



Our Dementia Journey Journal

This journal is adapted by and for the general public

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 noting your reflections and diary keeping



Green Pages: resources for when you are feeling overwhelmed

Welcome to Our Dementia Journey Journal.

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 Center at SE Health.

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

In case of loss, please return to:

Name: _____

Contact: _____

Dementia is a journey



Dementia is a term used to describe symptoms that may include memory loss, difficulty thinking, problem-solving, or language-related problems.

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.

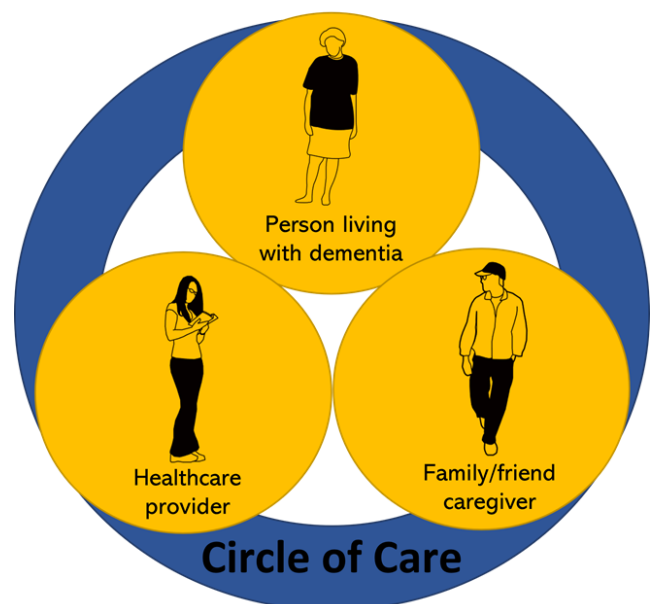
These conditions can affect everyone differently, but the most common symptoms are memory loss, personality changes, and difficulty completing tasks. Dementia is a progressive disorder which means that symptoms will change over time in predictable and unpredictable ways.

Dementia is often described as a journey that the person living with dementia and the people who support them take together.

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 ODJJ 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.



Visual Representation of The Circle of Care

Table of contents

Our Dementia Journey Journal is for people living with dementia, their family/friends, and care providers to support strong relationships between them throughout the dementia journey. This journal is divided into sections, and you can use the sections however you would like.

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

Sections:

Guiding framework

How to use the journal



Blue pages: to share information to support relationship building.

My Questions About Dementia

All About Me – A Conversation Starter

My Top 5 Things

The Care Collage Activity



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

Well-being Communication Chart for Concerns

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

Monthly Check-in on Symptoms of Dementia



Peach pages: a place to note your reflections and for diary keeping

Diary Entries

Reflection



Green pages: Available Resources

Acknowledgments

Guiding framework

Respect the circle of care:

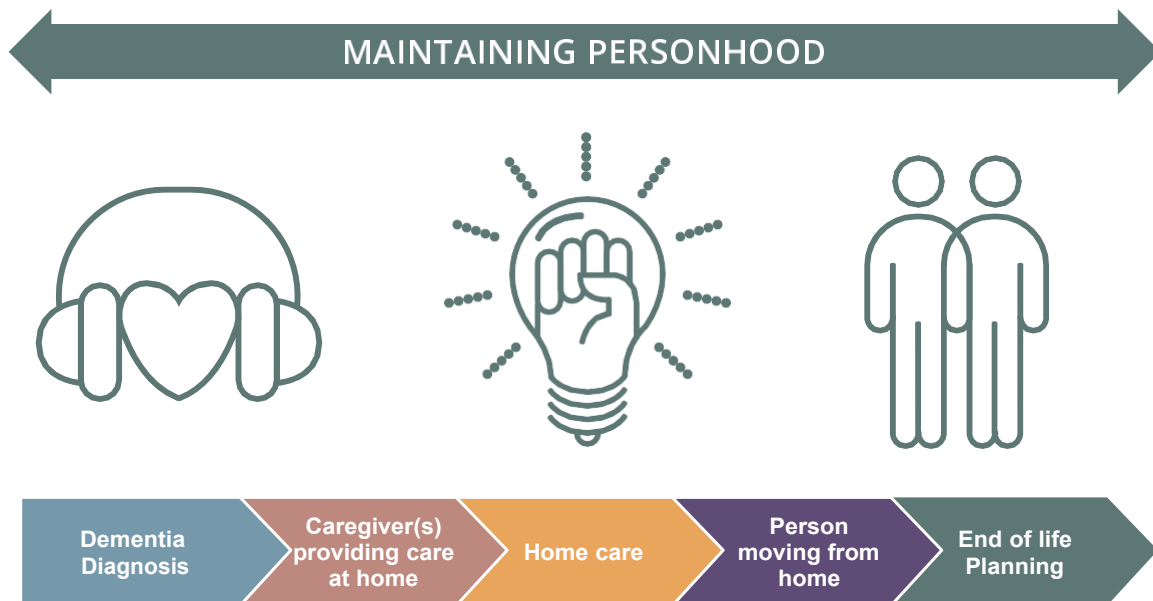
Realize that everyone in the circle of care has linked lives as you are on the dementia journey together. Strengthen this circle of care, respect the needs of the person living with dementia and their family and friends and build stronger relationships with care providers in professional roles.

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.



Help by

Hear me

Empathize- Provide emotional support

Normalize- Demonstrate understanding

Empower me

Provide resources to support

Share knowledge and information services

Take action

Recognize, assess and take immediate action

Co-ordinate care/help caregiver get access to services

How to use this



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 care 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:

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



Share Information

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:



My questions about dementia:

Date:

Date:

Date:

Date:

Date:

Date:



All About Me



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 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

The content can 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

All about me 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) © November 2014. Retrieved from: https://alzheimer.ca/sites/default/files/documents/all_about_me_a_conversation_st



All About Me

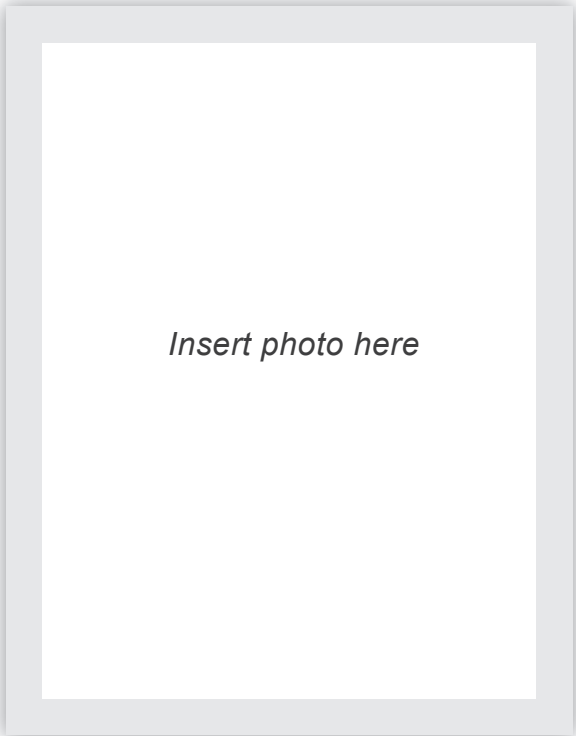
A Conversation Starter

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.



I enjoy...

Note the things you enjoy such as favourite foods, activities, topics of conversation, people, music, etc.

I don't like...

Note your dislikes, such as severe allergies or types of foods, music, weather, topics of conversation. This information can help others understand some possible triggers that make you uncomfortable

A typical day for me could include...

Note how you like to have your day start and end, such as morning and evening routines, social and leisure activities, and meal times. What brings you comfort and pleasure?



My Top 5 Things



Purpose

The purpose of this activity is 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, including the person living with dementia, family/friends who help care for them and any care provider.

- 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 unable to do so, this activity may be completed by their family members or friends and care provider(s).



Materials

1. My Top 5 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.



Top 5 Things: About Me

- Person living with dementia
 Caregiver Care provider

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.

Top 5 Things: About Me

Person documenting:

- Person living with dementia
 Caregiver Care provider

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

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?



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?



The Care Collage

Date: _____



The Care Collage

Date:



The Care Collage

Date: _____



The Care Collage

Date: _____



The Care Collage

Date:





Share my Journey

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:

- Person living with dementia
 Caregiver Care provider

I'm concerned about:

Why:

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

Response:



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:

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I'm concerned about:

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Response:



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:

- Person living with dementia
 Caregiver Care provider

I'm concerned about:

Why:

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

Response:



Bi-weekly Check-In



Purpose

This activity can help you think about your overall well-being by asking five simple questions. Using this tool can help you understand or communicate your feelings. If your overall score decreases over time, you may want to seek help or talk to someone about what's happening in your life.



Timing

We suggest completing this activity every two weeks, but you can use it as often or as little as you like.



Participants

Everyone in the circle of care is encouraged to track their wellbeing.

The World Health Organization's Well-Being Index

Instructions:

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

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



Bi-weekly Check-In

Person documenting:

Person living with dementia

Caregiver Care provider

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
						Total Score:

Person documenting:

Person living with dementia

Caregiver Care provider

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
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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
						Total Score:



Bi-weekly Check-In

Name:

Date:

Person documenting:

Person living with dementia

Caregiver Care provider

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:

Person living with dementia

Caregiver Care provider

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
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My daily life has been filled with things that interest me	5	4	3	2	1	0
						Total Score:



Bi-weekly Check-In

Person documenting:

Person living with dementia

Caregiver Care provider

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
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My daily life has been filled with things that interest me	5	4	3	2	1	0
						Total Score:

Person documenting:

Person living with dementia

Caregiver Care provider

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
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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
						Total Score:



Bi-weekly Check-In Score Tracker

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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



Bi-weekly Check-In Score Tracker

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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



Bi-weekly Check-In Score Tracker

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

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

Person documenting:

- Person living with dementia
 Caregiver Care provider

Name:

Date	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__	__/__/__



Monthly check-in on symptoms of dementia

Using the "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

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 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.

Person's Name: _____ Date of Birth: _____ Date: _____

Orientation	Daily	Weekly	Monthly	Never
Forgets name of close family or friends				
Forgets address or hometown				
Forgets date/time of year/time of day				
Asks repetitive questions				
Communication	Daily	Weekly	Monthly	Never
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				
Bathing and Grooming	Daily	Weekly	Monthly	Never
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				
Nutrition and Hydration	Daily	Weekly	Monthly	Never
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)				
Behaviour	Daily	Weekly	Monthly	Never
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: _____

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-Centered 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 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.

Person's Name: _____ Date of Birth: _____ Date: _____

Orientation	Daily	Weekly	Monthly	Never
Forgets name of close family or friends				
Forgets address or hometown				
Forgets date/time of year/time of day				
Asks repetitive questions				
Communication	Daily	Weekly	Monthly	Never
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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				
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Resists bathing (showering)				
Refuses to shave/brush teeth or hair				
Exhibits fear/anxiety regarding water or undressing				
Becomes combative during bathing or grooming				
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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)				
Behaviour	Daily	Weekly	Monthly	Never
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: _____

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-Centered 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 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.

Person's Name: _____ Date of Birth: _____ Date: _____

Orientation	Daily	Weekly	Monthly	Never
Forgets name of close family or friends				
Forgets address or hometown				
Forgets date/time of year/time of day				
Asks repetitive questions				
Communication	Daily	Weekly	Monthly	Never
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				
Bathing and Grooming	Daily	Weekly	Monthly	Never
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				
Nutrition and Hydration	Daily	Weekly	Monthly	Never
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)				
Behaviour	Daily	Weekly	Monthly	Never
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				
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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				
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Judgement	Daily	Weekly	Monthly	Never
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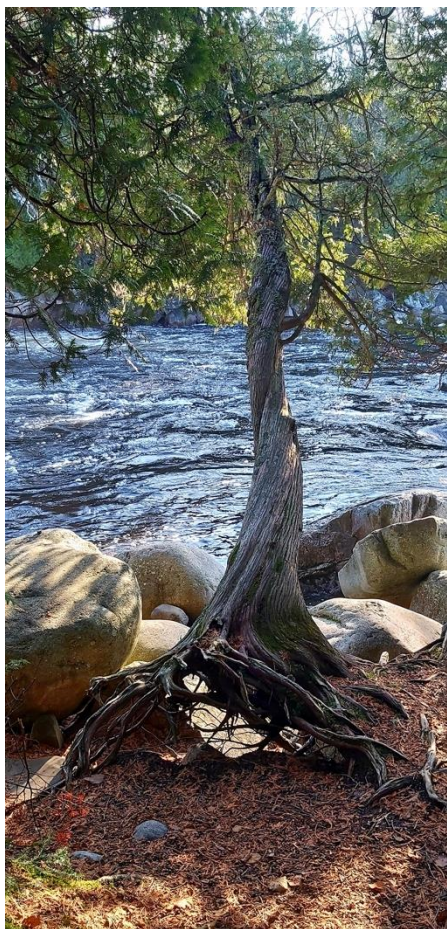
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Diary Entries and Reflection

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 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.



Reflecting on joyful moments



If you're looking for an opportunity to focus on the positive during your dementia journey, keeping a journal is one way.

Write two or three things that make you happy each day with these pages.

You should write the date of each entry.

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

- Write about an act of kindness you saw today
- Write down your favorite memory
- Write about what someone has done for you
- Ten things you love about your spouse, brother, mother, sister, father, etc.



Date:

Lined writing area consisting of 25 horizontal lines.





Available resources

Learning together along the journey



Here are some useful resources to consult along your journey:

- Alzheimer Society of Canada - <https://alzheimer.ca/en/Home>
- SE Health's ELIZZ - <https://elizz.com/>
- Alzheimer's Society UK Talking Point Forum - <https://forum.alzheimers.org.uk/>
- Dementia specific training - <https://tdn.alz.to/listings/dementia-specific-education-and-training/>
- Toronto Support Group - <https://alz.to/dementia-support-services/support-groups/>
- Behavioural Supports Ontario - <https://www.behaviouralsupportsontario.ca>
- About Dementia (Teepa Snow): <https://teepasnow.com/about-dementia/>

Other components of this journal could include:

- Information sheets about what to expect along the dementia journey
- Beginning of memory problems
- Dealing with aggressive behaviour/violence/safety
- Complex symptoms
- Activities
- Communication
- Finance/Power of Attorney
- How to manage sudden deterioration or specific crisis
- Request for information about services
- Respite care/caregiver exhaustion
- Decline in the caregiver's own health
- Denial of symptoms/refusal of help, especially with personal care
- Family dynamics

Support is available through your local Alzheimer Society:

Phone Number: _____

Website: _____



Activities Calendar

Name:

Year:

The Activities Calendar is your space 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 of the circle of care.

January

February

March

April

May

June



Activities Calendar

Name:

Year:

July

August

September

October

November

December



Activities Calendar

Name:

Year:

The Activities Calendar is your space 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 of the circle of care.

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June



Activities Calendar

Name:

Year:

July

August

September

October

November

December



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.

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.

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.



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.

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.

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.

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.



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.

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.

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

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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 or if you have any suggestions on how to improve this journal, please contact research@sehc.com