



# Our Dementia Journey Journal

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 noting your reflections and diary keeping



**Green pages:** available resources and services

# Welcome to Our Dementia Journey



This journal was created by family members of persons living with dementia, healthcare workers, representatives from the Alzheimer Society of Canada and the SE Research Centre at SE Health.

This version was adapted with the help of people from South Asian communities in Canada. They shared their knowledge and understanding to make sure it fits well with the unique experiences in South Asian communities in Canada.

You can use this journal along with your friends, family and health care providers as you experience the dementia journey together. We hope you find the journal helpful.

You can choose which activities or pages will be most helpful. We suggest storing these papers in a binder to keep them together.

If you found this, please return it to:

Name: \_\_\_\_\_

Contact: \_\_\_\_\_

\_\_\_\_\_



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# Outline of Key Features

Our Dementia Journey Journal is for people living with dementia, their family/ friends, and healthcare providers to support strong relationships between them throughout the dementia journey.

Each section has a different purpose and colour associated with it. You can choose which sections you want to use and how.

## Sections:



### **Purple pages: an introduction to the Journal**

The dementia journey and the circle of care - key definitions

How to use the Journal

Guiding principles



### **Blue pages: for sharing information to support relationship building**

My questions about dementia

Get to know me - a conversation starter

Care collage activity

My five important things



### **Pink pages: a place to document your journey and well-being**

Well-being communication

Well-being check-in (WHO's Health Index)

Person-centred symptom tracker



### **Orange pages: a place to note your reflections and for diary keeping**

Diary keeping

Reflecting on joyful moments



### **Green pages: available resources and services**

List of available resources and services

Dementia: 10 warning signs

Activities calendar



# Dementia is a journey

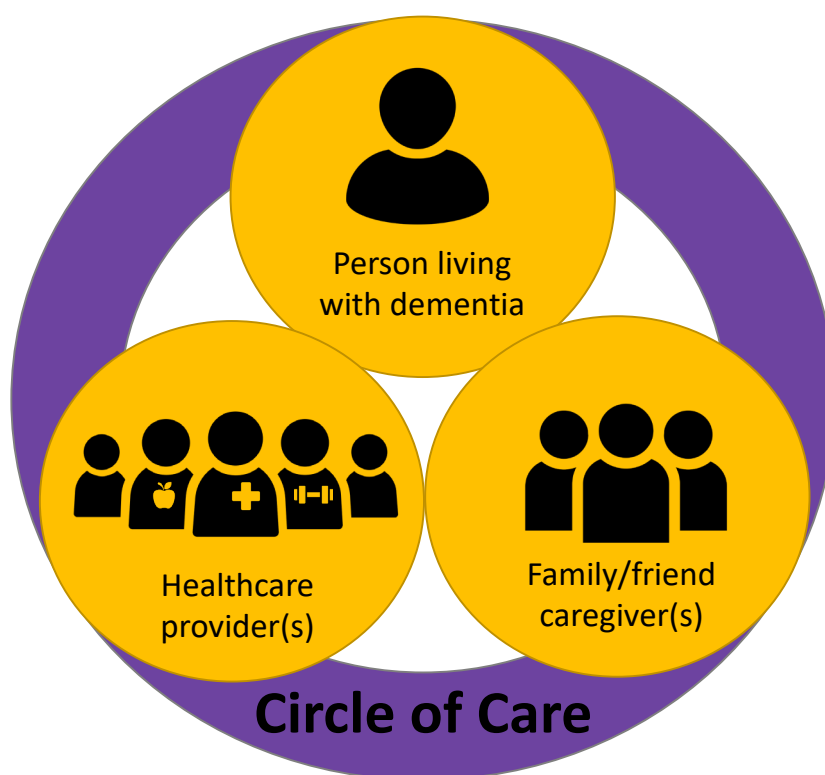
Dementia is a medical term used to describe symptoms like memory loss, trouble with thinking, problem-solving, or speaking.

There are many types of dementia—the most common ones you may have heard of are Alzheimer’s disease, Lewy body dementia, frontotemporal lobe dementia, or mixed dementia. Sometimes people also refer to dementia as a neurocognitive disorder.

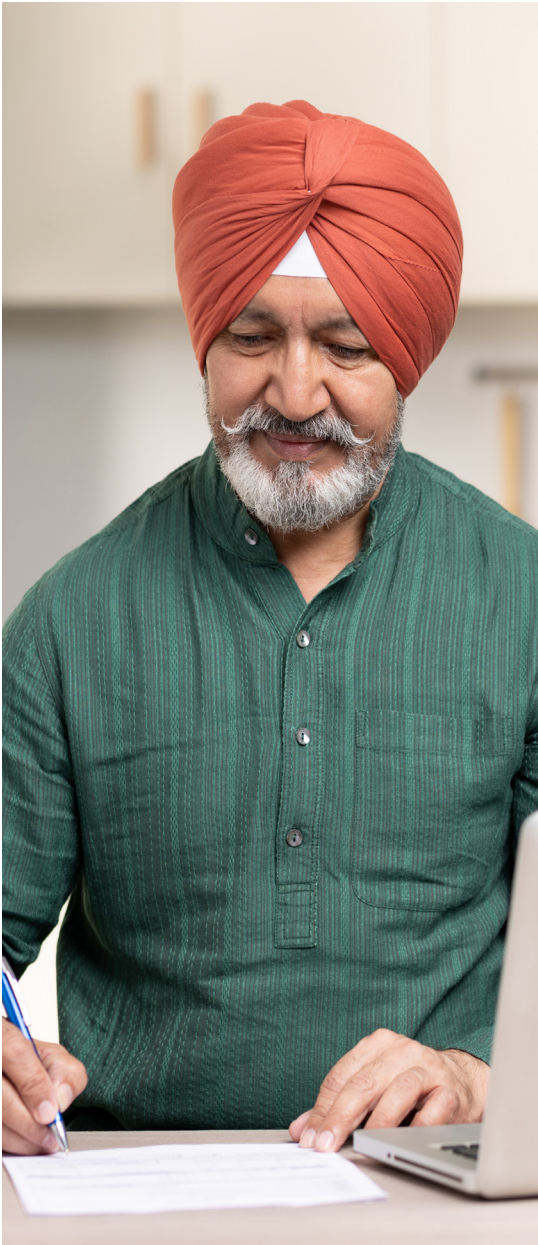
Even though dementia shows up differently in each person, common symptoms include memory loss, personality changes, and difficulty with tasks. It’s important to note that dementia is a progressive condition, meaning that symptoms may evolve over time.

Instead of thinking of dementia as a negative experience, it can be seen as a unique journey shared by the person living with dementia and those who support them.

One way to make the journey easier is to create a circle of care. The term **“circle of care”** means a group of people who work together to support the person living with dementia. This group includes the person living with dementia, family and friends who help or care for them, and healthcare providers such as personal support workers, dieticians, physical therapists, occupational therapists, speech and language pathologists, nurses and doctors. Building strong relationships and keeping open communication within this circle of care, can make the dementia journey more manageable.



# How to use this journal



## **Who should contribute to this journal?**

Anyone who is within the circle of care can contribute to this journal. This may include the person living with dementia, family or friends who help or care for them, and healthcare providers who help care for a person living with dementia.

## **What can you use this journal for?**

This journal contains activities designed to help you on your dementia journey. The journey is full of changes, and these activities can help you prepare for them and address the challenges ahead.

## **When can you use this journal?**

You can use this journal as much or as little as you feel you want or need. Some activities have a suggested time to complete; others are up to you to choose.

## **How can you use this journal?**

The journal can be used in many ways. It is up to you to decide which parts are helpful to you.

## **Some ways to use the journal include:**

- Take it to appointments to share your concerns or observations
- Share memories and essential information about the person with dementia
- Take care of your mental health with self-care activities
- Build relationships with new members of the circle of care as the circle expands to meet the needs of the person with dementia.



# Guiding principles

## **Respect the circle of care:**

Realize that everyone in the circle of care has linked lives as you are on the dementia journey together. Strengthen this circle of care, respect the needs of the person living with dementia and their family and friends and build stronger relationships with care providers in professional roles.

## **Use an individual and family-centred approach:**

Focus on building strong relationships with each individual in the circle of care. Provide care that considers all of the different dimensions of wellness, and offer proactive, timely, well-coordinated support to promote wellness.

## **Share your knowledge, and accept the difference:**

Recognize the value each person brings to the circle of care, information that only they know.



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*If you want to learn more about the Dimensions of Wellness go to the green pages.*





# Share Information



# My questions about dementia

On this page, write questions you have about dementia that you can share with others in the circle of care. For example:

Who to ask	Sample questions
The person living with dementia	<ul style="list-style-type: none"><li>• What did you notice or feel today that was different?</li><li>• What was different today that you want to understand?</li></ul>
Family/friends	<ul style="list-style-type: none"><li>• How are you taking care of yourself while providing care for the person living with dementia?</li><li>• Are there any specific concerns or questions that you would like to discuss?</li></ul>
Healthcare provider(s)	<ul style="list-style-type: none"><li>• What lifestyle changes can support overall well-being for someone living with dementia?</li><li>• How can we address behavioral and emotional changes that may come with dementia?</li><li>• Are there services or support groups available for both the person with dementia and their family and/or friends?</li><li>• How often should we schedule check-ups, and what should we keep an eye on?</li></ul>





# My questions about dementia

Write your questions here:

Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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# My questions about dementia

Write your questions here:

Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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# My questions about dementia

Write your questions here:

Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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Date: \_\_\_\_\_

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# Get to know me

## A conversation starter



### **Purpose**

This activity is meant to help all members of the circle of care to get to know each other better.



### **Participants**

This activity can be completed by anyone within the circle of care including the person living with dementia, their care providers and family members or friends who help or care for them.



### **Timing**

Content may be reviewed and updated as needed and/or as changes occur.



### **Instructions**

This activity is intended to be a conversation between members of the circle of care. Please feel free to skip any questions or topics that you don't want to talk about, and don't hesitate to add your own!

### **Acknowledgement**

This activity has been adapted by the SE Research Centre with advice from and permission of the communities that participated in the co-design of Our Dementia Journey Journal, and, with permission of the people and organizations who created the following:

• “All About Me – A Conversation Starter”, by Alzheimer Society of Canada ([www.alzheimer.ca](http://www.alzheimer.ca)) © November 2014. Retrieved from: [https://alzheimer.ca/sites/default/files/documents/all\\_about\\_me\\_a\\_conversation\\_starter\\_e.pdf](https://alzheimer.ca/sites/default/files/documents/all_about_me_a_conversation_starter_e.pdf)

• © Indigenous Cognition & Aging Awareness Research Exchange and North East Behavioural Supports Ontario. Kristen Jacklin, Karen Pitawanakwat, Melissa Blind, Louise Jones, Jerry Otowadjiwan, Emily Piraino, Roxanne Makela, Bob Spicer, Monica Bretzlaff. “P.I.E.C.E.S. of my Relationships” (1151320, Industry Canada). Retrieved from: <https://www.i-caare.ca/practicetools>

• North East Behavioural Supports Ontario. “North Bay Regional Health Centre, PIECES of my PERSONHOOD” (RHC1380 - Oct 2018 beaulme). Retrieved from: [https://northeast.behaviouralsupportsontario.ca/335/PIECES\\_of\\_my\\_Personhood/](https://northeast.behaviouralsupportsontario.ca/335/PIECES_of_my_Personhood/)





# Get to know me

## A Conversation Starter

Date: \_\_\_\_\_

### Name, preferred language & places

*Individual's name, nickname, title or traditional name. Ask questions like: What is your preferred language? Where are you from? Where were you born? When did you move to your current location?*

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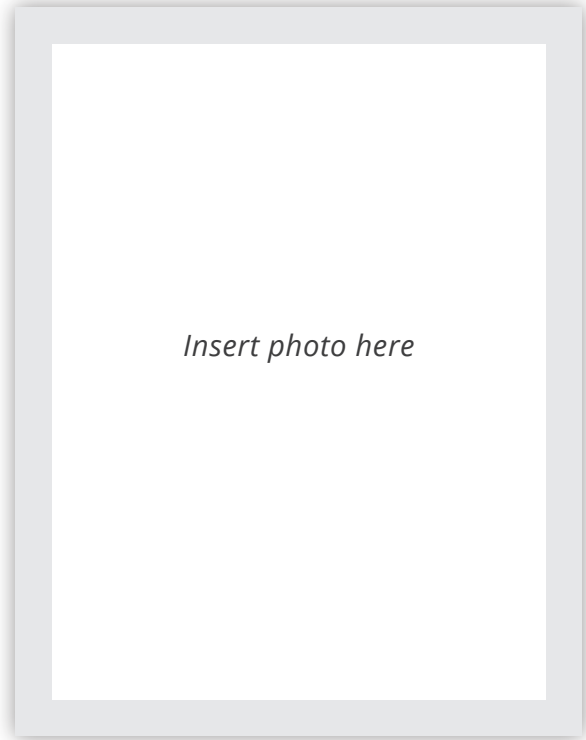
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### Life roles/occupations, significant events & achievements

*Ask questions like: What kind of things were you gifted at? What are you proud of? What memories do you hold in your heart?*

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### Spirituality, religion & traditions

*Ask questions like: Are you part of a spiritual community? What beliefs bring you comfort and strength? Are there specific spiritual or cultural practices that are important to you?*

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## What keeps me going?

Ask questions like: What are your hobbies? For example, crafts, singing, cooking, knitting, cutting vegetable or fruits, storytelling. What are your favourite topics of conversation/music? What makes you happy? What are some ways you express your gratitude?

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## Important people in my life

Record the names and relationships of individuals who are essential. Ask questions like: Tell me about your parents, grandparents, siblings, or friends. Who do you identify as your family? Who do you trust? Who do you like to spend time with? Who helps you do what you need to do? Have you ever had a pet or cared for an animal? What is/was their name?

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## What helps me feel connected every day

How a person spends a typical day, including morning and evening routines and social and recreational activities. Ask about: Socialization preferences. Are you happy with visitors? Are you happy eating with others? When do you prefer to be alone? What do you like to do during the day? (e.g., watching TV, playing cards)

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## Sleep/wake preferences

*Do you sleep well? When do you go to sleep, and when do you wake up? What do you like to do when you wake up?*

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## Food preferences

*What food do you like? What food do you dislike?*

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## Other personal preferences

*For example, likes to be clean-shaven and wear makeup, favorite clothing items, and rituals/routines followed.*

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# The Care Collage



## Purpose

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 in the circle of care will work together on this activity.

- 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.



## Material

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



## Instructions

Create a collage representing your experiences and thoughts about dementia care. Discuss your collage with your circle of care. Alternately, you can create a song and poems as part of this activity.



## Suggested Discussion Questions

1. What does each image mean to you?
2. What does “care” to you?
3. What does each person see as their role in dementia care?



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# The Care Collage

Date: \_\_\_\_\_



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# The Care Collage

Date: \_\_\_\_\_



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# The Care Collage

Date: \_\_\_\_\_





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# My 5 Important Things



## Purpose

To help you share the most important things about you with the other members of the circle of care. This is especially important when a new member joins the circle of 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 in the circle of care will work together on this activity.

- Early in the journey, this activity may be best suited for the person living with dementia and their family or friends to complete together.
- If the person living with dementia is unable to do so, this activity may be completed by their family members or friends and care provider(s).



## Materials

1. My 5 Important Things template
2. Pen or pencil



## Instructions

- This activity can be completed from the different perspectives of those in the circle of care
- Using the template below, first, reflect and list the “Top 5 Important Things” you wish a new care provider knew. Then match each “important thing” with a reason why it is important for the care provider to know.
- Use this page as a “cover letter” when a new person joins your circle of care to help communicate what’s really important in your journey.



# My 5 Important Things

Date:  
Name:

*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 tie his turban every morning*

→  
Why is this important to you ?

*Because how he looks is important to him.*

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

→  
Why is this important to you ?

*It helps me find balance in my life*

*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.*



# My 5 Important Things

Date:  
Name:



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



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

# My 5 Important Things

Date:  
Name:



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



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

# My 5 Important Things

Date:  
Name:



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



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 my  
Journey**

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# 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.



**Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**I'm concerned about:**

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**Why:**

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

**Response:**

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# 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.



**Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**I'm concerned about:**

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**Why:**

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

**Response:**

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# 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.



**Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**I'm concerned about:**

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**Why:**

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

**Response:**

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# Well-being 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.



## Instructions

- Please indicate for each of the five statements which most closely 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.

Name:

Date:

Score\*:

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

\*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.



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



# Well-being Check-In

Please indicate for each of the five statements which most closely 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.

Name:

Date:

Score\*:

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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

Name:

Date:

Score\*:

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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
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Please indicate for each of the five statements which most closely 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.

Name:

Date:

Score\*:

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I have felt calm and relaxed	5	4	3	2	1	0
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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

Name:

Date:

Score\*:

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

\*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.



# Well-being Check-In

Please indicate for each of the five statements which most closely 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.

Name:

Date:

Score\*:

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

Name:

Date:

Score\*:

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

\*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.



# Well-being Check-In Score Tracker

Use the tables below to keep track of your Well-Being Check-In score over time. The score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life. If your overall score decreases over time, you may want to seek help or talk to someone about what's happening in your life.

Name:

Date DD/MM/YY	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Score						

Name:

Date DD/MM/YY	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Score						

Name:

Date DD/MM/YY	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Score						

Name:

Date DD/MM/YY	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Score						





# Alzheimer's and Dementia Person-Centred Symptoms Tracker



## Purpose

The purpose of this activity is to keep track of symptoms of dementia on a monthly basis. You should take the symptoms tracker pages with you when you talk to a healthcare provider or someone you trust.



## Timing

We suggest you update these pages every 30 days. If you notice a big change in the person with dementia that you want to keep a record of, you can update this page more often.



## Participants

This activity was originally designed to help friends or family of someone living with dementia in monitoring their symptoms. However, it can be used by anyone in the circle of care to keep track of dementia-related symptoms.



## Instructions

1. Use the table to track the type and frequency of symptoms that the person living with dementia is exhibiting
2. Update the table once every 30 days
3. Discuss any changes or concerns with other members of the circle of care including health care providers



# Alzheimer's and Dementia Person-Centred Symptoms Tracker

Each person's experience with Alzheimer's or Dementia is unique to them. Symptoms may change frequently and progress differently with each person and can be affected by many factors. This tool was designed to help the family or friend caregiver track the type and frequency of the symptoms your loved one is exhibiting to support better communication and planning with your medical team and other healthcare providers as you collaborate in identifying the best possible treatment and interventions based upon your specific situation.

Patient Name:

Date of Birth:

Date:

<b>Orientation</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Forgets name of close family or friends				
Forgets address or hometown				
Forget date/time of year/time of day				
Asks repetitive questions				
<b>Communication</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Has trouble using words to express needs				
Becomes frustrated when speaking				
Repeats key words/phrases/gestures				
Talks to/looks at people that aren't there				
Has difficulty with written or verbal comprehension				
<b>Bathing and Grooming</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Refuses to change clothes				
Resists bathing (showering)				
Refuses to shave/brush teeth or hair				
Exhibits fear/anxiety regarding water or undressing				
Becomes combative during bathing or grooming				
<b>Nutrition and Hydration</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Eats less than usual				
Eats only a few types of food				
Eats 50% or less of meals				
Takes in less than 8 glasses of water/liquid per day				
Rapid weight loss (5 or more #s/month)				
Rapid weight gain (5 or more #s/month)				
<b>Behaviour</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Refuses or resists medications				
Accuses others of theft or malice				
Yells, curses or engages in name calling				
Strikes out/throws things/hits people or things				
Fearful of new people or situations				
Disrobes inappropriately				
Exhibits sexual aggressiveness				



Judgement	Daily	Weekly	Monthly	Never
Mismanages money or bills				
Dresses inappropriately for weather or outings				
Unable to recognize potential danger				
Inability to comprehend consequences				
Engagement	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				
Has difficulty self-initiating hobbies or pleasant pastimes				
Does not want to attend ceremonies				
Toileting	Daily	Weekly	Monthly	Never
Accidents/incontinent of urine				
Accidents/incontinent of bowel				
Attempts to "go" in places other than the toilet				
Is unaware of need to use bathroom				
Is unaware when wet, soiled or has incontinent related odor				
Physical	Daily	Weekly	Monthly	Never
Has difficulty walking				
Walks with a "shuffling" gait				
Has difficulty transitioning from sitting to standing/standing to sitting				
Appears to have pain				
Changes in facial expression/drooping				
Changes in sleeping habits				
Falls (with or without injury)				
Increase in bruising/unexplained injuries				
Wandering and Safety	Daily	Weekly	Monthly	Never
Is unsafe around the stove or hot surfaces				
Is unsafe around water or faucets				
Attempts to eat things that are not food				
Has gotten lost away from home/loses caregiver on outings				
Attempts to leave home				
Is currently or still asks to drive a car				

Other Concerns: \_\_\_\_\_

Completed by: \_\_\_\_\_ Date Completed: \_\_\_\_\_

Caregiver's Relationship to Patient: \_\_\_\_\_ Contact Phone: \_\_\_\_\_

**Next Steps:** Take this form to your physician/medical appointments to help guide discussions about possible treatment options and interventions. Update this form every 30 days or upon significant change in condition. Keep copies in dated order for your own records.



# Alzheimer's and Dementia Person-Centred Symptoms Tracker

Each person's experience with Alzheimer's or Dementia is unique to them. Symptoms may change frequently and progress differently with each person and can be affected by many factors. This tool was designed to help the family or friend caregiver track the type and frequency of the symptoms your loved one is exhibiting to support better communication and planning with your medical team and other healthcare providers as you collaborate in identifying the best possible treatment and interventions based upon your specific situation.

Patient Name:

Date of Birth:

Date:

<b>Orientation</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Forgets name of close family or friends				
Forgets address or hometown				
Forget date/time of year/time of day				
Asks repetitive questions				
<b>Communication</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Has trouble using words to express needs				
Becomes frustrated when speaking				
Repeats key words/phrases/gestures				
Talks to/looks at people that aren't there				
Has difficulty with written or verbal comprehension				
<b>Bathing and Grooming</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Refuses to change clothes				
Resists bathing (showering)				
Refuses to shave/brush teeth or hair				
Exhibits fear/anxiety regarding water or undressing				
Becomes combative during bathing or grooming				
<b>Nutrition and Hydration</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Eats less than usual				
Eats only a few types of food				
Eats 50% or less of meals				
Takes in less than 8 glasses of water/liquid per day				
Rapid weight loss (5 or more #s/month)				
Rapid weight gain (5 or more #s/month)				
<b>Behaviour</b>	<b>Daily</b>	<b>Weekly</b>	<b>Monthly</b>	<b>Never</b>
Refuses or resists medications				
Accuses others of theft or malice				
Yells, curses or engages in name calling				
Strikes out/throws things/hits people or things				
Fearful of new people or situations				
Disrobes inappropriately				
Exhibits sexual aggressiveness				



Judgement	Daily	Weekly	Monthly	Never
Mismanages money or bills				
Dresses inappropriately for weather or outings				
Unable to recognize potential danger				
Inability to comprehend consequences				
Engagement	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				
Has difficulty self-initiating hobbies or pleasant pastimes				
Does not want to attend ceremonies				
Toileting	Daily	Weekly	Monthly	Never
Accidents/incontinent of urine				
Accidents/incontinent of bowel				
Attempts to "go" in places other than the toilet				
Is unaware of need to use bathroom				
Is unaware when wet, soiled or has incontinent related odor				
Physical	Daily	Weekly	Monthly	Never
Has difficulty walking				
Walks with a "shuffling" gait				
Has difficulty transitioning from sitting to standing/standing to sitting				
Appears to have pain				
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Other Concerns: \_\_\_\_\_

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# Diary writing and Reflection

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# Diary Entries

There are many ways to reflect on your dementia journey.

You may use these reflection pages to note the activities that happen in a day and your feelings about them.

Record or draw any emotions you are feeling; this is where you can record ups and downs.

Some people feel better or more confident when they write things down. Others like to look back after some time to see how they were feeling in the past.
























# Available Resources




# Available resources and services

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

## Specialized Dementia Services

Resource	Purpose	Language	Who It's For	Access
Alzheimer Society of Canada	Educational materials and support services for individuals and families affected by Alzheimer's disease and dementia.	English, French	Everyone	 Alzheimer.ca
Behavioral Supports Ontario (BSO)	Specialized services and resources to support individuals with dementia who exhibit challenging behaviors.	English, French	Persons living with dementia Healthcare providers	 Behavioural supports ontario.ca
SE Health's ELIZZ	Offers caregiving services and resources to support individuals caring for people living with dementia.	English	Family/friend caregivers	 Elizz.com

## Community and Peer Support

Resource	Purpose	Language	Who It's For	Access
Toronto Support Group, Alzheimer Society	Join a support group for individuals caring for people living with dementia. Connect with others, share experiences, and receive valuable support and guidance.	English	Family/friend caregivers	 Alz.to/ dementia support services/ support-groups/
Indus Community Services	Provides culturally appropriate services to newcomers, families, women, and seniors, promoting healthy aging with privacy and dignity.	Hindi, Punjabi, Tamil, Urdu, Bengali Gujarati, Arabic	Everyone	 Induscs.ca
Apna Health	Offers health and wellness information in multiple South Asian languages. Direct assistance available via hotline (905-366-1010)	Hindi, Urdu, Tamil, Bengali, Punjabi	Everyone	 Apna health.org



# Available resources and services




## Educational Guides and Materials

Resource	Purpose	Language	Who It's For	Access
Talking to Your Doctor About Dementia	Provides tips for discussing dementia concerns with your doctor, including conversation starters, questions to ask, and seeking support for assessment and diagnosis.	English, French	Family/friend caregivers	 <a href="https://www.alzheimer.ca/diagnosis">Alzheimer.ca/diagnosis</a>
Dementia, Your Companion Guide	Information and resources for individuals and families navigating the dementia journey.	Punjabi, Tagalog, Arabic, English, French	Family/friend caregivers	 <a href="https://www.mcgill.ca/dementia/resources/dementia-your-companion-guide">Mcgill.ca/dementia/resources/dementia-your-companion-guide</a>
Seven Dimensions of Wellness	Explore the Seven Dimensions of Wellness to promote well-being and vitality across all stages of life.	English	Everyone	 <a href="https://www.icaa.cc/activeagingandwellness/wellness.htm">ICAA.cc/activeagingandwellness/wellness.htm</a>
Dementia-Specific Training	Provides courses and educational materials to enhance understanding and skills in providing care and support for individuals living with dementia.	English	Family/friend caregivers Healthcare providers	 <a href="https://www.alz.to/professional-courses-learning-programs/">Alz.to/professional-courses-learning-programs/</a>
Interacting with Persons with Dementia in South Asian Communities	Scenarios and strategies to facilitate interactions with persons with dementia by presenting common scenarios. Available in written and conversational audio formats.	Hindi, Punjabi	Family/friend caregivers Healthcare providers	 <a href="https://source.sheridancollege.ca/fahcs_persons_with_dementia/">SOURCE.sheridancollege.ca/fahcs_persons_with_dementia/</a>



# Available resources and services

## Educational Guides and Materials Continued

Resource	Purpose	Language	Who It's For	Access
Changing Perceptions of Dementia in the Punjabi Community	Gain insights into cultural perspectives and initiatives to raise awareness and reduce the stigma surrounding dementia.	Punjabi, English	Persons living with dementia Family/friend caregivers	 <a href="https://www.alzheimers.org.uk/blog/changing-perceptions-dementia-punjabi-community">Alzheimers.org.uk/blog/changing-perceptions-dementia-punjabi-community</a>
Memories in Harmony: A South Asian Guide to Dementia Care	A comprehensive guide for individuals and care partners navigating dementia within the South Asian community.	English, Punjabi, Hindi, Tamil, Urdu, Gujarati	Everyone	 <a href="https://apnahealth.org/dementia/">Apnahealth.org/dementia/</a>
Forward with Dementia	Provides guidance after diagnosis, personal stories and strategies to combat dementia stigma, specifically tailored to the South Asian community.	Punjabi, Hindi, Urdu, French, English	Everyone	 <a href="https://forwardwithdementia.ca/southasian/">Forwardwithdementia.ca/southasian/</a>

**Other components that you could add to this journal include information, forms or activities about:**

- What to expect along the dementia journey
- Beginning of memory problems
- Dealing with aggressive behaviour/violence/safety
- Complex symptoms
- Communication
- Activities
- Finance/Power of Attorney
- How to manage sudden deterioration or specific crisis
- Request for information about services
- Respite care/caregiver fatigue
- The decline in the caregiver's health
- Unaware of symptoms/uncomfortable with help, especially with personal care
- Family dynamics



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# Dementia

## 10 warning signs

Whether you're concerned for yourself or someone you care about, it's important to know the warning signs of dementia so you can ensure an early diagnosis. Here are 10 of the most common warning signs for dementia.

Please list any concerns you have and take this sheet with you to the doctor. Note: This list is for informational purposes only and is not a substitute for consultation with a qualified professional.

- 1. MEMORY CHANGES THAT AFFECT DAILY LIFE.** It is normal to sometimes forget meetings or co-worker names only to remember them a short time later. But a person with dementia may forget things more often. Or it might be hard for them to remember information they just learned.

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- 2. DIFFICULTY DOING FAMILIAR TASKS.** Busy people can be so distracted sometimes that they may forget to serve part of a meal, only to remember it later. But a person living dementia may have trouble doing tasks they have done all their lives, such as preparing a meal or playing a game.

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- 3. CHANGES IN LANGUAGE AND COMMUNICATION.** Anyone can have trouble finding the right word. But a person with dementia may forget simple words. Or they may use the wrong words, making that person hard to understand.

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**4. DISORIENTATION IN TIME AND SPACE.** It is common to forget the day of the week or your destination — for a moment. But a person with dementia may become lost on their own street. They may not know how they got there or how to get home.

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**5. IMPAIRED JUDGEMENT.** Sometimes, people may make bad decisions such as putting off seeing a doctor when they are not feeling well. But a person with dementia may not recognize a medical problem that needs attention, or wear heavy clothing on a hot day.

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**6. PROBLEMS WITH ABSTRACT THINKING.** Sometimes, people may have difficulty with tasks that require abstract thinking, such as managing finances. But a person with dementia may experience challenges with understanding what numbers are and how they are used.

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**7. MISPLACING THINGS.** Anyone can temporarily misplace a wallet or keys. But a person with dementia may put things in inappropriate places, such as an iron in the freezer or a wristwatch in the sugar bowl.

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**8. CHANGES IN MOOD, PERSONALITY AND BEHAVIOUR.** Sometimes people feel sad and moody, or experience changes in their behaviour. But a person living with dementia may experience more severe changes. For example, they may quickly become tearful or upset for no obvious reason. They may be confused or suspicious and withdraw from others. They may act differently from what is normal for them.

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**9. LOSS OF INITIATIVE.** It is normal to lose interest in housework, business activities or social obligations sometimes. But most people regain their initiative. A person with dementia may become passive and disinterested. They may need cues and prompts to become involved.

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**10. CHALLENGES UNDERSTANDING VISUAL AND SPATIAL INFORMATION.** A person with dementia may have problems with vision, depth perception and movement. They might not see objects in their way when walking. Or they might have challenges placing items on a table.

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# Activities Calendar

Use the Activities Calendar to keep track of upcoming events related to care such as day programs, appointments, or support groups. You may keep a separate calendar for each member.

Name: \_\_\_\_\_

Year: \_\_\_\_\_

**January**

**February**

**March**

**April**

**May**

**June**



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# Activities Calendar

Name: \_\_\_\_\_

Year: \_\_\_\_\_

**July**

**August**

**September**

**October**

**November**

**December**



# Acknowledgements

We would like to acknowledge the contributions of all those who worked to co-design this journal.

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*Société Alzheimer Society*  
CANADA



Public Health  
Agency of Canada

Agence de la santé  
publique du Canada

This prototype of Our Dementia Journey Journal is provided for gathering feedback and evaluating how it can be improved to be more useful to people living with dementia, their caregivers and their care providers.

If you would like to reproduce any parts of Our Dementia Journey Journal, please contact [research@sehc.com](mailto:research@sehc.com)