

Our Dementia Journey Journal

“Share more. Care together. Stay connected”



ODJJ
Our Dementia
Journey Journal

Agenda

ABOUT OUR DEMENTIA JOURNEY JOURNAL

KEY MESSAGE & TESTIMONIALS

NEXT STEPS

Q&A

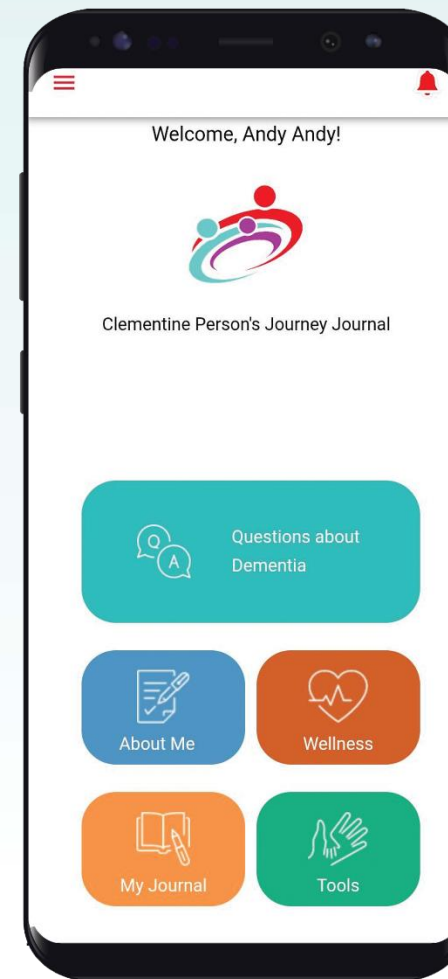
THE OUR DEMENTIA JOURNEY JOURNAL



The Our Dementia Journey Journal (ODJJ) is an interactive resource that was codesigned with and for people living with dementia, their family/friend caregivers, and their healthcare providers.

ODJJ VERSIONS & LANGUAGES

*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



ODJJ
Our Dementia
Journey Journal

This journal is adapted by and for South Asian communities in Canada



ODJJ
Our Dementia
Journey Journal

This journal is adapted by and for First Nations people



Notre journal de bord avec la démence

Ce journal a été adapté par et pour un publique francophone



ਸਾਡਾ ਡਿਮੈਂਸ਼ੀਆ ਜਰਨੀ ਜਰਨਲ

ਇਹ ਸਾਪਨ ਤੁਹਾਡੇ ਲਈ ਹੈ। ਤੁਸੀਂ ਇਸਦੀ ਵਰਤੋਂ ਜਿਵੇਂ ਚਾਹੋ ਕਰ ਸਕਦੇ ਹੋ।



हमारा डिमेंशिया जर्नी जर्नल

यह साधन आपके लिए है। आप जैसे चाहें इसका इस्तेमाल कर सकते हैं।



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!



Purple Pages: an introduction to this Journal

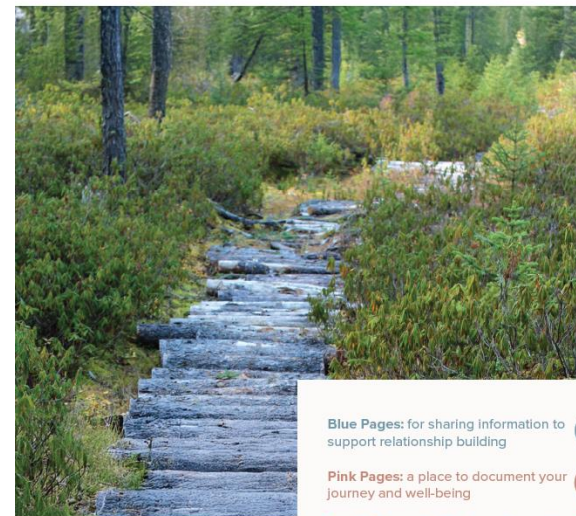
Blue Pages: for sharing information to support relationship building

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!



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!



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

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.



ਜਾਮਨੀ ਪੰਨੇ: ਇਸ ਜਰਨਲ ਦੀ ਜਾਣ-ਪਛਾਣ

ਨੀਲੇ ਪੰਨੇ: ਸਾਂਝੇਦਾਰੀ ਦੇ ਨਿਰਮਾਣ ਲਈ ਜਾਣਕਾਰੀ ਸਾਂਝੀ ਕਰਨ ਲਈ ਹੁੰਦੇ ਹਨ

ਗੁਲਾਬੀ ਪੰਨੇ: ਤੁਹਾਡੀ ਯਾਤਰਾ ਅਤੇ ਤੰਦਰੁਸਤੀ ਨੂੰ ਦਾਖਲੇਬੰਦੀ ਬਣਾਉਣ ਲਈ ਜਗ੍ਹਾ ਦੀ ਪੇਂਚਕਥ ਕਰੋ

ਸੰਤਰੀ ਪੰਨੇ: ਤੁਹਾਡੇ ਪ੍ਰਤੀਬਿੰਬਾਂ ਨੂੰ ਨੋਟ ਕਰਨ ਅਤੇ ਜਰਨਲ ਲਈ ਜਗ੍ਹਾ

ਹਰੇ ਪੰਨੇ: ਉਪਲਬਧ ਸੰਸਾਧਨ ਅਤੇ ਸੇਵਾਵਾਂ



ਕੈਮਨੀ ਪੰਨੇ: ਇਸ ਜਰਨਲ ਦਾ ਪਰਿਚਯ ਦੇਣੇ ਹਨ

ਨੀਲੇ ਪੰਨੇ: ਸਾਂਝੇਦਾਰੀ ਦੇ ਨਿਰਮਾਣ ਲਈ ਜਾਣਕਾਰੀ ਸਾਂਝਾ ਕਰਨੇ ਦੇ ਲਿਓਂ ਹਨ

ਗੁਲਾਬੀ ਪੰਨੇ: ਆਪਣੀ ਯਾਤਰਾ ਅਤੇ ਤੰਦਰੁਸਤੀ ਨੂੰ ਦਾਖਲੇਬੰਦੀ ਬਣਾਉਣ ਲਈ ਜਗ੍ਹਾ ਦੀ ਪੇਂਚਕਥ ਕਰੋ

ਸੰਤਰੀ ਪੰਨੇ: ਆਪਣੇ ਵਿਚਾਰ ਅਤੇ ਡਾਢਾਈ ਲਿਖਣ ਦੇ ਲਿਓਂ ਵਰਤਣ

ਹਰੇ ਪੰਨੇ: ਉਪਲਬਧ ਸੰਸਾਧਨ ਅਤੇ ਸੇਵਾਵਾਂ

ODJJ FEATURES



**Pose and
answer
questions**



**Share with
your Circle of
Care**



**Track your
well-being**



**Journal and
Reflection**



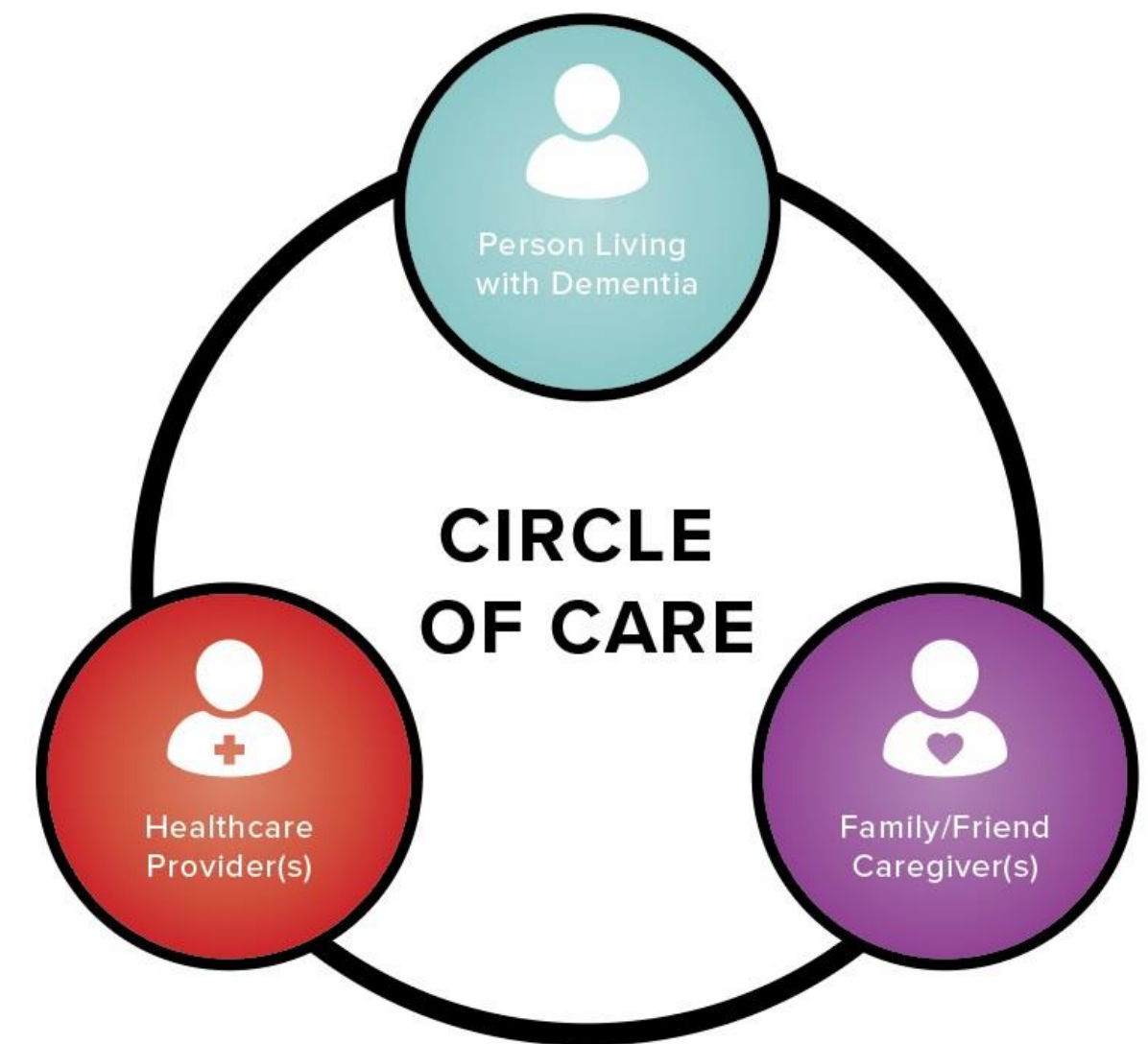
**Collect
useful
resources**



Chat

THE CIRCLE OF CARE

The Circle of Care is made up of a person living with dementia, their family and friends in caregiving roles and health care providers such as personal support workers, nurses, doctors, and others.



TRIAL PERIOD FEEDBACK

The ODJJ was trialed in 7 diverse communities in Onratio and Alberta between March 2024 and January 2025.

(included: continuing care/long-term care homes, First Nation communities, South Asian community organizations, adult day program)



KEY MESSAGES:

Support, Personalization, and Learning Along the Dementia Journey

The ODJJ offers a variety of tools that provide:

1. More support to caregivers
2. Tools to learn about dementia and dementia care
3. More ways to provide person-centered care
4. More access to dementia care resources (includes resources for cultural communities such as First Nations, French, South Asian communities)
5. More dementia care resources tailored to specific communities (First Nations, and Punjabi, French and Hindi speaking communities)
6. Conversations to help de- stigmatize dementia

1. More support to caregivers

“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

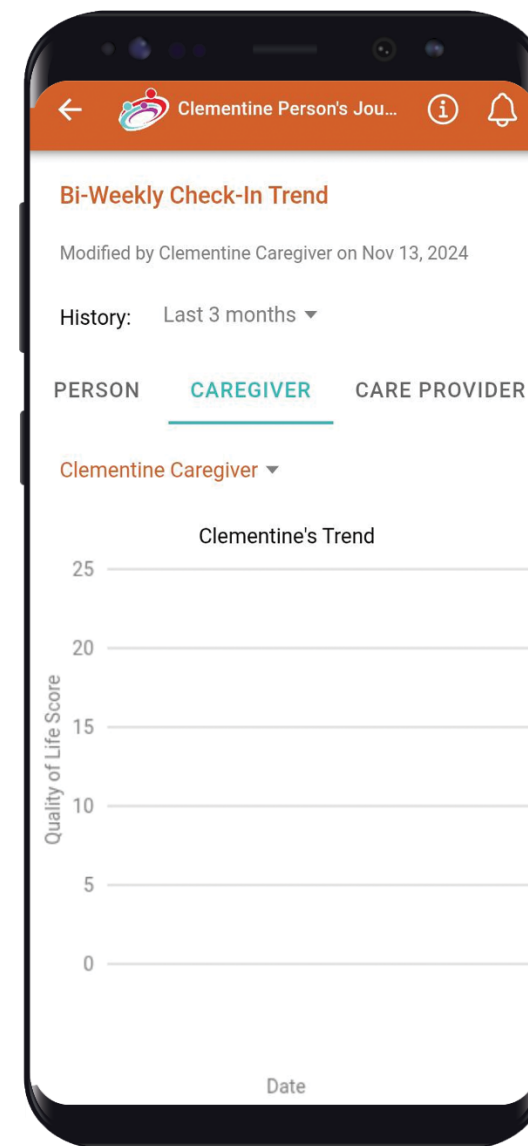
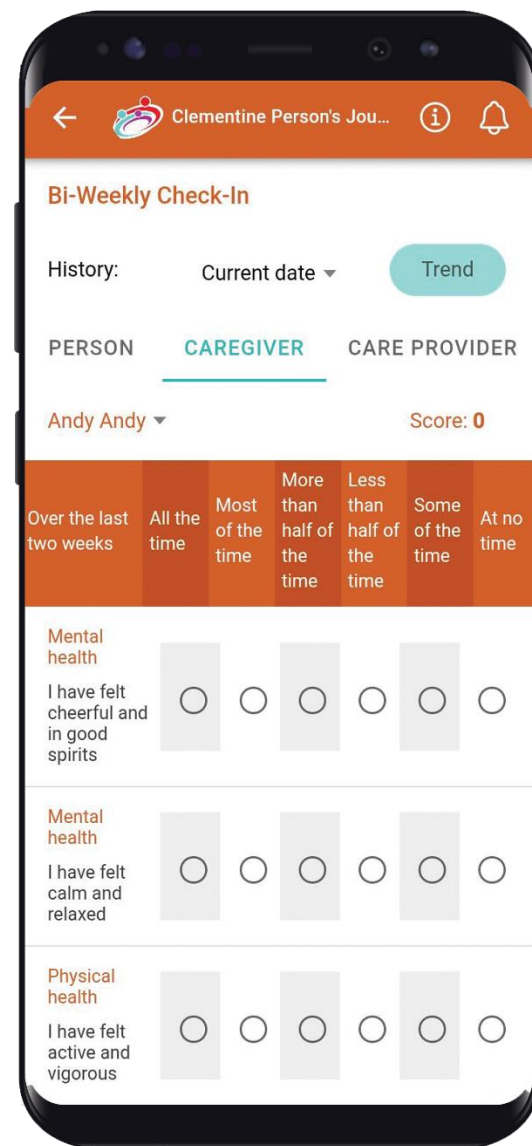
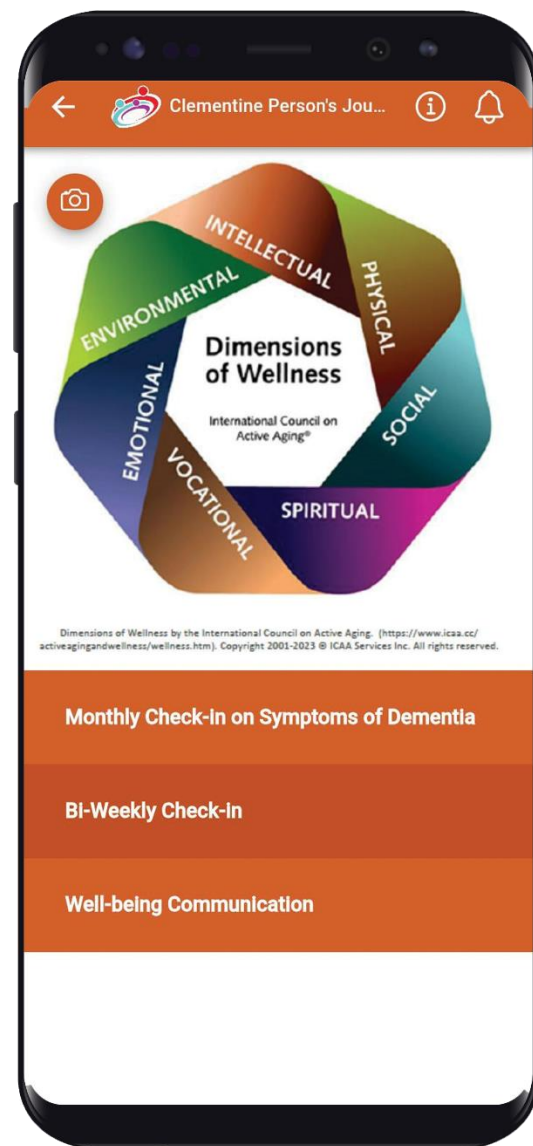
Bi-Weekly Check-In

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. Learning 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

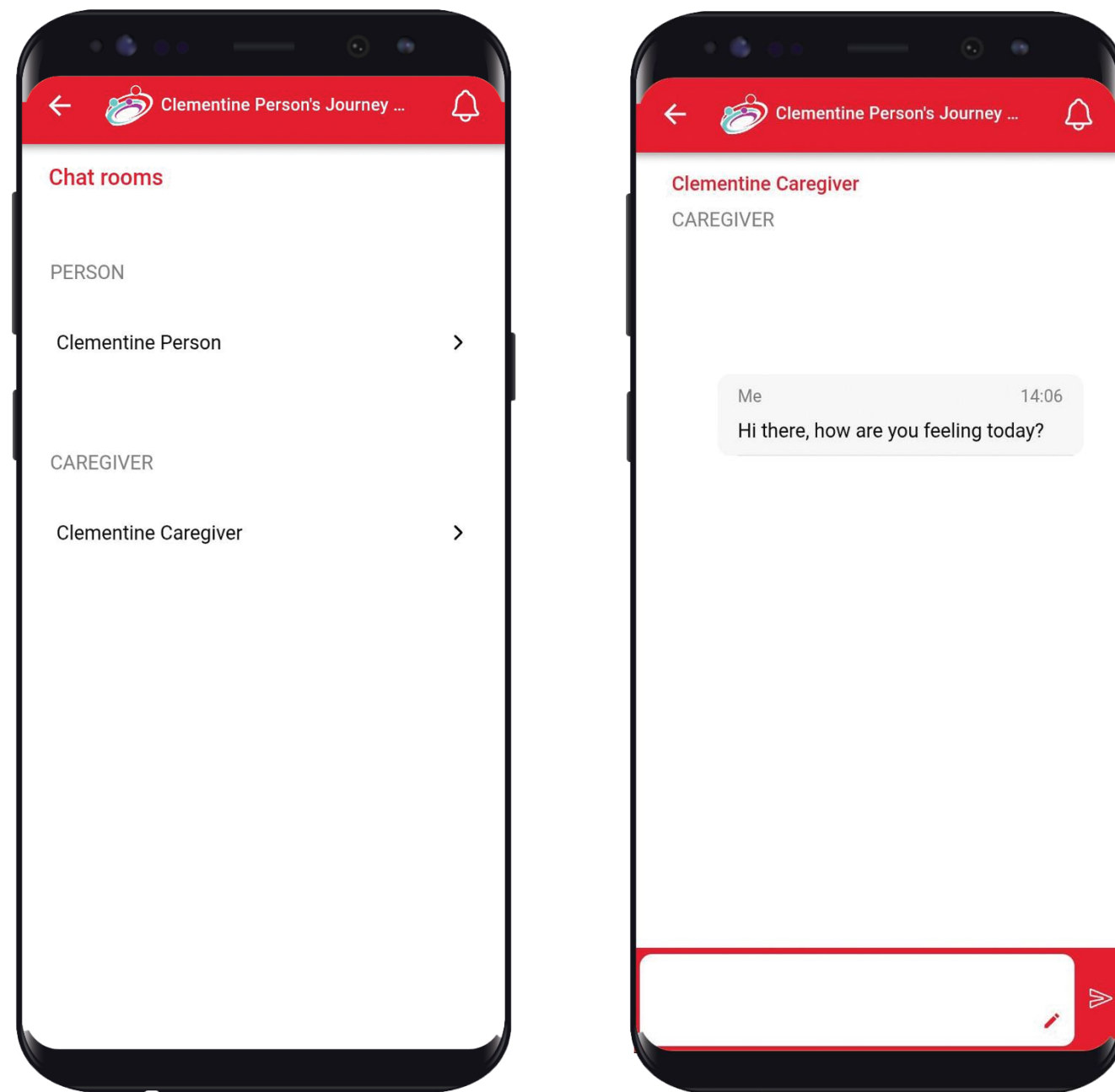
Chat

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.



Chat Feature



3. More ways to 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

KEY FEATURE #3

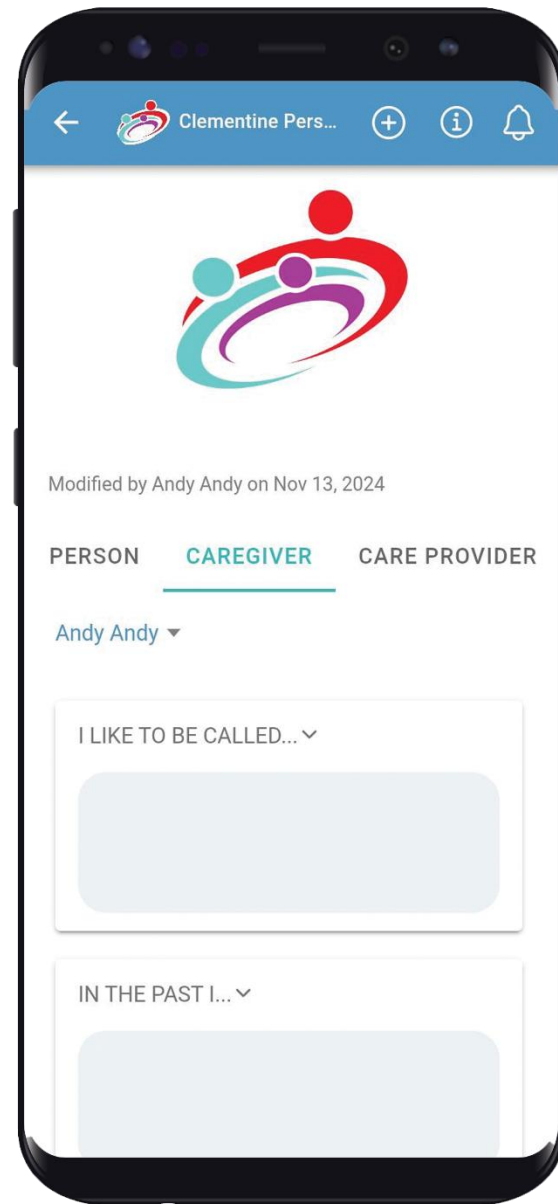
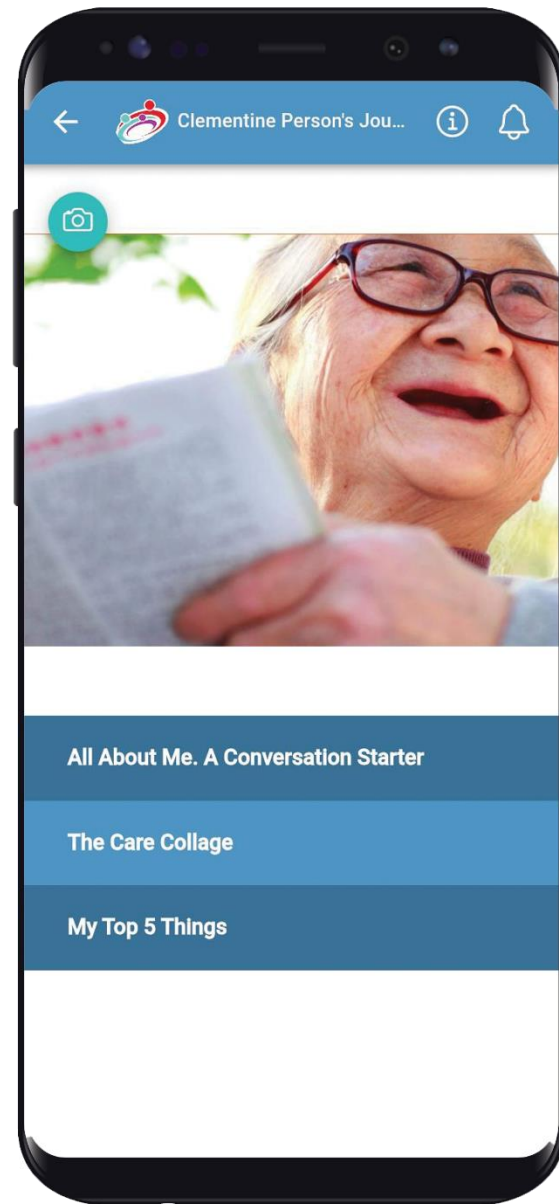
All About Me

All About Me outlines the Circle of Care

- Preferences
- Behaviours
- History
- Interests



All About Me



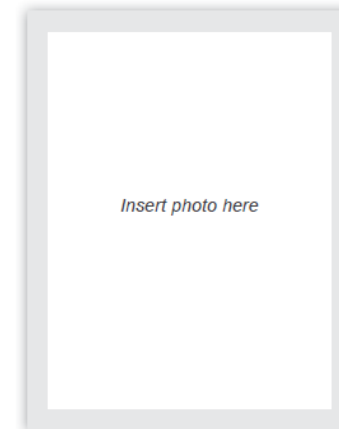
All About Me A Conversation Starter

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. More access to 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”

KEY FEATURE #4

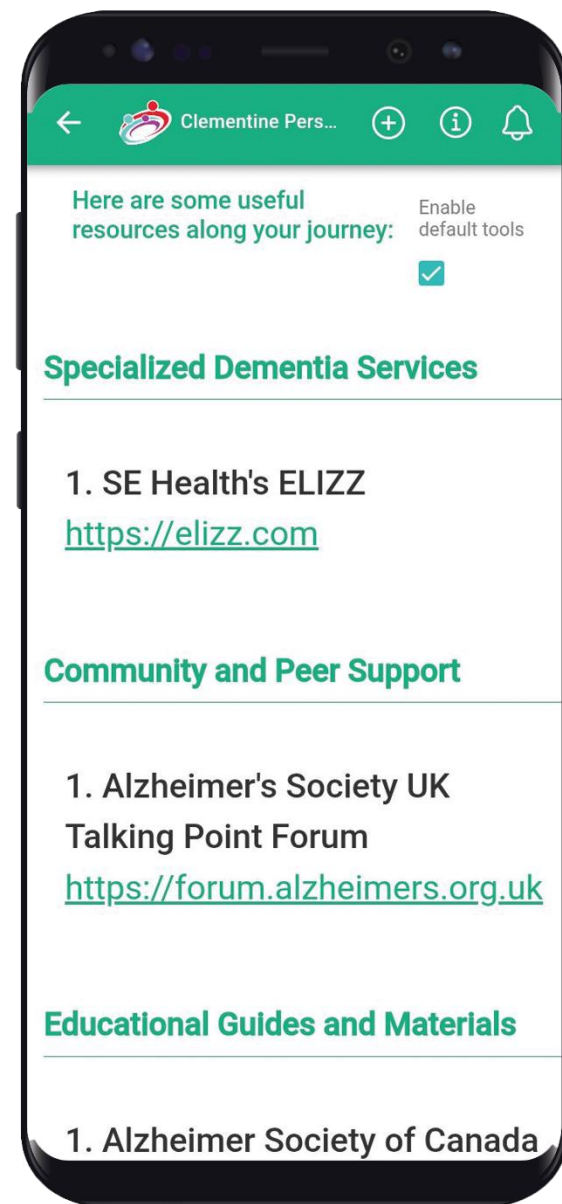
Resource Section

The Resource Section

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



Resources





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. Tailored dementia care resources to specific communities

“...It’s[ODJJ] increasing awareness about this disease because it’s a new disease for South Asian community, and there’s a lot of stigma attached to mental health and neurocognitive disorders.”

- Care Provider

6. De-stigmatizing Dementia

“... 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
2. If you'd like to share/Promote ODJJ to Your Community or Organization, visit our resource page
 - Access ready-to-share materials to present the ODJJ in meetings, events, or internal communications
3. If you'd like to access resources to implement or use the ODJJ with your organization, community or group, visit our website.

Thank you

