Pages: a place to document your journey and well-being
Orange Pages: for diary keeping and noting your reflections
Green Pages: available resources and services

This is your journal, use it however you like!

ਸਾਡਾ ਡਿਮੈਂਸ਼ੀਆ ਜਰਨੀ ਜਰਨਲ
 ਇਹ ਸਾਪਨ ਤੁਹਾਡੇ ਲਈ ਹੈ। ਤੁਸੀਂ ਇਸਦੀ ਵਰਤੋਂ ਜਿਵੇਂ ਚਾਹੋ ਕਰ ਸਕਦੇ ਹੋ।

ਜਾਮਨੀ ਪੰਨੇ: ਇਸ ਜਰਨਲ ਦੀ ਜਾਣ-ਪਛਾਣ
ਨੀਲੇ ਪੰਨੇ: ਸਾਂਝੇਦਾਰੀ ਦੇ ਨਿਰਮਾਣ ਲਈ ਜਾਣਕਾਰੀ ਸਾਂਝੀ ਕਰਨ ਲਈ ਹੁੰਦੇ ਹਨ
ਗੁਲਾਬੀ ਪੰਨੇ: ਤੁਹਾਡੀ ਯਾਤਰਾ ਅਤੇ ਤੇਜ਼ਗੀ ਨੂੰ ਦਰਜ ਕਰਨ ਲਈ ਜਗ੍ਹਾ ਦੀ ਪੇਸ਼ਕਸ਼ ਕਰਦੇ ਹਨ
ਸੰਤਰੀ ਪੰਨੇ: ਤੁਹਾਡੇ ਪ੍ਰਤੀਬਿੰਬਾਂ ਨੂੰ ਨੋਟ ਕਰਨ ਅਤੇ ਜਰਨਲ ਲਈ ਜਗ੍ਹਾ
ਹਰੇ ਪੰਨੇ: ਉਪਲਬਧ ਸੰਸਥਾਨ ਅਤੇ ਸੇਵਾਵਾਂ

हमारा डिमेंशिया जर्नी जर्नल
 यह साधन आपके लिए है। आप जैसे चाहें इसका इस्तेमाल कर सकते हैं।

बैंगनी पन्ने: इस जर्नल का परिचय देते हैं
नीले पन्ने: साझेदारी के निर्माण के लिए जानकारी साझा करने के लिए हैं
गुलाबी पन्ने: आपकी यात्रा और तेजस्वी को दर्शाते हैं बनाने के लिए एक जगह हैं।
संतरी पन्ने: आपके विचार और डायरी लिखने के लिए स्थान
हरे पन्ने: उपलब्ध संसाधन और सेवाएं

ODJJ FEATURES



Ask: Record and answer questions within the Circle of Care.



Share: Share words, pictures and videos with the Circle of Care.



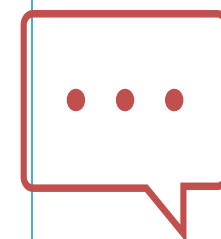
Track well-being: Monitor wellness over time.



Reflect: Journal and share notes or reflections.



Resources: Collect information from sources like the Alzheimer Society.



Chat: Send and receive messages and updates within the Circle of Care.



Validation & preparation for spread

The ODJJ was launched in 7 diverse communities in Ontario and Alberta between March 2024 and January 2025.

- Continuing care/long-term care homes
- First Nation communities,
- South Asian community organizations, adult day program)



KEY MESSAGES:

The ODJJ offers a variety of tools to:

- 1.Support caregivers and their well-being
- 2.Learn about dementia & dementia care
- 3.Provide person-centered care
4. Access dementia care resources (includes resources for cultural communities such as First Nations, French, South Asian communities)
- 5.De-stigmatize Dementia through conversations

1. Support caregivers and their well-being

“ANYTHING TO HELP HER CARE AND HELP THE PEOPLE WHO ARE CARING FOR HER, I FEEL BETTER ABOUT, AND MY WIFE FEELS BETTER ABOUT IT AS WELL. THERE’S SO MUCH GUILT AROUND LOOKING AFTER FAMILY MEMBERS ... IT WOULD ENHANCE MY QUALITY OF LIFE. BECAUSE CERTAINLY WHEN MY MOM IS DOING BETTER, I FEEL BETTER.” - Caregiver

KEY FEATURE #1

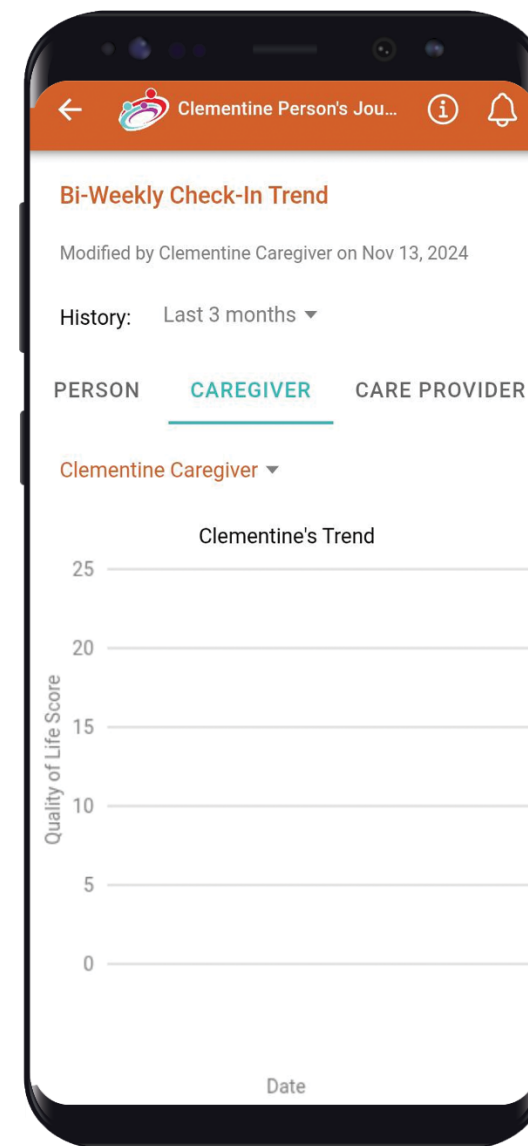
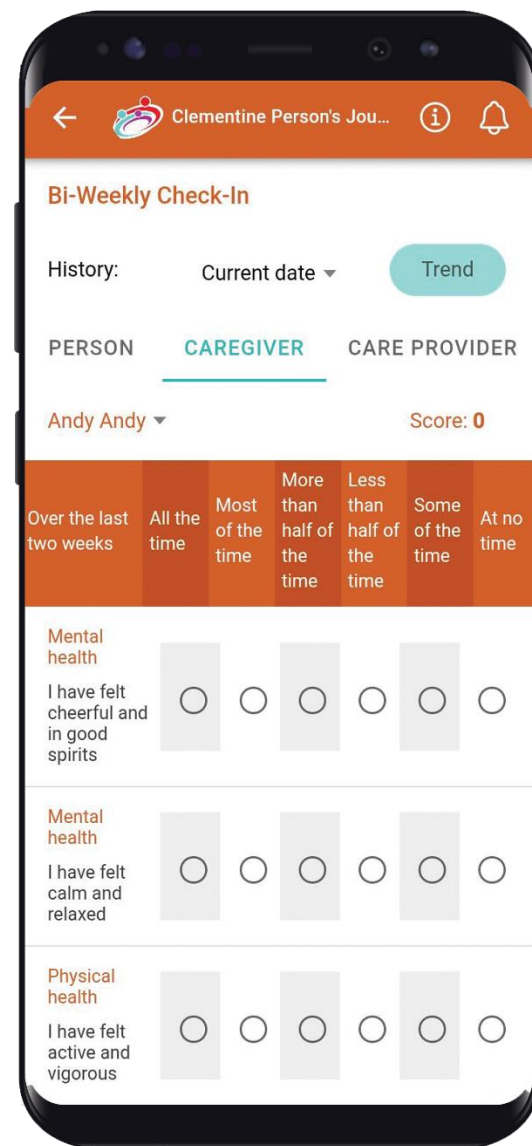
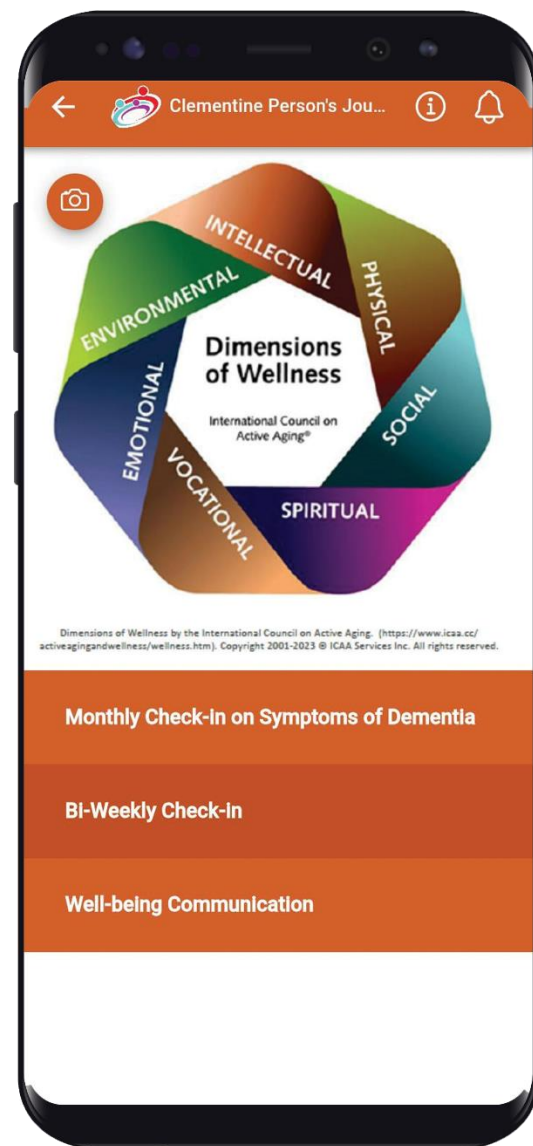
Bi-Weekly Check-In

A space for members of the Circle of Care to check-in with themselves:

- Complete every 2 weeks or whenever works for you
- Monitor your score over time
- Seek support when you notice your score is declining (e.g. support groups, other sections of ODJJ)



Bi-Weekly Check-In



Bi-weekly Check-In

- Purpose**
This activity can help you think about your overall well-being by asking five simple questions. Using this tool can help you understand or communicate your feelings. If your overall score decreases over time, you may want to seek help or talk to someone about what's happening in your life.
- Timing**
We suggest completing this activity every two weeks, but you can use it as often or as little as you like.
- Participants**
Everyone in the circle of care is encouraged to track their wellbeing.

The World Health Organization's Well-Being Index

- Instructions:**
- Please indicate for each of the five statements which closest describes how you have been feeling over the past two weeks.
 - Note that higher numbers mean better wellbeing.
 - Example: If you felt happy and in a good mood more than half of the time during the past two weeks, put a tick in the box numbered 3 in the upper right corner.
 - Your score is calculated by totaling the figures of the five answers. The score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life.
 - There is space below each table to record your score and a tracker to help you monitor your scores over time.

Over the last two weeks:	Date:					
	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
I have felt cheerful and in good spirits	5	4	3	2	1	0
I have felt calm and relaxed	5	4	3	2	1	0
I have felt active and vigorous	5	4	3	2	1	0
I woke up feeling fresh and rested	5	4	3	2	1	0
My daily life has been filled with things that interest me	5	4	3	2	1	0

World Health Organization. 1998. Well-being Index.

You can use the orange pages to reflect on your score. Can you talk to someone about how you are feeling?

2. Learn about dementia and dementia care

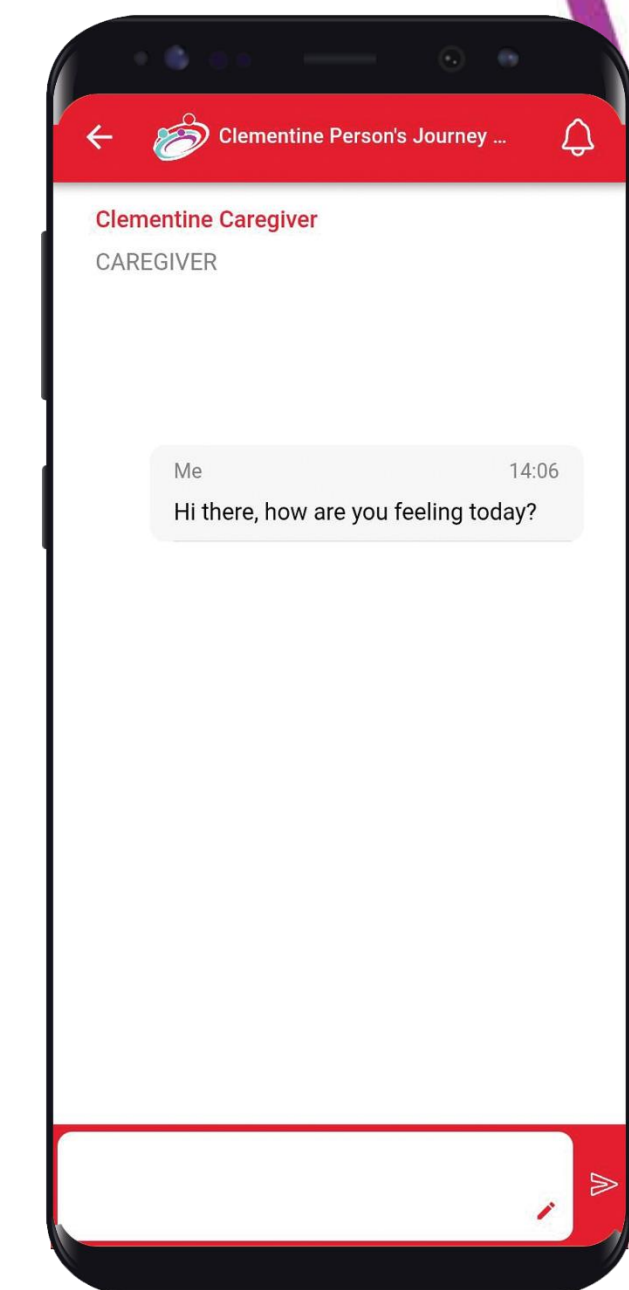
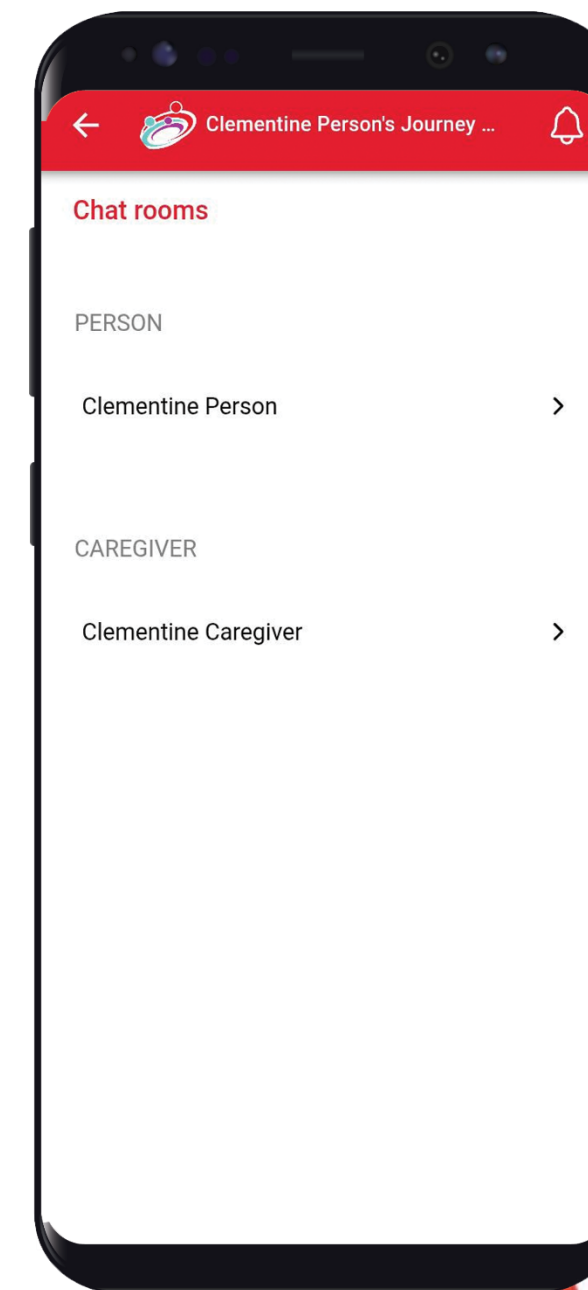
“I could say [in the chat function of the app], ‘His blood sugar was really low this morning and he didn’t eat much breakfast and he’s kind of in a mood and he’s a bit grumpy.’” – Caregiver

KEY FEATURE #2

Chat

A space for members of the Circle of Care to instantly message:

- Updates to care providers (e.g. sleep, blood sugar, etc.)
- Day to day necessities
- Communicate with long-distance caregivers (e.g. siblings or other family members in a different city/country)
- Document changes
- Utilizing this feature can support communication across the Circle of Care.



3. Provide person-centered care

“My mom was still playing the piano, and it was things like that. When there’s musical entertainment in there, I don’t ever want her to miss it” - Caregiver

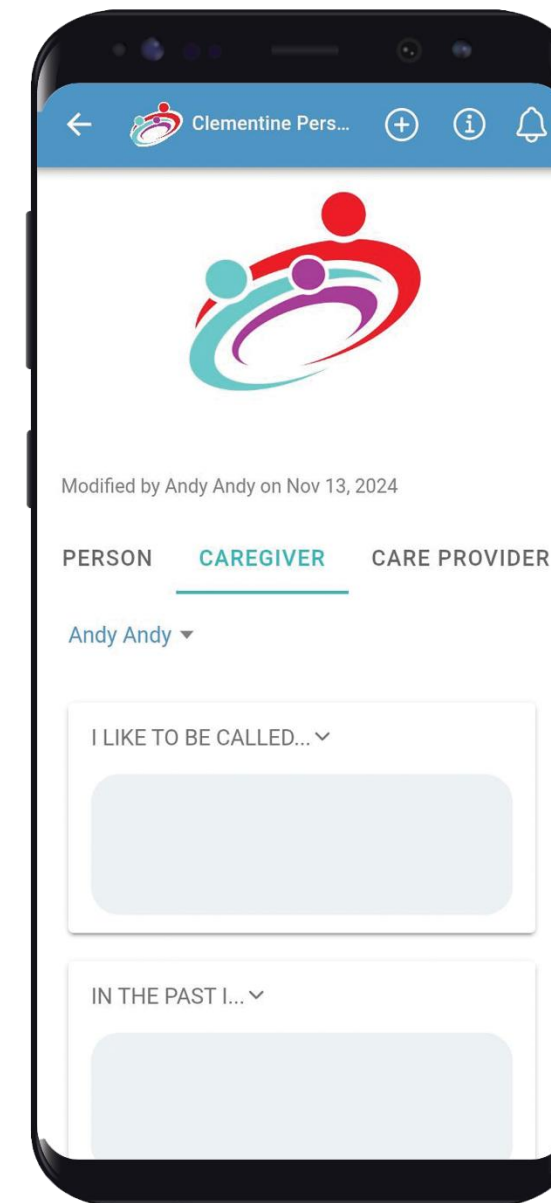
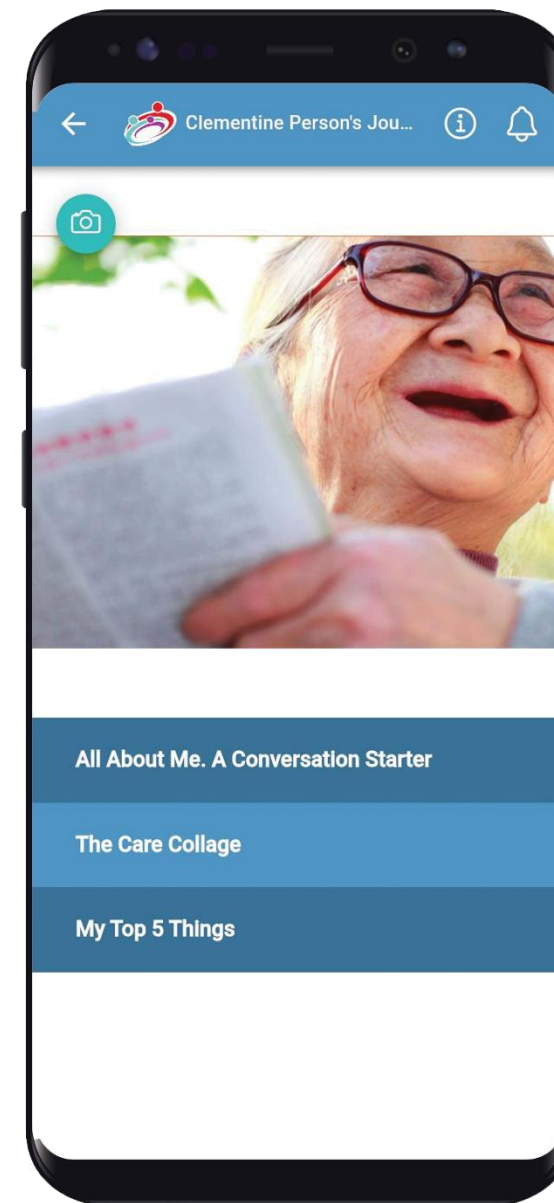
Family members play a vital role in helping staff provide person centered care by sharing what they know about the person living with dementia.

KEY FEATURE #3

All About Me

All About Me outlines the Circle of Care

- Preferences
- Behaviours
- History
- Interests



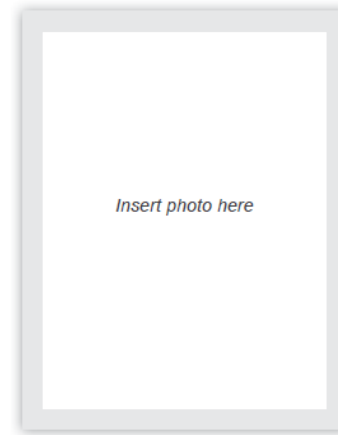
All About Me A Conversation Starter

Date:

This activity can be completed by anyone within the circle of care of a person living with dementia. Content may be reviewed and updated as needed and/or as changes occur through the dementia journey. You do not need to respond to the questions that you prefer not to answer.

I like to be called...

What is your name, nickname or preferred name?



In the past I...

In this section, note past careers, places the person lived, favourite events or activities and important aspects of your past.



4. Access dementia care resources

(includes resources for cultural communities such as First Nations, French-speakers, and South Asian)

“I think that’s a good idea to have that to it right at your fingertips and you don’t have to search for anything.” - Caregiver

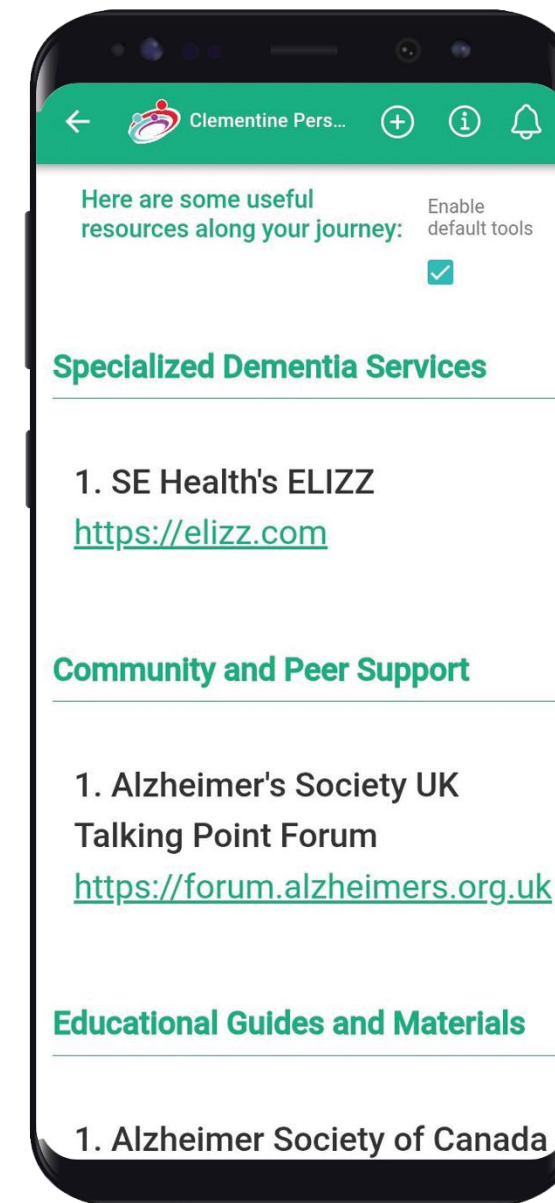
“Because a lot of times, resources, by the time you figure out what resources are there, you’re in the next stage of the journey” - Caregiver

KEY FEATURE #4

Resource Section

The Resource Section

- Standard list of resources
- Upload your own resources as links, files, or pictures



Available resources and services

Here are some resources that you may wish to consult along your journey:

Tip: Access these resources by scanning the QR codes below or by looking up the key words under the 'Resource' column in Google.

Specialized Dementia Services

Resource	Purpose	Language	Who It's For	Access
SE Health's ELIZZ	Offers caregiving services and resources to support individuals caring for people living with dementia.	English	Family/friend caregivers	
Rare Dementia Support	Services, resources and support for people living with rare types of dementia and their care partners.	English	Everyone	

Community and Peer Support

Resource	Purpose	Language	Who It's For	Access
Alzheimer's Society UK Talking Point Forum	Offer or receive support from other dementia care partners by taking part in an online discussion forum.	English	Everyone	
AlzConnected	Offer or receive support from other dementia care partners by taking part in an online discussion forum.	English	Everyone	



5. De-stigmatize dementia through conversations

“... Everyone feels like you’re alone in this whole thing, right? And this whole process. So, when we start talking about resources that are available, then everybody sits up and listens. And also it’s good to know how each one manages their day. ... this app also kind of draws us closer together....” - Caregiver

NEXT STEPS

1. Visit our website to explore the ODJJ further (www.odjj.ca)
1. If you'd like to access resources to use the ODJJ, visit our resource page

Thank you

