



# ODJJ

Our Dementia  
Journey Journal

This journal is adapted by and  
for First Nations people



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



# Welcome to Our

This journal was created by a group of caregivers, care providers, representatives from the Alzheimer Society of Canada and the SE Research Centre at SE Health.

This is a journal that you can use to build relationships between your friends, family and health care providers as you experience the dementia journey together. We hope you find the journal to be supportive.

You can choose which activities or pages would be most helpful and print them. We suggest you store these papers in a binder to keep them together.

In case of loss, please return to:

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

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

\_\_\_\_\_

\_\_\_\_\_



Dementia is a term that is used to describe a set of symptoms that can include memory loss, difficulty thinking, problem solving, or issues with language. There are many types of dementia- the most common ones you may have heard about are Alzheimer's disease, lewy body dementia, fronto-temporal lobe dementia, or mixed dementia. These conditions can affect everyone differently, but the most common symptoms are memory loss, personality changes, and trouble completing tasks. Dementia is a progressive disorder which means that the symptoms will change in predictable and unpredictable ways as time goes on.

Dementia is often described as a journey that the person living with dementia and the people who support them go on together. One way to make the journey easier is to build circles of care that involve the person living with dementia, their family and friends, and care providers such as personal support workers, nurses and doctors. Having strong relationships and good communication within the circle of care can make the journey less lonely and easier.

If you have questions or concerns about dementia,

**THE CIRCLE OF CARE.** One way to make the journey easier is to create a circle of care that includes the person living with dementia, their family and friends in caregiving roles, and care providers such as personal support workers, nurses and doctors.

Having strong relationships and good communication within the circle of care can make the journey less lonely and easier. This journal is designed to support this relationship building, particularly between the family and friend caregivers and healthcare providers.

While the ODJ focuses on the relationship between caregivers and health care providers, building trust, teamwork and understanding of one another is hoped to help provide better care for a person living with dementia.



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# Outline of

Our Dementia Journey Journal is for people living with dementia, their caregivers, and care providers to support strong partnerships along the dementia journey. It is broken down into sections that allow its users to adapt the journal to meet their unique needs.

Colour coded sections make this journal easy to make your own. Each section has a different purpose and colour associated with it, so you can choose how you'd like to use this journal.

## Sections:

### **Introduction to the journal**

How to use the journal

Guiding principles



**Blue pages:** *to share information about you*

My Questions About Dementia

My Whole Self activity

The Care Collage activity



My Top 5 Things

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

Well-being documentation chart for concerns

Bi-weekly Check-in (WHO's Well-Being Index)

Monthly Check-in on symptoms of dementia



**Orange pages:** *a place to note your reflections and to journal*

Written Reflections

Sharing Joyful Moments



**Green pages:** *other information and tools to cope*

Activities Calendar

Early Detection tool

Acknowledgments

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# How to use this journal:



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

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

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

This journal is full of activities that are designed to help you on the dementia journey. The journey is full of changes, and these activities can help you prepare for them and address challenges as they come.

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

You can use this journal as much or as little as you feel you would like to or need to.

- Some activities have a suggested time to complete them, others are up to you to choose

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

The journal can be used in many different ways. It is up to you to decide which parts are useful for you. Some of the ways you could use the journal include

- taking it to appointments to share your concerns or observations
- sharing memories and important information about the person with dementia
- taking care of your mental health with self care activities
- building relationships with new members of the circle of care when the circle expands to meet the needs of the person with dementia

**Honour the circle of care:**

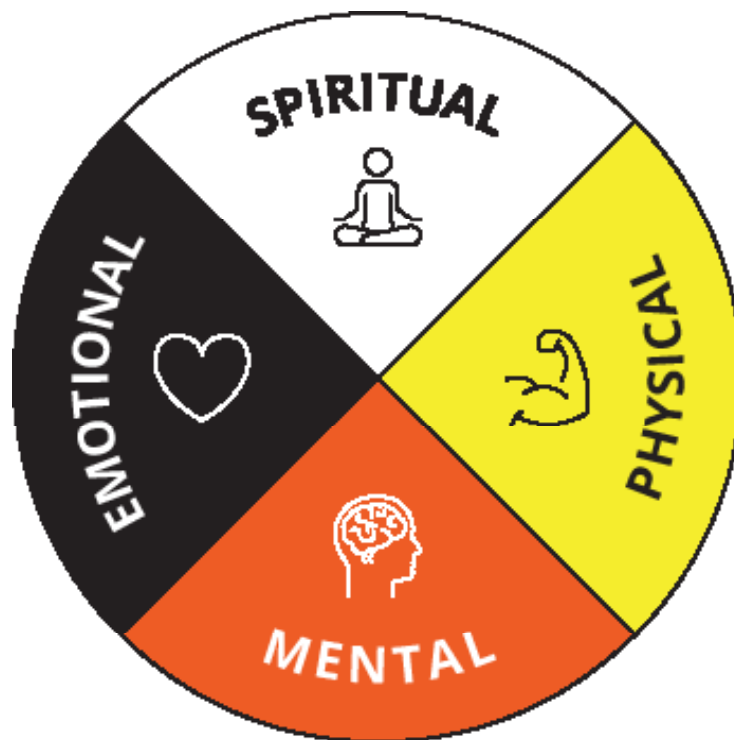
Understand that everyone in the circle of care has linked lives because you are on this dementia journey together. Strengthen this circle of care, respect the needs of the person living with dementia and their caregiver(s) and build partnerships with care providers in professional roles.

**Use a person and family centered approach:**

Embrace relationship- centred working, holistic care, and support for well-being through care that is pro- active, timely, and coordinated.

**Share your knowledge, acknowledge gaps:**

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





**Share  
Information**

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# My questions about dementia:

On this page, keep a record of questions you have about dementia, about symptoms, about your feelings, about who will do what, etc.

- “What did you notice or feel today that was different?”
- “What lifestyle changes can support overall well-being for someone living with dementia?”

1. Date: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. Date: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. Date: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. Date: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. Date: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

6. Date: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



# My Whole Self



## Purpose

This activity is intended to provide an opportunity for all members of the circle of care to get to know each other better.



## Participants

This activity can be completed by anyone in the circle of care of the person living with dementia.



## Timing

The content can be reviewed and updated as needed and/or when there are transitions through the care system.



## Acknowledgements

*My Whole Self 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/)



## Additional Resources

*The following tool provides useful guidelines about how health care providers might approach older Indigenous adults:*

- © 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. “A Quick Guide to... Approach” (1151319, Industry Canada). Retrieved from: <https://www.i-caare.ca/practicetools>













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# The Care Collage



## Purpose

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



## Timing

We suggest you complete this activity in times of change. This could include when you first receive a diagnosis, when you need help from home care for the first time, or when the person with dementia moves to long term care.



## Participants

Assess the situation- ideally, whoever is involved in the journey including the caregiver(s), care provider(s), and person living with dementia will work on this activity together.

- Early on in the journey this activity might be best suited for caregiver(s) and persons living with dementia to complete together
- If the person living with dementia is not able to then this activity is suited for the caregiver(s) and care provider(s)

## Materials

1. a variety of pre-cut images from personal photos, magazines newspapers
2. glue or tape
3. pens, pencils, or markers



and



## Instructions

Assemble into a collage a representation of your experiences and views of dementia care. When you have each assembled your collages, you are encouraged to talk about your collages.

## 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 dementia care triad?



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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 Top 5 Things

## **Purpose**

This activity is intended to support transitions in the dementia journey.

## **Timing**

We suggest you complete this activity in times of change. This could include when you first receive a diagnosis, when you need help from home care for the first time, or when the person with dementia moves to long term care.

## **Participants**

Assess the situation- ideally, whoever is involved in the journey including the caregiver(s), care provider(s), and person living with dementia will work on this activity together.

- Early on in the journey this activity might be best suited for the caregiver and the person living with dementia to complete together
- If the person living with dementia is not able to then this activity is suited for the caregiver and care provider.

## **Materials**

1. My Top 5 things template
2. Pen or pencil

## **Instructions**

This activity can be completed from the various perspectives of those involved in the dementia care triad. Using the template below, first, reflect and list the “Top 5 things” about that you want a new care provider to know. Then match each “important thing” with a reason as to why it’s important for the care provider to know this.

Use this page as a “cover letter” when you are changing to a new place of care or care provider to help guide conversation about what is really important in your journey.



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



# Top 5 Things: About Me

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

My name: \_\_\_\_\_

## Top Five things about me

*My Mom likes to watch the sunrise*



Why is this important to you ?

*It lifts her spirits and connects her to the Creator*



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



Why is this important to you ?



# Top 5 Things: About Me

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

My name: \_\_\_\_\_

Top Five things about me



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 ?



# Top 5 Things: About Me

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

My name: \_\_\_\_\_

Top Five things about me



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 ?



# Top 5 Things: About Me

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

My name: \_\_\_\_\_

Top Five things about me



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 ?



# Top 5 Things: About Me

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

My name: \_\_\_\_\_

Top Five things about me



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 ?



# Top 5 Things: About Me

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

My name: \_\_\_\_\_

Top Five things about me



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 ?



# Top 5 Things: About Me

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

My name: \_\_\_\_\_

Top Five things about me



Why is this  
important  
to you ?



Why is this  
important  
to you ?



Why is this  
important  
to you ?



Why is this  
important  
to you ?



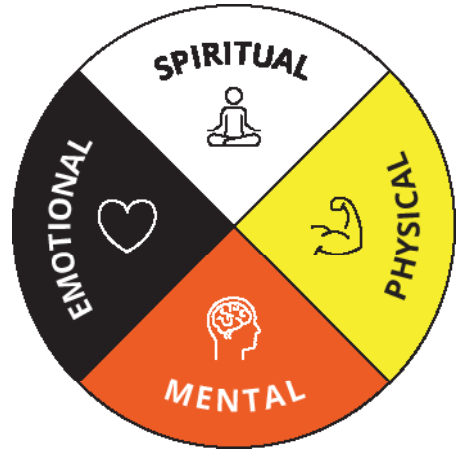
Why is this  
important  
to you ?





# Share My Journey

# Well-being Communication



Throughout your journey you may want to document concerns you feel. Use this page as often as you would like to share your experiences. You may want to take this form to your physician/medical appointments to help guide discussions about possible treatment options and interventions.

Today's date: \_\_\_\_\_

Person documenting: \_\_\_\_\_

I'm concerned about:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

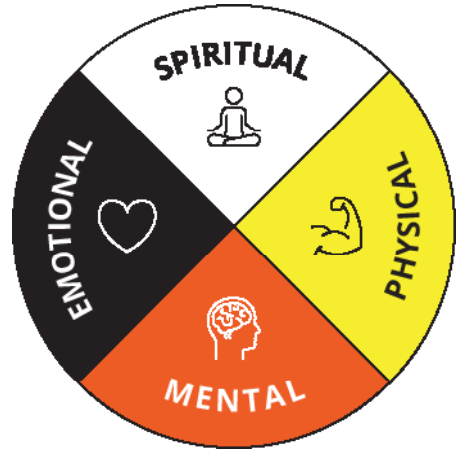
Why:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I need someone to:  Hear me       Help me       Take action

Response:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



# Well-being Communication



Throughout your journey you may want to document concerns you feel. Use this page as often as you would like to share your experiences. You may want to take this form to your physician/medical appointments to help guide discussions about possible treatment options and interventions.

Today's date: \_\_\_\_\_

Person documenting: \_\_\_\_\_

I'm concerned about:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Why:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

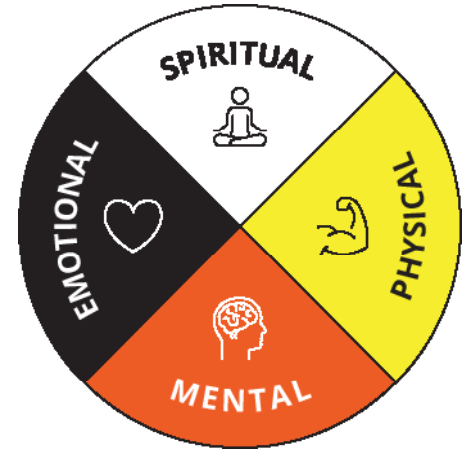
I need someone to:  Hear me       Help me       Take action

Response:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



# Well-being Communication

Throughout your journey you may want to document concerns you feel. Use this page as often as you would like to share your experiences. You may want to take this form to your physician/medical appointments to help guide discussions about possible treatment options and interventions.



Today's date:

Person documenting:

---

I'm concerned about:

---

---

---

---

Why:

---

---

---

---

I need someone to:  Hear me  Help me  Take action

Response:

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# Well-being Communication

Throughout your journey you may want to document concerns you feel. Use this page as often as you would like to share your experiences. You may want to take this form to your physician/medical appointments to help guide discussions about possible treatment options and interventions.



Today's date: \_\_\_\_\_

Person documenting: \_\_\_\_\_

I'm concerned about:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Why:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I need someone to:  Hear me     Help me     Take action

Response:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



Along your journey, it is important to check in on our wellbeing. This tool can help you think about your overall wellbeing by asking five simple questions. We suggest using the World Health Organization's Well-Being Index (1998 version) every two weeks, but you can use it as often or as little as you like.

We know that some days are harder than others. The tool asks you to think about your overall experience in the past two weeks. Using this tool may help you understand or communicate what you are feeling. If you notice your overall score is going down over time, you might want to ask for help or speak to someone about what is happening in your life.

### The World Health Organization's Well-Being Index

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

#### Person documenting:

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
Mental health	I have felt cheerful and in good spirits	5	4	3	2	1	0
Mental health	I have felt calm and relaxed	5	4	3	2	1	0
Physical health	I have felt active and vigorous	5	4	3	2	1	0
Physical health	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.



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



# Bi-Weekly Check-In

Name:

Date:

Person documenting:

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
						Total Score:

Name:

Date:

Person documenting:

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
						Total Score:



# Bi-Weekly Check-In

Name:

Date:

Person documenting:

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
						Total Score:

Name:

Date:

Person documenting:

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
						Total Score:



# Bi-Weekly Check-In

Name:

Date:

Person documenting:

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
						Total Score:

Name:

Date:

Person documenting:

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
						Total Score:



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# Bi-weekly Check-In Score Tracker

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						



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# Bi-weekly Check-In Score Tracker

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						

Name:

Person documenting:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__
Total Score						



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# Monthly check-in on symptoms of dementia

## Alzheimer's and Dementia

### Person-Centered 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 and 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**

Each person's experience with Alzheimer's or dementia is unique. Symptoms may change frequently and progress differently with each person and can be affected by many factors. This tool was designed to help family caregivers (friends/family members of the person living with dementia) track the type and frequency of 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.



# Alzheimer's and Dementia Person-Centered Symptoms Tracker

We suggest you update this page every 30 days. If you notice a big change in the person with dementia that you want to keep a record of, you could update this page more frequently. You may want to take this page with you when you talk to a health care provider or when speaking to someone you trust.

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				
Forgets 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				

*Continued on next page...*



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 or vice versa				
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: \_\_\_\_\_

Caregivers Relationship to Person: \_\_\_\_\_ Contact Phone: \_\_\_\_\_

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# Alzheimer's and Dementia Person-Centered Symptoms Tracker

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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				
Forgets 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				

*Continued on next page...*



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 or vice versa				
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: \_\_\_\_\_

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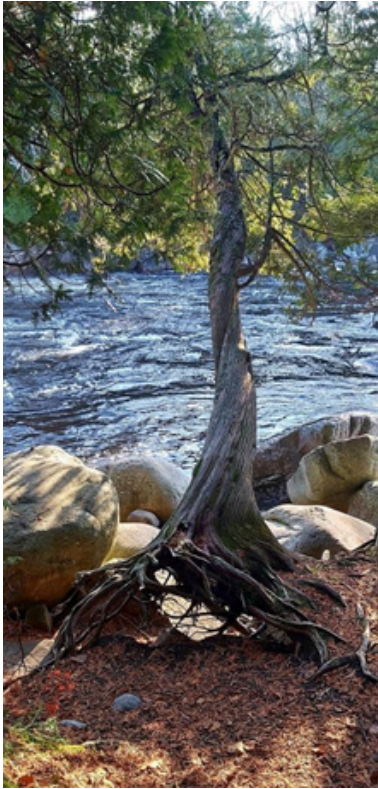




# Written Reflections and Share Joyful Moments

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# Written Reflections

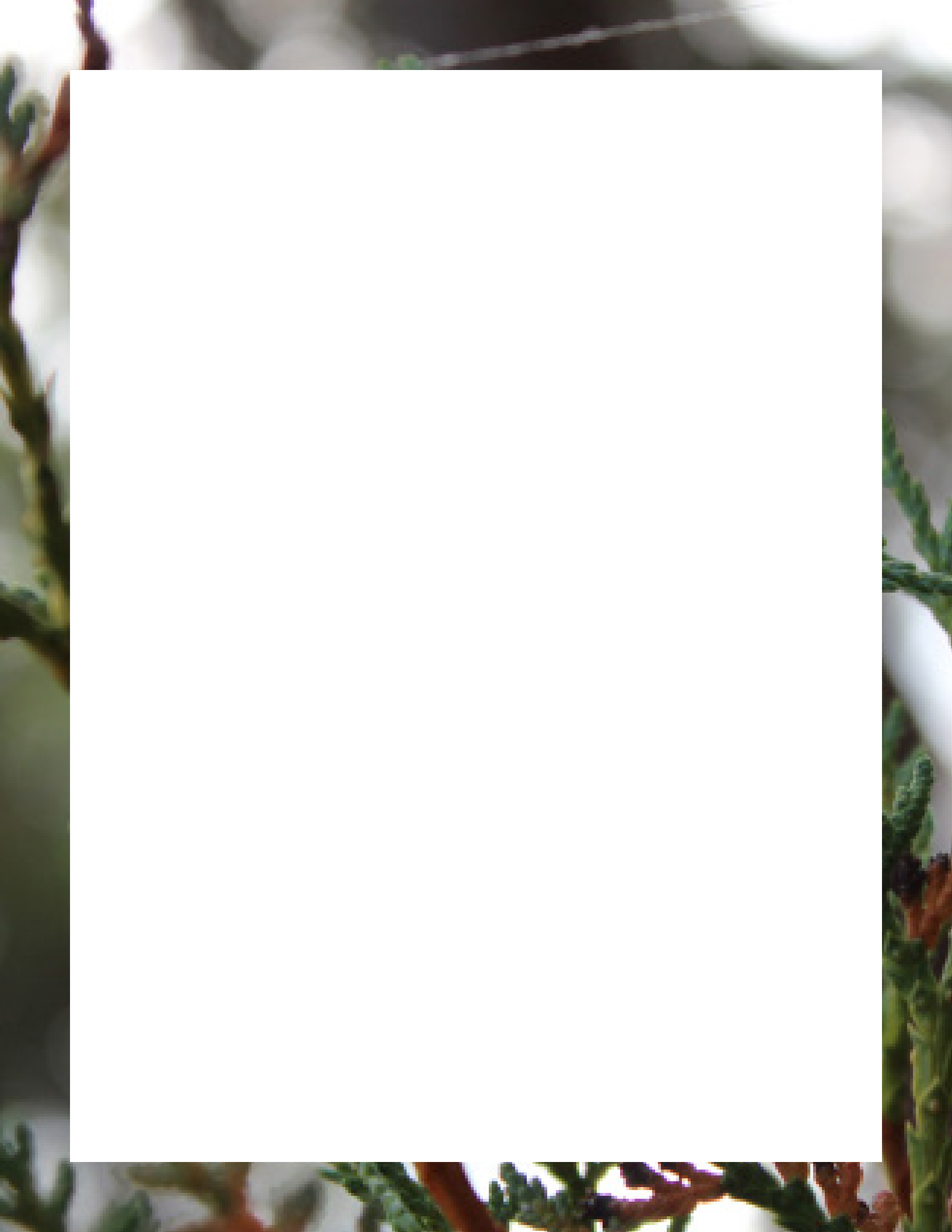


There are many ways to reflect on your dementia journey.

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

Feel free to record any emotions you are feeling; this is a place where you can record ups and downs. Some people feel better or more confident when they write things down or draw them. Others like to be able to look back after some time to see how they were feeling in the past.





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# Reflecting on Joyful Moments



If you are looking for an opportunity to focus on the positive throughout the dementia journey, keeping a journal is a way to do this.

Each day you could use these pages to write two or three things that made you smile. You might want to write in the date of each entry.

You can also use the prompts below to guide your reflection or just write from the heart about anything you choose.

- Write about an act of kindness you witnessed today
- Write your favorite memory
- Write down 3 things you would tell your younger self
- Write about an incident that went better than you thought it would
- Write about something nice someone did for you
- 10 things you love about your spouse, brother, mother, sister, dad etc.

*"A good laugh and a long sleep are the two best cures for*











# Resources

## Learning together along the journey



Visit our website to access more resources and support  
for the ODJJ [www.odjj.ca](http://www.odjj.ca)

# 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 Elizz	Offers caregiving services and resources to support individuals care for people living with dementia	English, French	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	



# Available resources and services






## Educational Guides and Materials

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	
PIECES Framework	A guide to approaching and getting to know a person living with dementia in an	English	Healthcare providers	
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	
About Dementia (Teepa Snow)	Provides resources on how to take a positive approach to dementia care.	English, Spanish	Family/friend caregivers	
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	



# Available resources and services




## Educational Guides and Materials

Resource	Purpose	Language	Who It's For	Access
Dementia, Your Companion Guide	Information and resources for individuals and families navigating the dementia journey.	English, French, Punjabi, Tagalog, Arabic	Family/friend caregivers	
Seven Dimensions of Wellness	Explore the Seven Dimensions of Wellness to promote well-being and vitality across all stages of life.	English	Everyone	
Forward With Dementia	Provides guidance after diagnosis, personal stories and strategies to combat dementia stigma. Includes resources tailored to specific communities (e.g., Italian, Chinese, South Asian)	English, French, Italian, Simplified Chinese, Traditional Chinese, Punjabi, Hindi, Urdu	Everyone	
Communication with people living with dementia	Strategies to facilitate interactions with persons living with dementia.	English, French	Family/friend caregivers Healthcare providers	
Dementia Information in Multiple Other Languages	Provides information and resources for individuals and families navigating the dementia journey in various languages	Simplified Chinese, Punjabi, Hindi, Spanish, Portuguese	Everyone	



# Available resources and services

## Educational Guides and Materials

Resource	Purpose	Language	Who It's For	Access
BrainXChange by Behavioral Supports Ontario	Tools and resources to support individuals with dementia who show responsive behaviours	English, French	Persons living with dementia Healthcare providers	
Research Institute on Aging - Words of Wisdom	Series of resources offering support, guidance, and reassurance for persons living with dementia and their care partners	English	Persons living with dementia Family/friend caregivers	 

**Tip:** Collect and add resources you receive from other caregivers or your care providers in this section of the ODJJ

### More topics that may be of interest (search using Google):

- 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 caregiver's own health
- Being unaware of symptoms/uncomfortable with help, especially with
- Personal care
- Family dynamics

**Note:** This is a standardized list and some of the links may no longer be active. If you are not directed to the page you are looking for after scanning the QR code, please try searching up the title of the resource directly in Google Search.



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# Activities Calendar

Name:

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Year:

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**January**

**February**

**March**

**April**

**May**

**June**



---

# Activities Calendar

Name:

Year:

---

**July**

**August**

**September**

**October**

**November**

**December**



---

# Activities Calendar

Name:

---

Year:

---

**January**

**February**

**March**

**April**

**May**

**June**



---

# Activities Calendar

Name:

Year:

---

**July**

**August**

**September**

**October**

**November**

**December**



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# Have you noticed any of these 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 information only and not a substitute for a consultation with a qualified professional.*

**1. MEMORY LOSS THAT AFFECT DAY-TO-DAY ABILITIES.** 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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# Acknowledgements

We would like to gratefully acknowledge the communities that participated in the review of the Our Dementia Journey Journal. Their input provided valuable feedback to help ensure this journal would be useful for Indigenous people as caregivers and care recipients living with dementia. We gratefully acknowledge the Elders who provided spiritual care and Traditional guidance during the three community sessions. We would also like to acknowledge the courage, compassion and kindness of the caregivers and care recipients living with dementia that participated in the community sessions held in Thessalon First Nation, Sagamok Anishnawbek and the Sault Ste Marie Indian Friendship Centre. The sessions would not have been possible without the support of the community champions who graciously took on the role of coordinating each of the sessions. We also extend our gratitude to Maamwesying North Shore Community Health Services Inc. Home and Community Support Services for their partnership in these sessions.

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*Peggy Robinson*, Bloomington Cove Caregiver

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*Mona Imenpour*, Bloomington Cove Care Provider

*Praveena Sivabaalan*, Bloomington Cove Care Provider

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*Société Alzheimer Society*  
CANADA



Public Health  
Agency of Canada

Agence de la santé  
publique du Canada

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The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

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