

All about

me



This is a booklet about a person living with Alzheimer's disease or other dementia.

Name: _____

Alzheimer *Society*



Please put a photo of yourself
in the space provided.

The Alzheimer Society is the leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities across Canada, the Society:

- Offers information, support and education programs for people with dementia, their families and caregivers
- Funds research to find a cure and improve the care of people with dementia
- Promotes public education and awareness of Alzheimer's disease and other dementias to ensure people know where to turn for help
- Influences policy and decision-making to address the needs of people with dementia and their caregivers.

For more information, contact your local Alzheimer Society or visit our website at alzheimer.ca.

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Introduction

This booklet is all about you, a person living with Alzheimer’s disease or other dementia.

Although you have a form of dementia, you are still the same person you have always been. This booklet is designed to focus on the positive: what you are good at rather than what is no longer possible.

You and your primary caregiver* know what makes you feel comfortable better than anyone. By answering the questions in this booklet, you will have a record of what makes you content and at ease that can be used when your primary caregiver cannot be with you and others need to provide care and support. Anyone can use this booklet to give you the best day possible now and as the disease progresses.

The first section of this booklet is designed to help someone new to supporting you get to know you better. It will also suggest conversation topics that may make you feel more at ease and contribute to more enjoyable times together.

Other sections of this booklet allow you and your caregiver to outline your usual habits: your daily routines, your likes and dislikes and what makes you enjoy each day. This information will help new caregivers maintain the routines that give you a sense of security, comfort and pleasure.

When completing this booklet, always keep in mind the main purpose: to give as clear a picture as possible of you to help others provide care when the person who usually supports you is unavailable.

To help others provide effective care, keep this book in an easy-to-find location. You and your caregivers can review it from time to time to note changes and plan for the future. There are replacement pages at the back that you can use to make any updates or changes.

*The term “caregiver” is used throughout this booklet to mean anyone who supports you.

Contact information

This booklet contains information about: _____

Some of the information is provided by: _____

Names, phone numbers, email addresses of significant people in my life (family, friends, neighbours):

Name: _____
Relationship: _____
Phone number: _____
Email address: _____

Name: _____
Relationship: _____
Phone number: _____
Email address: _____

Name: _____
Relationship: _____
Phone number: _____
Email address: _____

Name: _____
Relationship: _____
Phone number: _____
Email address: _____

Date: _____

Other important numbers

Family doctor (name, phone number, address): _____

Ambulance: _____

Police: _____

Fire: _____

Poison Control: _____

Local Alzheimer Society: _____

Home-care services: _____

Spiritual or faith leader: _____

Other: _____

Medical information

Other than having dementia, are there other medical issues that the caregiver should know about?

Please provide any important information on:

Allergies:

Hearing:

Vision:

Medications (attach list, if necessary) – include dosage and frequency:

Date: _____

This section is like a photograph. Try to use as much detail as you can to give readers a real sense of your personality.

My personal life

How do you like to be addressed? (e.g. nickname, Mr., Mrs., Miss, first name)

When were you born? _____

Where? _____

Single/married/partner/longstanding relationship(s) with _____

Name: _____

We've been together since _____ (year)

Where have you lived?

Describe this relationship (e.g. loving, difficult, supportive)

Children (names and where they are now living)

Are they involved in your life now? If so, how?

Do you have any pets? If so, what are their names?

Date: _____

In the past

What kind of jobs did you have? (e.g. homemaker, lawyer, nurse, electrician, teacher)

How do you feel about the job(s) you have done? (e.g. proud, satisfied, indifferent)

If you were asked about the major milestones in your life, what would you likely talk about? (e.g. major life events, favourite places visited)

Likes and dislikes

What makes you physically more comfortable? (e.g. always have glasses on, have a hearing aid in, daily lotion to prevent dry skin, toe spacers)

What makes you happy? (e.g. conversation topics, activities, sports, music performances, being around children/animals)

What do you dislike? (e.g. foods, activities, topics of conversation, music, smells)

What comforts you when you're upset?

What frightens you?

Date: _____

Life story (Please describe any other details of your life that would help create a full picture of you as a "whole person." What would you want others to know about you?)

Date: _____

A typical day

Routine is important for all of us, but can be especially helpful for a person with dementia.

Writing down your daily routine will help you see how you spend your time and help others who might be providing care.

Try to look at your care through the eyes of someone who has never met you before. Do you like to sleep in, have a bath in the evening, or go for a daily walk?

Use this section to describe regular daytime activities. Include activities you are involved in as well as your caregiver. Include anything that provides pleasure, comfort, or something you particularly don't like.

Morning (usual wake up time _____). How do you start your day?

Afternoon

Evening

Night (usual bedtime _____)

Date: _____

Enjoying each day

A person living with dementia is just like everyone else, a whole person with likes and dislikes, opinions, values and experience. Though some skills are lost as the disease progresses, many remain. Here are some activities that may bring you pleasure and will help you continue to live a full life while adding enjoyment to time spent with others.

Music

Do you like to listen to music? Yes No

If yes, what kind? (e.g. classical, jazz, folk, blues, or all kinds of music)

What effect does it have on you?

Do you play an instrument? Yes No

If yes, what kind of instrument do you play? (e.g. guitar, violin, clarinet)

Do you enjoy singing? Yes No

What effect does it have on you?

Reading

Do you like to read? Yes No

If yes, what do you like to read? (e.g. classics, science fiction, romance, adventure, fantasy, news, short stories)

Do you like to be read to? Yes No

Date: _____

Television

Do you like watching TV? Yes No

If yes, what are your favourite shows?

Games

Do you like to play games? Yes No

If yes, what kind of games do you like? (e.g. cards, crosswords, puzzles, Sudoku)

Sports

Are you interested in sports? Yes No

If yes, what sports do you like to play or follow? (e.g. golf, hockey, tennis, skating)

Hobbies

Do you have hobbies that you enjoy? Yes No

If yes, what kind of hobbies? (e.g. scrapbooking, crafts, photography)

Do you do household chores? (e.g. meal preparation, dusting, sweeping) Yes No

If yes, is there any household chore you particularly enjoy?

What other activities do you enjoy? (e.g. car rides, attending community programs, sitting by the window)

Date: _____

Help with daily living

How much help, if any, do you need with routine daily activities such as dressing, bathing or getting in and out of bed?

The chart on the next page lists typical routine daily activities. Feel free to change the chart to include activities that apply to you.

Where you are able to be completely independent, write “no help needed.” When you need help, note how much help you need.

The “Useful tips” section is a good place for caregivers to note the degree of stress the activity creates and what special approaches might be helpful.

Here is a sample chart to guide you.

Activity	Useful tips	Is help needed?
Tub/shower Usual time: 8:00 a.m. Twice a week	<ul style="list-style-type: none"> • Prefer shower, don't like bath • Enjoy music or conversation during bath time • Give lots of time • Respect privacy • Be patient 	<ul style="list-style-type: none"> • Need help in and out
Dressing	<ul style="list-style-type: none"> • Can button shirt, put on underwear and socks • Need to take dirty clothes away immediately • Can dress independently if clothes put on bed in right order • Offer help tying shoe laces 	<ul style="list-style-type: none"> • May need help from time to time

Activity	Useful tips	Is help needed?
Tub/shower		
Dressing		
Dental care/dentures		
Eye care/glasses		
Hearing aid		
Hair care <ul style="list-style-type: none"> • Professional style/cut 		
Makeup/shave		
In/out of chair		
In/out of bed		

Date: _____

Activity	Useful tips	Is help needed?
On stairs		
Use of toilet		
Use of appliances <ul style="list-style-type: none"> • e.g. kettle, stove, electric shaver 		
Household tasks <ul style="list-style-type: none"> • e.g. sweeping, dusting, vacuuming, meal preparation, garden work 		
Financial <ul style="list-style-type: none"> • Responsibility with money 		
Walking <ul style="list-style-type: none"> • Habits, usual routes, ability to be independent 		
Preparing for bed		

Meal time

An enjoyable breakfast:

Lunch:

Dinner:

Snacks:

Any particular likes or dislikes?

What assistance, if any, is required?

Cutting:

Use of cutlery:

Hot and cold liquids:

To learn more about how to make meal times more enjoyable, read the Alzheimer Society's information sheet on the topic, available at alzheimer.ca/mealtimes.

Date: _____

Regular weekly activities calendar

Use this calendar to show regular outings or appointments. You can use pencil so changes can be made every month, or a make a copy for each month.

Month: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Date: _____

Note: The questions in this section are designed to be answered by your primary caregiver. Your input will be valuable to give the best information possible.

Alzheimer's disease and other dementias progress over time. As the disease progresses, your abilities will change.

The information in this section will help anyone supporting you know what these changes are and how they affect your mood, behaviour and abilities. Your caregiver can suggest ways that help you feel content, engaged and secure. For example – is there a special approach that helps? Does your behaviour change only at certain times? Are there warning signs?

Below are examples of common situations.

The term "family member" is used to mean anyone with dementia whom you support.

Unsafe walking (e.g. "wandering")

Does your family member walk outside in ways that are unsafe? (e.g. will go out in winter wearing only a dressing gown) Yes No

If yes, what safety precautions do you use? (e.g. camouflaged doors, ID bracelet, regular walks with a neighbour)

Do they become upset when returned home? Yes No

If yes, is there a special approach to use to help them feel calm?

Night time restlessness

Does this occur? Yes No

If "yes," what safety precautions do you use? (e.g. nightlight, disconnecting stove or turning off water valves before retiring at night, locking closet door to prevent dressing at odd hours)

What helps to re-settle the person?

Date: _____

Restlessness

Does this occur at certain times of the day?

What helps to settle the person? (e.g. a walk or a distracting activity)

Anger or agitation

Does this occur at certain times? (e.g. bathing, meal time)

What usually triggers this? (e.g. rushing the person, too many instructions given at once)

When anger occurs, what responses tend to be helpful?

Does your family member suspect people of stealing from them? How do you deal with this?

Repetition

When they repeat themselves over and over, what responses are helpful?

Hiding or hoarding articles

Are there particular places to check where your family member "stores" specific things?

Does anything need to be kept out of reach? (e.g. knives, tools such as electronic drills)

Safety precautions

List any additional information that is important for other caregivers. (e.g. doors or cupboards to be kept locked, such as where toxic cleaning fluids are stored)

Are any other safety measures being used? (e.g. alarms, GPS locating devices)

Communication

If your family member has difficulty understanding and following instructions, what do you do? Is there anything that helps?

To learn more about Communication, please read the Alzheimer Society's information sheet on the topic, available at alzheimer.ca/communication.

Are there any other areas of concern and/or tips for care that comfort, reassure, support the person?

Date: _____

Alzheimer’s disease follows a number of stages. While these stages can be somewhat predictable, the course of the disease will vary from person to person. Changes in physical condition, such as flu, pneumonia, infection or constipation can often result in changes in mood and behaviour. By noting changes, the person who supports you may be able to determine a pattern and prevent a situation from getting worse. It is particularly important to keep a record when medications are used. Recording these items in a journal will help caregivers when they are talking with your doctor. Caregivers should take this “All about me” booklet to your appointments.

Anyone providing care can use these pages to record all the events in a particular day.

Here is a sample journal.

Date	Comments
Mar. 30/12	To bed 8:30 p.m. -- up again 2:00 a.m. Wandered through house, could not settle down. Did not recognize me.
Mar. 31/12	Another night with no sleep!
Apr. 1/12	Still won't sleep. Now dozing all day. Doctor's appointment April 4/12.
Apr. 5/12	On new medication for an infection. Slept till 6:00 a.m. I'm trying to keep her awake during the day. I think things are getting better.

Photocopy this page to create your own journal.

Date	Comments

This page outlines things that have changed since I first filled out this booklet.

Date	Changes

Date: _____

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Alzheimer *Society*

Alzheimer Society of Canada

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