

Learn about the Our Dementia Journey Journal Features



ODJJ
Our Dementia
Journey Journal

THE OUR DEMENTIA JOURNEY JOURNAL

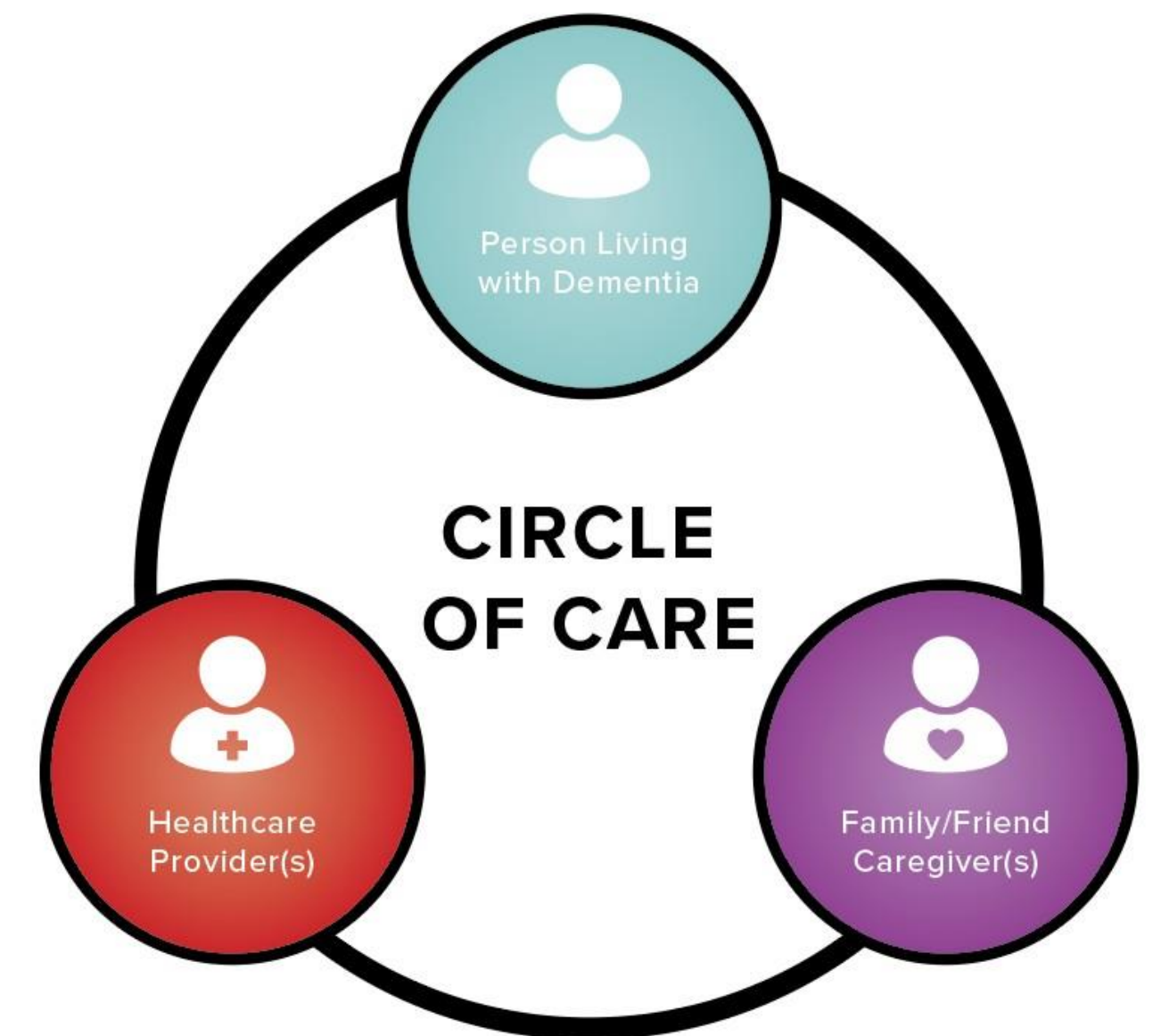
The Our Dementia Journey Journal (ODJJ) is an interactive resource that was co-designed with and for people living with dementia, their family/friend caregivers, and their healthcare providers.



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.

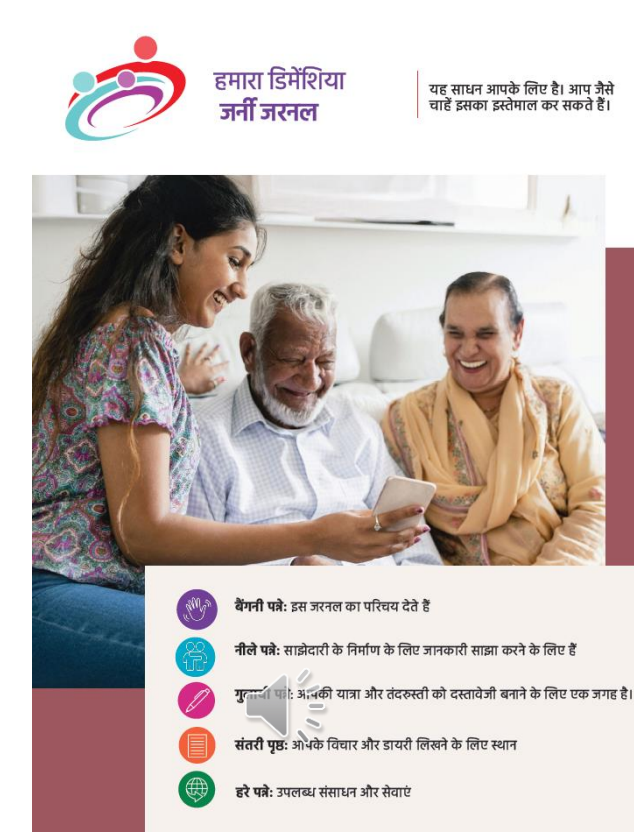
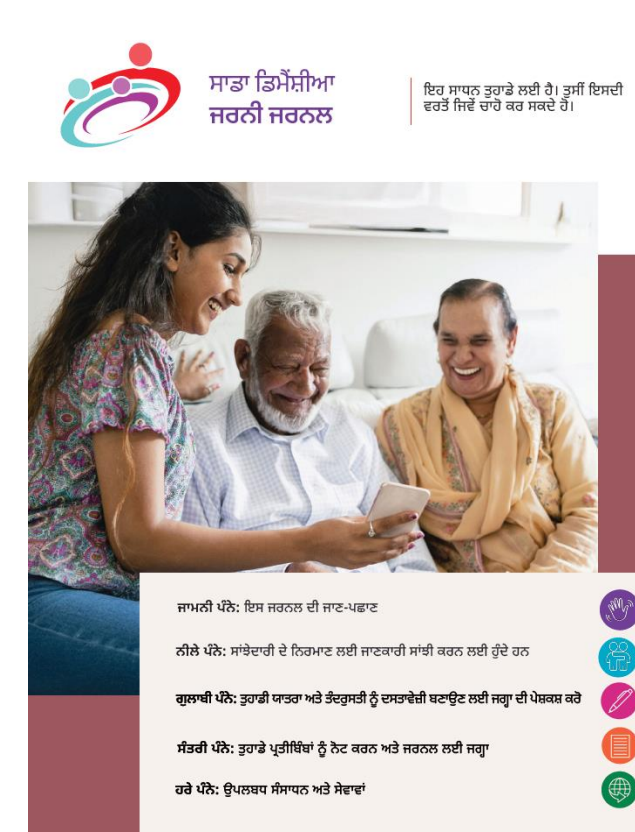
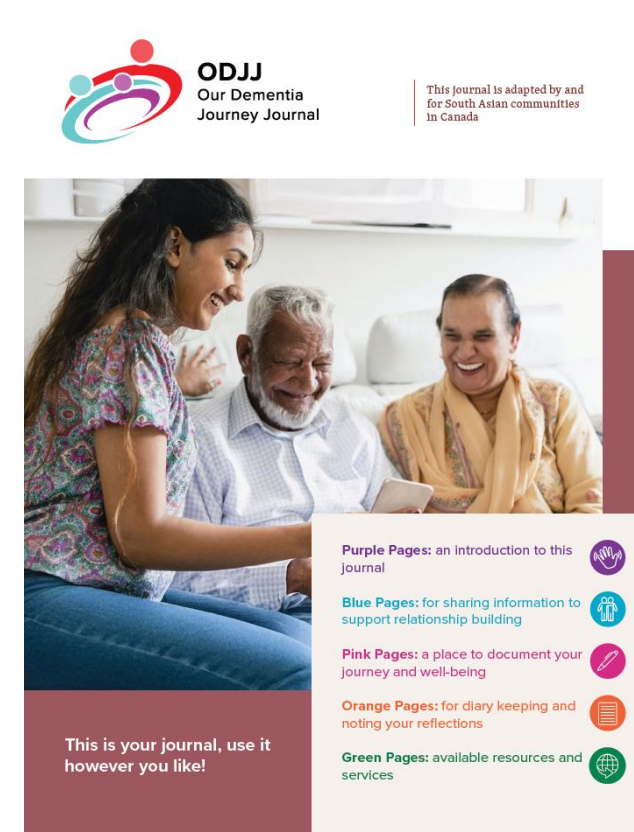
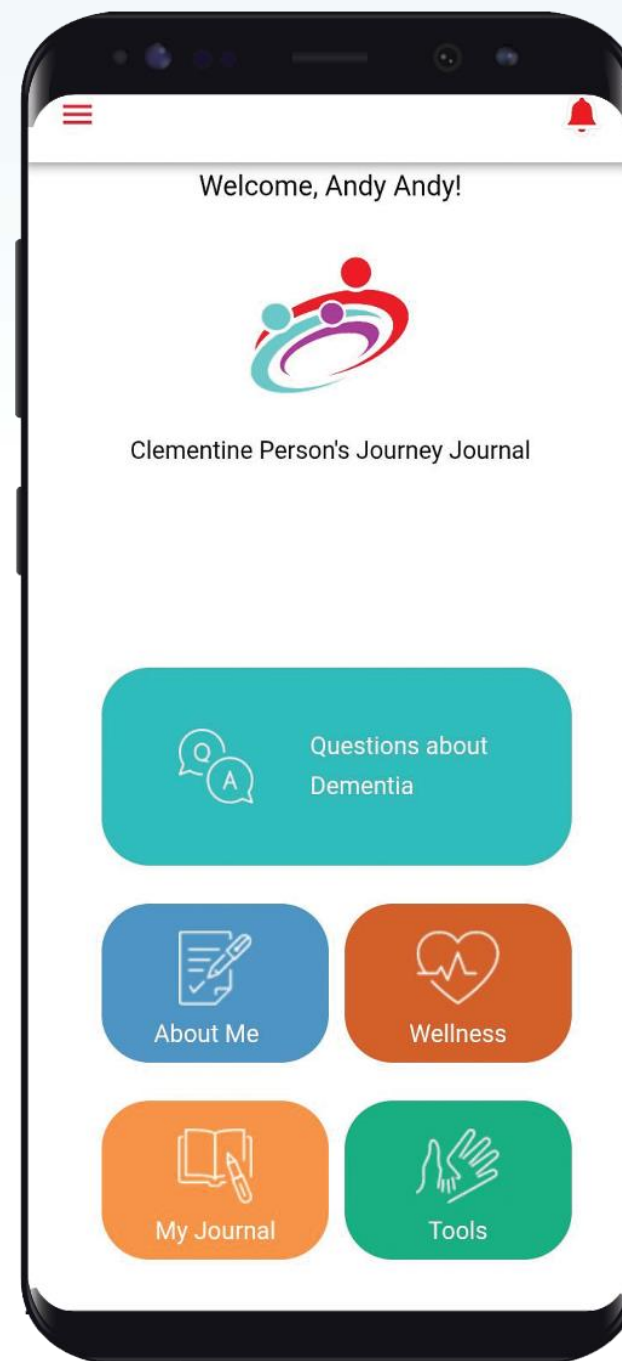


ODJJ VERSIONS & LANGUAGES

Formats - Apple and Android app or paper-based resource

Versions - Generic, First Nations, and South Asian

Languages - English, French, Hindi, and Punjabi



ODJJ FEATURES



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



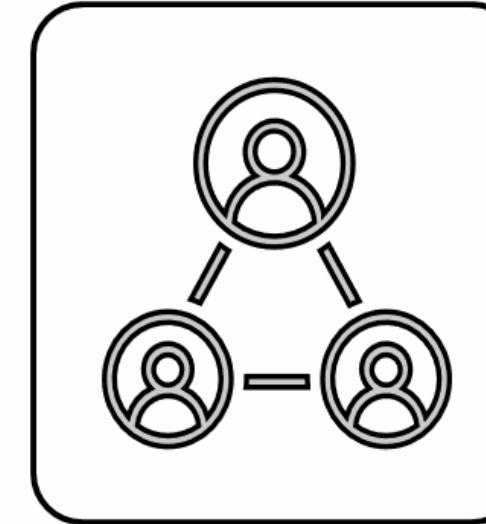
Share: Share words, pictures and videos with the Circle of Care.



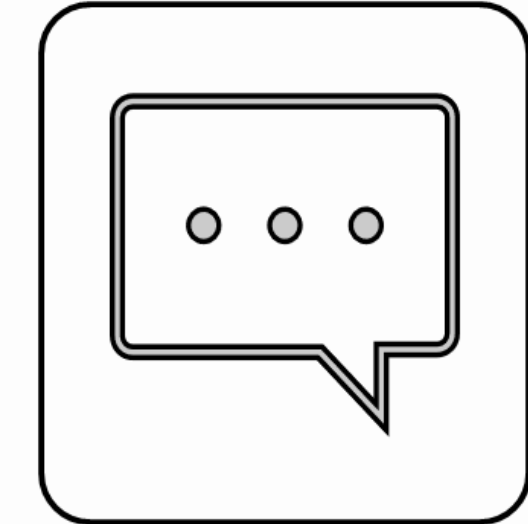
Track well-being: Monitor wellness over time.



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.



Ask: Pose and answer questions

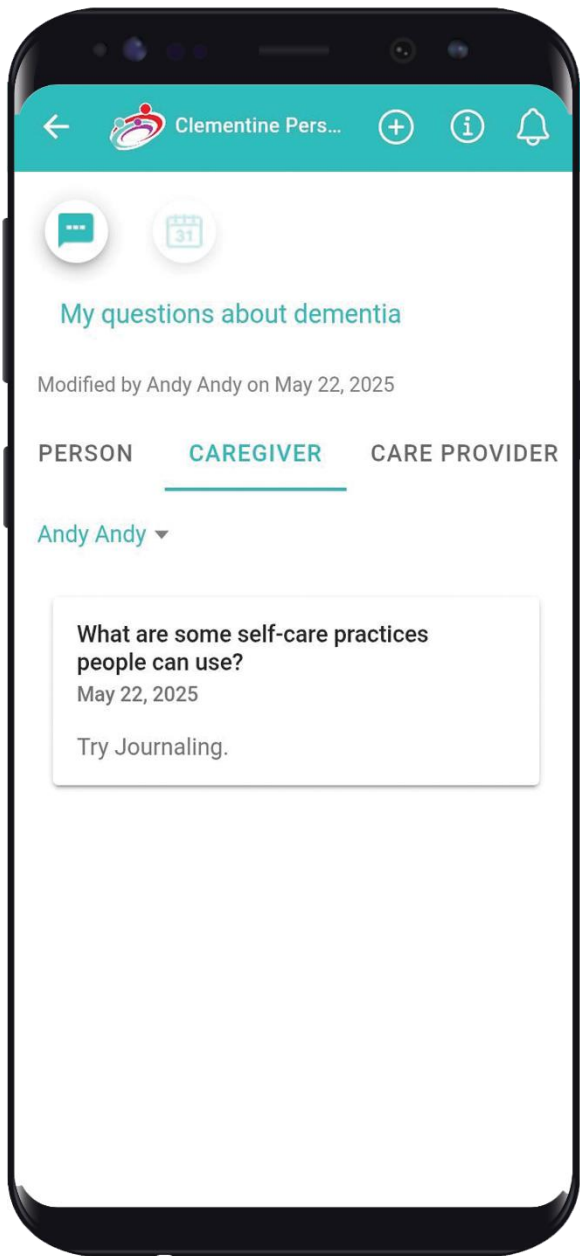
This is a space to record your questions for the other members of the Circle of Care.

Functions:

- Pose new questions
- View and respond to questions of other users
- Sort questions by date (in app only)

Tips:

- Keep track of questions ahead of appointments/meetings with your circle of care.



My questions about dementia:

On this page, write questions you have about dementia that you can share with others. For example:

- "What did you notice or feel today that was different?"
- "What was different today that you want to understand?"
- "What lifestyle changes can support overall well-being for someone living with dementia?"
- "How often should we schedule check-ups, and what should we keep an eye on?"

Date: _____

Date: _____

Date: _____

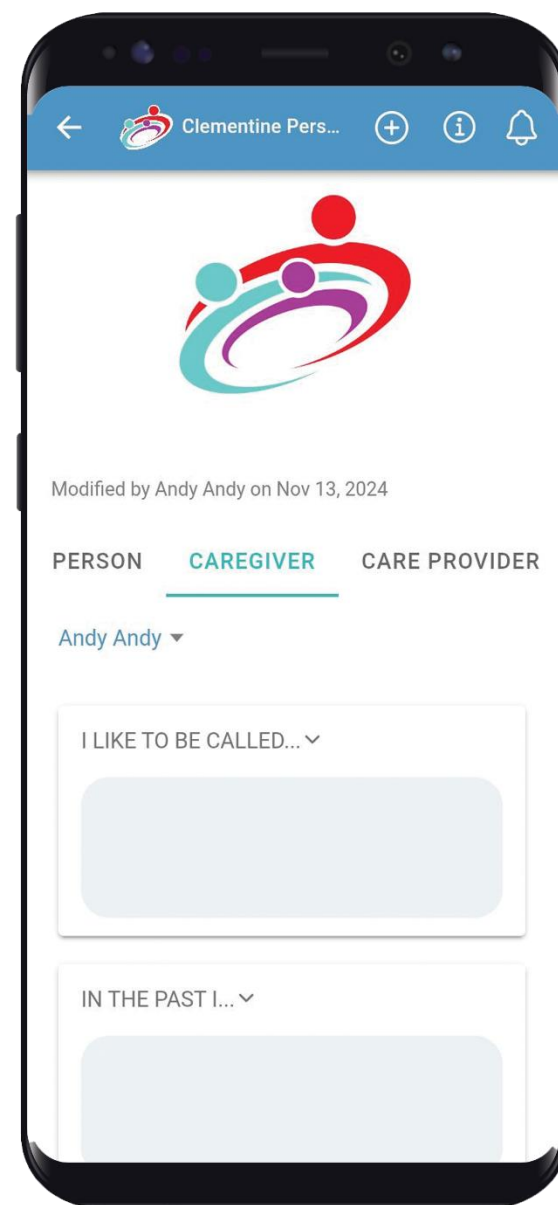
Date: _____

Date: _____

Date: _____



Share: Get to know and communicate



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.

Every member of the Circle of Care can fill out the All About me sections to share important information about themselves with the rest of their Circle of Care

Activity 1: All About Me

Functions:

- Fill out and respond to the standard prompts
- Create your own prompts to respond to
- Complete for yourself or the person living with dementia
- View/share the response of other members in your Circle of Care

Tips:

- Fill in for a person living with dementia upon admission to a new setting (adult day program, long-term care, retirement home)
- Care providers in adult day programs, care homes or other setting can fill out and share responses as a team building exercise



Share: Get to know and communicate

Activity 2: My Top 5 Things

Functions:

- Fill out a “thing” and a reason for each one
- Complete for yourself or the PLWD
- View / share the responses of other users

Tips:

- Use this tool to quickly share important activities with a person living with dementia. Caregivers can share things that matter to them during the journey
- Using the paper version? Fill out responses and hang up in your space.

The mobile app interface shows a header with a back arrow, a profile icon, and a notification bell. The title is 'Clementine Person's Jou...'. Below the title is 'Top Five Things About Me'. There are three tabs: 'PERSON', 'CAREGIVER' (selected), and 'CARE PROVIDER'. Under 'CAREGIVER', there is a dropdown menu showing 'Andy Andy'. Below this are five numbered input fields, each with a dropdown arrow and a pencil icon. At the bottom is a red 'Save' button.

Top 5 Things: About Me

Date: _____
My name: _____

Top Five things about me

For example, my mom likes to watch the sunrise.

Why is this important to you?

It lifts her spirits and connects her to the Creator.

For example, my father likes to be clean shaven.

Why is this important to you?

Because how he looks is important to him.

For example, I like to take some time just for me every day.

Why is this important to you?

It helps bring me balance and peace.

For example, I like to be called by my nickname.

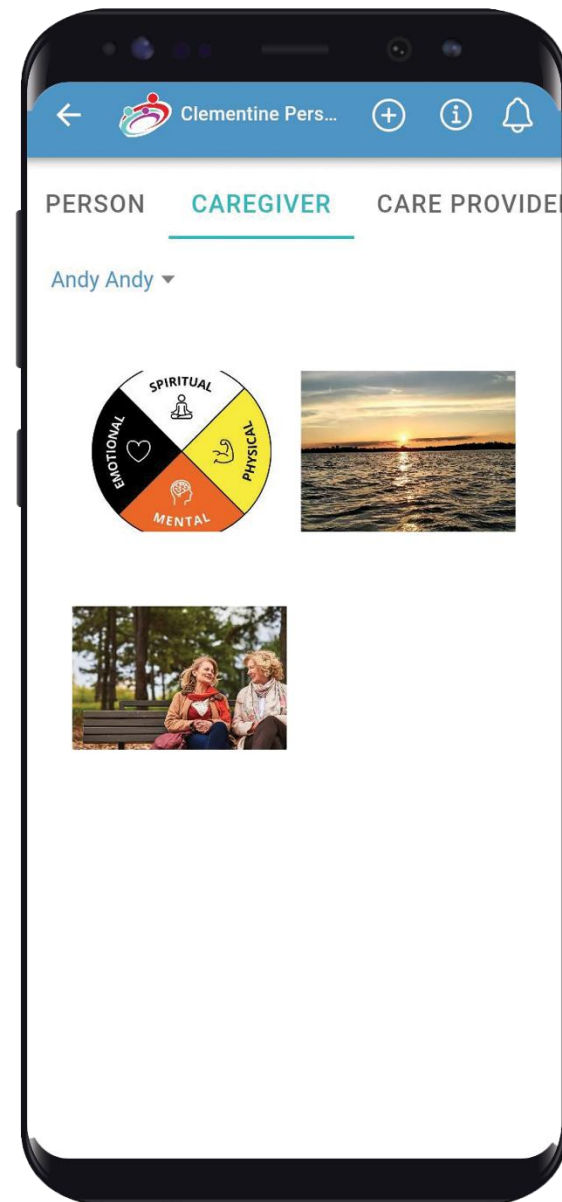
Why is this important to you?

It makes me happy

Why is this important to you?

💡 If you want to reflect more on one of your "5 Important Things," go to the orange pages.

Share: Get to know and communicate



The Care Collage



Purpose

The purpose of this activity is to create a visual representation of what each member of the circle of care has experienced and expects in dementia care.



Timing

We suggest that you complete this activity during any transition period along the dementia journey. This may include when you first get a diagnosis or when you first need help with home care.



Participants

Assess the situation – Ideally, anyone involved in the journey will work together on this activity, including the person living with dementia, their family/friends, and their care provider(s).

- Early in the journey, this activity may be best suited for the person living with dementia and their family/friend(s) to complete together.
- This activity is suitable for family members/friends and care provider(s) if the person living with dementia is unable to participate.



Materials

1. A variety of pre-cut images from personal photos, magazines and newspapers
2. Glue or tape
3. Pens, pencils, or markers



Instructions

Put together a collage representing your experiences and thoughts about dementia care. As you complete each collage, you are encouraged to talk about your collage.



Suggested discussion items

1. What does each image mean to you and why did you choose to include it?
2. What does "care" mean to you?
3. What does each person see as their role in the scope of dementia care?

Activity 3: Care Collage

Functions:

- Paper: Cut out and insert old family photos, magazine cut outs or other personal images
- App: Upload pictures from your camera roll, the apps stock gallery, your personal app gallery or your camera
- Add a caption

Tips:

- Complete for yourself or the person living with dementia
- Share the responses with other members of your Circle of Care



Track your well-being

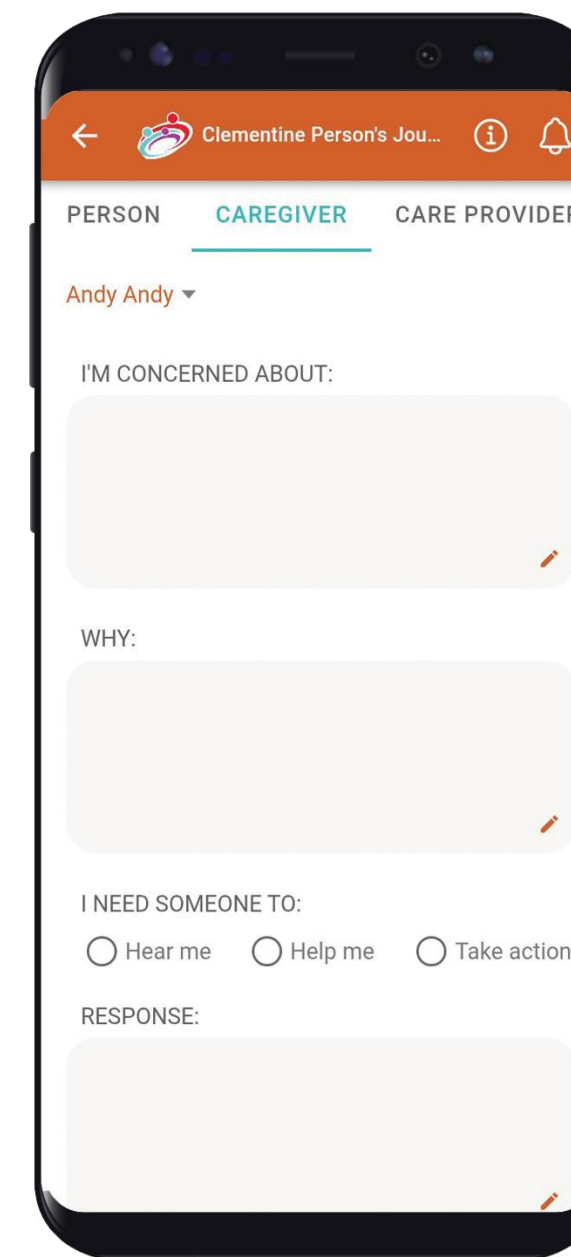
Activity 1: Well-being communication

Functions:

- Fill in the textboxes following the prompts
- Complete for yourself or the person living with dementia
- View the responses of other users

Tips:

- Use as a way to keep track of concerns to discuss with care providers upon your next appointment. Use this to guide next steps with the Circle of Care
- *(e.g. are you concerned about a recent hospitalization and not sure how to manage the transition?)*



The smartphone screen displays the 'Well-being Communication' app interface. At the top, there's a navigation bar with a back arrow, a profile icon, and a bell icon. Below the bar, there are three tabs: 'PERSON', 'CAREGIVER' (which is selected), and 'CARE PROVIDER'. The main content area shows a form for 'Andy Andy'. It includes a section 'I'M CONCERNED ABOUT:' with a large text input box, a 'WHY:' section with another large text input box, and a section 'I NEED SOMEONE TO:' with three radio button options: 'Hear me', 'Help me', and 'Take action'. At the bottom, there's a 'RESPONSE:' section with a large text input box. The app is titled 'Clementine Person's Jou...' in the header.

Well-being Communication

Throughout your journey, please document any concerns you feel. Use this page as often as you want to share your experiences. You can take this form to your doctor/medical appointments to help with the discussion.

Today's Date: _____ Person documenting: _____

I'm concerned about: _____

Why: _____

I need someone to: ☐ Listen to me ☐ Help me ☐ Take action

Response: _____



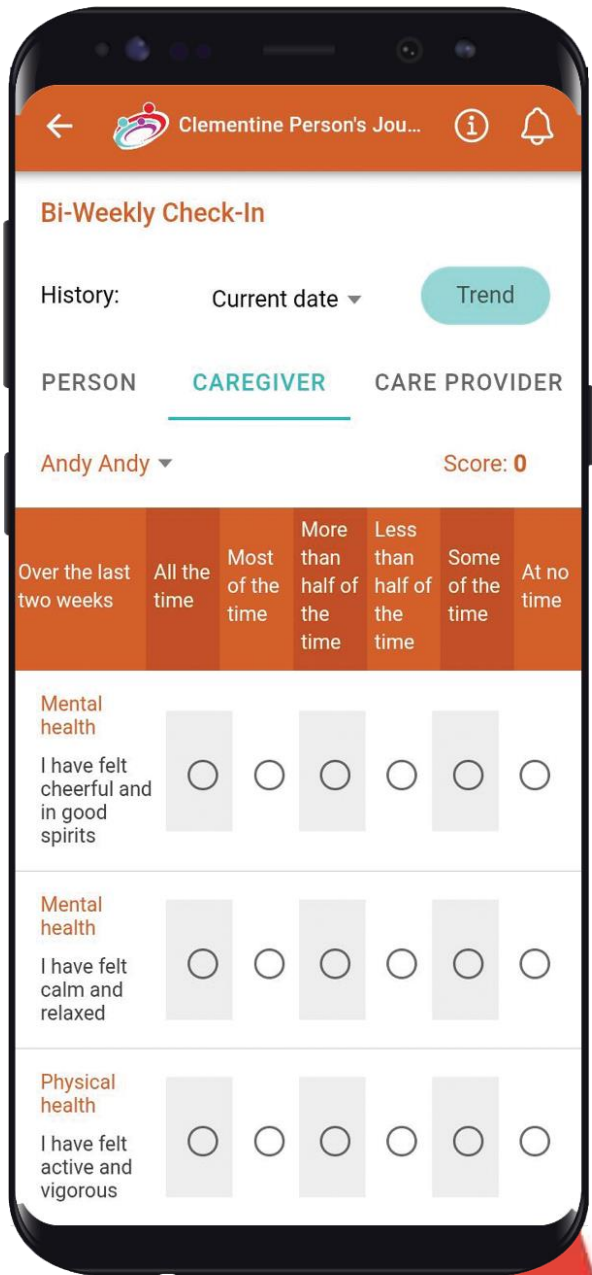
Track your well-being

Activity 2: Bi-Weekly Check-In

A well-being tracker for caregivers and care providers

Functions:

- Tap checkboxes to answer survey and get a score out of 25 where 25 is best possible well-being
- View 2-week average scores
- Sort entries by date
- Complete for yourself
- View the responses of other users
- If you notice a change in score for yourself or others in your Circle, seek or offer support



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 well-being.

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 well-being.
- 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.

Name:

Date:

Over the last two weeks:	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?

Track your well-being

Activity 3: Symptom Tracker

Functions:

- Select symptom category
- Tap checkboxes to change frequency
- Add and edit your own symptoms
- Complete for the person living with dementia

Tips: For caregivers new to the dementia caregiving journey, this tracker may be helpful to track new / emerging symptoms that you can share with your provider and discuss changes or additional support required.

The screenshot shows a mobile app interface for tracking symptoms. At the top, there's a navigation bar with a back arrow, a profile icon, and the text 'Clementine Pers...'. Below this is a header for 'Engagement' with a close button. A note indicates 'Modified by Clementine Caregiver on Dec 20, 2024'. The main section is a table with columns for 'Symptoms', 'Daily', 'Weekly', 'Monthly', and 'Never'. There are four rows of symptoms, each with radio buttons for frequency selection. A red dot indicates the selected frequency for each symptom. At the bottom, there is a red 'Save' button.

Symptoms	Daily	Weekly	Monthly	Never
Appears anxious or fearful	☐	☐	☐	☒
Appears sad or withdrawn	☐	☒	☐	☐
Has difficulty making eye contact or conversation	☒	☐	☐	☐
Demonstrates an overall lack of interest in daily life and activities	☐	☐	☐	☒



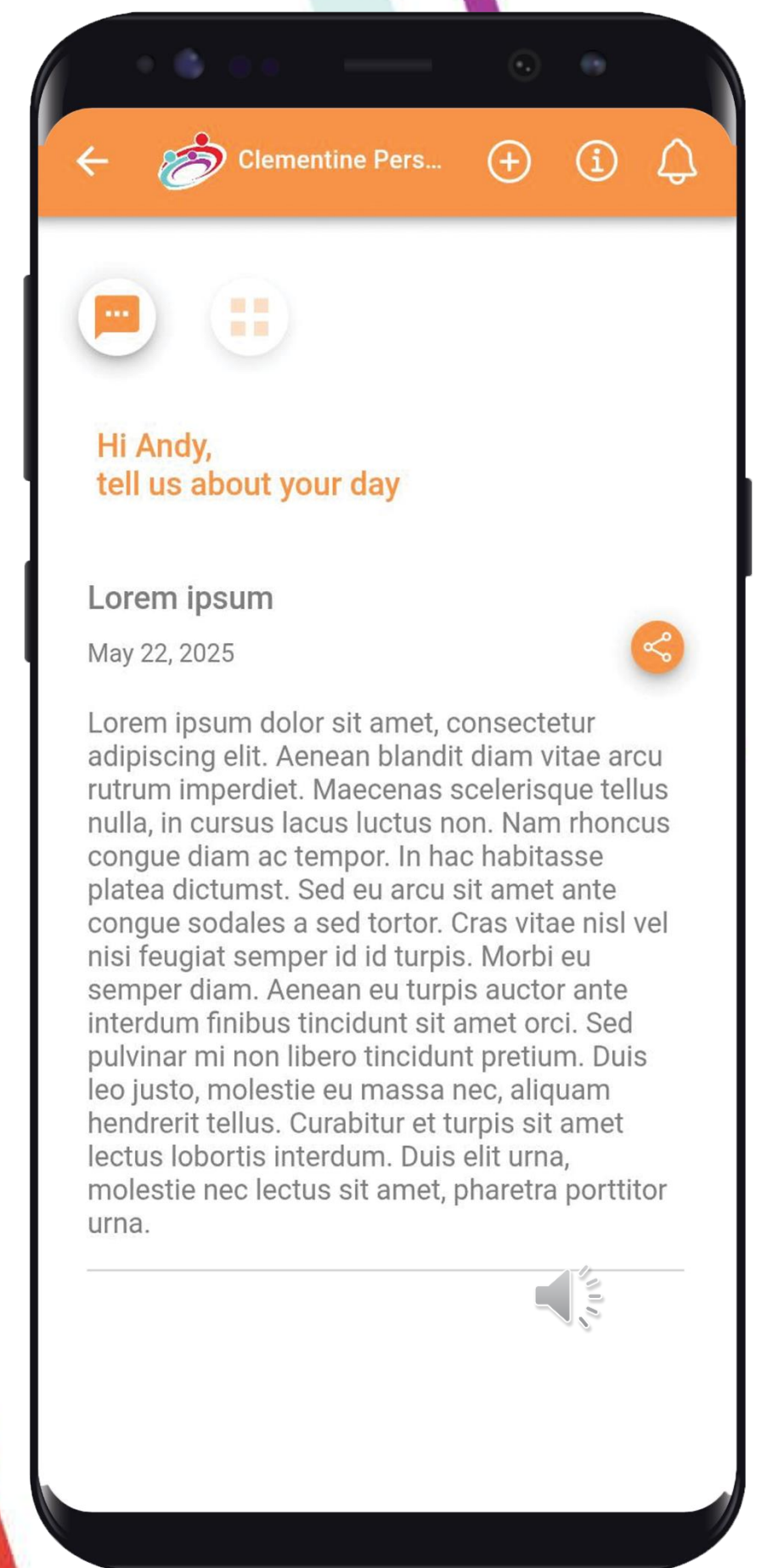
Reflect: Journal and Reflection

Functions:

- Create journal entries that include a title, caption, and multimedia such as photos or videos.
- Keep entries private or choose specific users for sharing within the app.
- Organize entries chronologically (within the app).

Tips:

- Care providers have the ability to take photos and write captions to share with caregivers while engaged in programs or events throughout the day.
- This is like social media posts, allowing you to share updates with others in your care network using the share button in the app.
- Adhere to the instructions provided on the guidance pages.



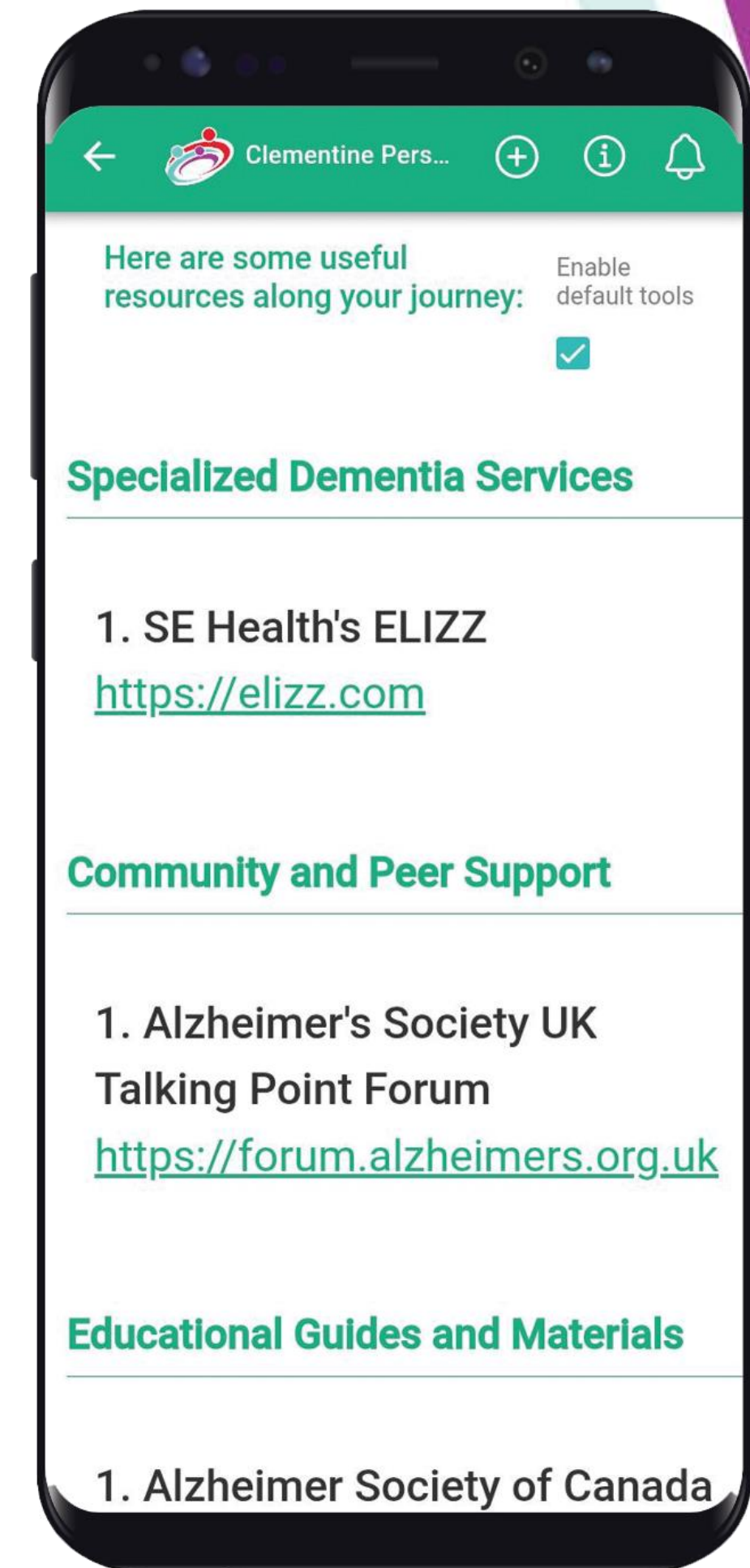
Get Help: Collect useful tools

Functions:

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

Tips:

- If using the paper version, collect paper copies from your local Alzheimer's Society or other organizations that you work with
- Organizations/groups can create a local resource page for your community to add within their resource section
- Add your own photos, pdf or links (in app).

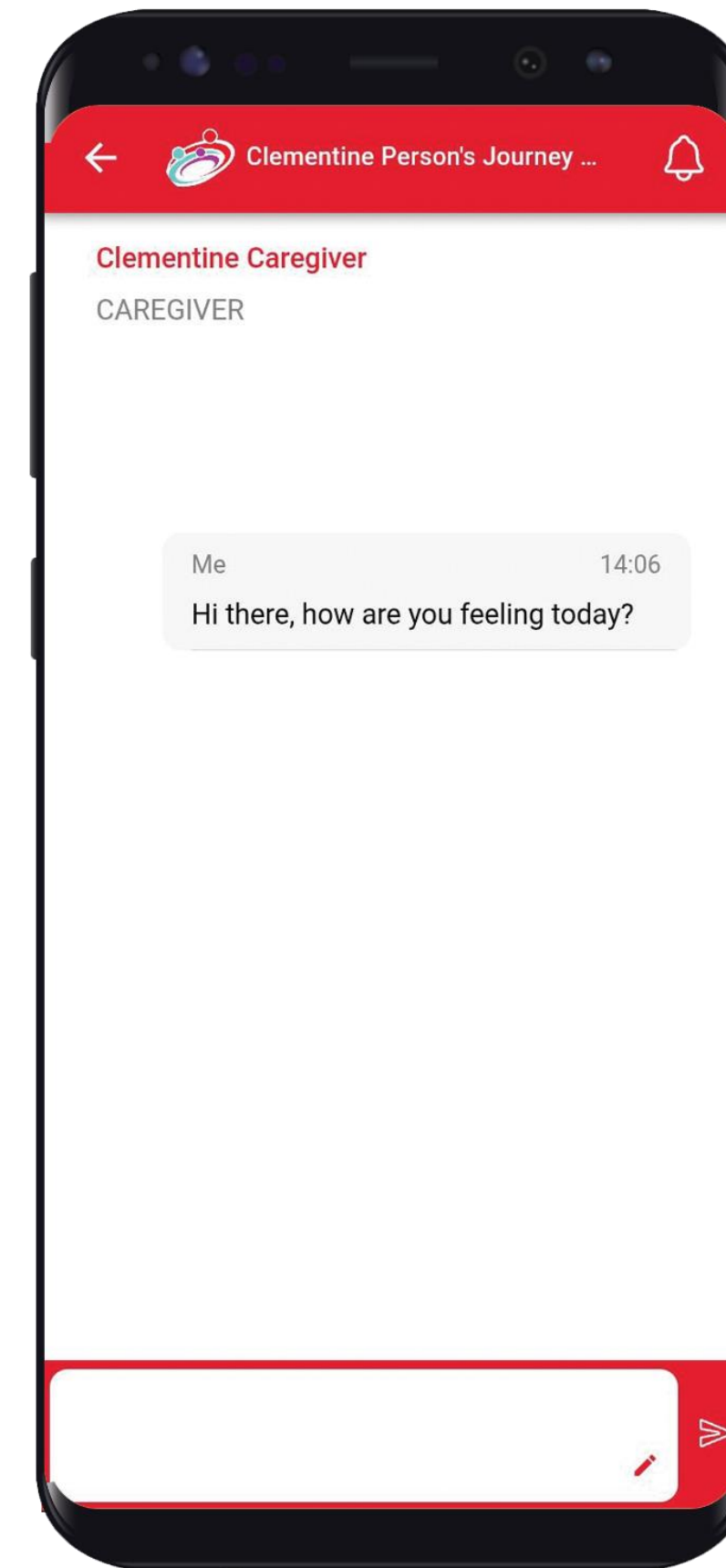


Chat function

Use the chat feature in the app to send direct messages to any member of the Circle of Care.

Tips:

- Share updates with your circle of care
- E.g. caregivers can notify providers at an adult day program of poor sleep or blood sugar prior to drop off so they know what to expect during the day
- Saves time for a phone call or in-person visit
- A way for long-distance caregivers to stay involved and communicate with the Circle of Care



Your ODJJ Journey

The Our Dementia Journey Journal is flexible and tailored to meet your needs. It is intended for use by everyone involved in the Circle of Care.

Begin with the features or activities that you find most beneficial, and add more as you and your Circle of Care are ready.

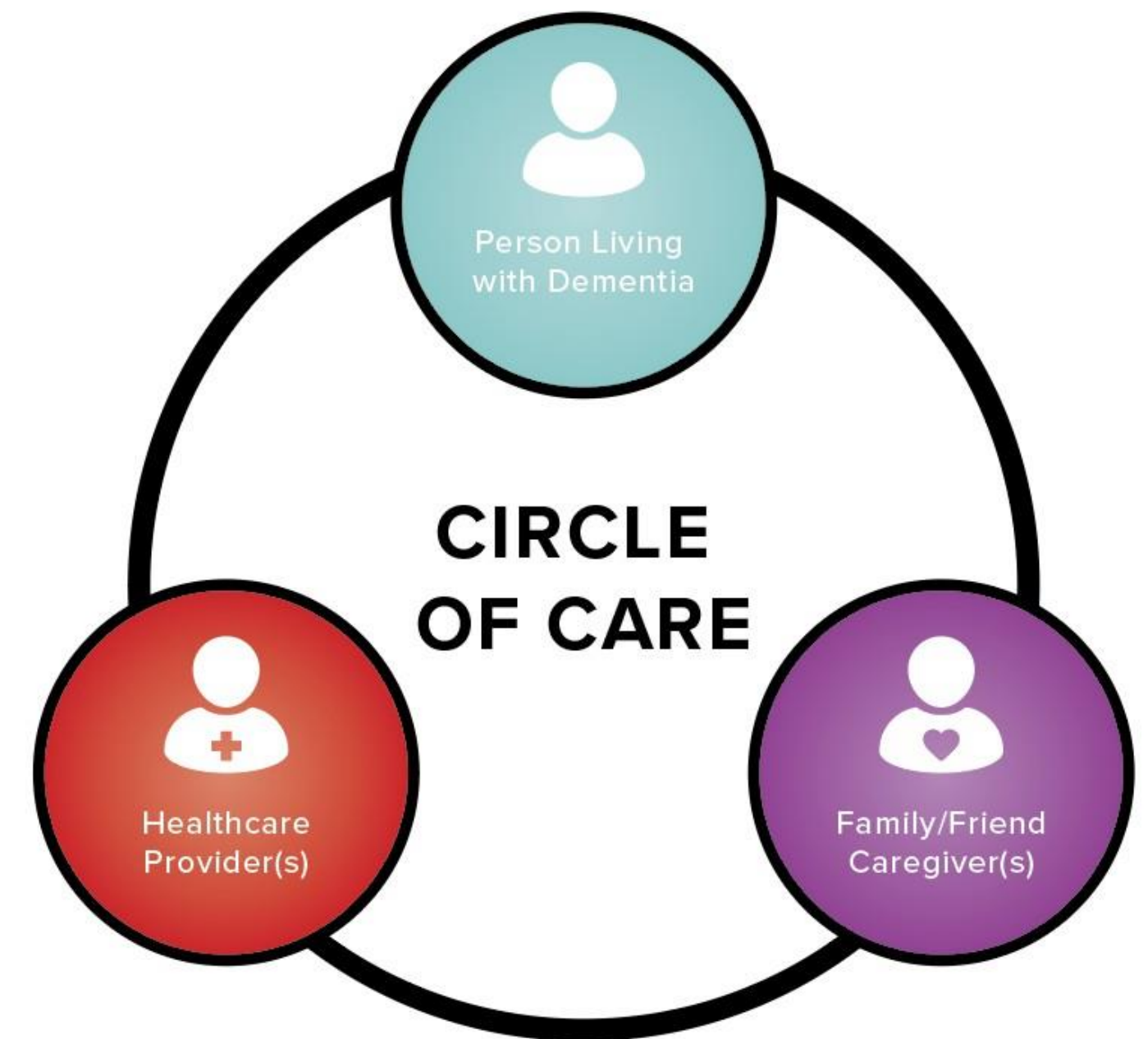
For instance, you might start with the journal section, share and create posts, and then move on to the available resources.



Your Information & Privacy

All data is securely stored on SE Health's servers.

Please note that any information entered in the Our Dementia Journey Journal app can be seen by all members of your Circle of Care.



Resources for You

If you are interested in resources to support implementing ODJJ with your organization or group,

&

If you are interested in resources to support using ODJJ

visit our website www.odjj.ca

