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Mukk Awanta'sualiw

Soci t  Alzheimer Society

NOVA SCOTIA

The Story is Mine

A booklet about
a person living with
Alzheimer's disease
or other dementia



My name is:

The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias.

**For more information, contact your local Home Health Centre
or the Alzheimer Society of Nova Scotia at 1-800-611-6345
or www.alzheimer.ca/ns**

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Introduction

This booklet is all about you, a person living with Alzheimer's disease or other dementia. The booklet was created with the support of First Nations communities across Nova Scotia.

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.

The first section of this booklet is designed to help someone new 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 partner in care to outline your usual habits: your daily routines, your likes and dislikes, and what makes you enjoy each day. This information will help new partners in care 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.

Note: The term "partner in care" 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:

Date: _____

Contact information for important people in my life:

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):

Health centre:

Community nurse:

Ambulance:

Poison control:

Police:

Fire:

Local Alzheimer Society:

Home-care services:

Spiritual or faith leader:

Other:

Medical information

Other than having dementia, are there other medical issues that the partner in care should know about?:

Please provide any important information on:

Allergies:

Hearing:

Vision:

Medications (attach list, if necessary) - List dosage & frequency:

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

My personal life

What language do you use most often? What language do you prefer to use? _____

What do you like to be called? _____

When were you born? Where? _____

Where have you lived?

Name of husband/wife: _____

Do you have any children? What are their names?

Do you have any grandchildren or great-grandchildren?

Date: _____

Likes and dislikes

What makes you happy?

What do you dislike?

What makes you comfortable when you're upset?

What frightens you?

Do you like animals? Do you have any pets?

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.

Morning - Eksitpu'k (usual wake-up time _____)

Afternoon - Miaw-Na'kwek

Evening - Miaw-La'kwek

Night - Wela'kw (usual bedtime _____)

Date: _____

Enjoying each day

Music

Do you like to listen to music? Yes No

If yes, what kind (drumming or singing)? What effect does it have on you?

Do you play an instrument? Yes No

If yes, what kind of instrument do you play?

Do you enjoy singing? Yes No

If yes, what do you like to sing?

Reading

Do you like to read? Yes No

If yes, what do you like to read?

Do you like to be read to? Yes No

Date: _____

Television

Do you like watching TV? Yes No

What are your favourite shows?

Games

Do you like to play games? Yes No

What kind of games do you like?

Sports

Are you interested in sports? Yes No

What sports do you like? (Hunting, fishing, trapping?)

Hobbies

Do you have hobbies you enjoy? Yes No

What kind? (Making dream catchers or baskets, bead work?)

Meals

Do you have a favourite meal? Yes No

Do you like moose meat or eel meat? How do you like it cooked?

Family and friends

Do you enjoy having company around? What do you like to do?

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?

Where you are able to be completely independent, write "no help needed." When you need help, note how much help you need. Here is a sample chart to guide you:

Activity	Useful tips	Is help needed?
Tub/shower Usual time: 8 a.m. Twice a week	<ul style="list-style-type: none"> • Prefer shower, don't like bath • Enjoy music or conversation at 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

Date: _____

Activity	Useful tips	Is help needed?
Tub/shower		
Dressing		
Dental care/ dentures		
Eye care/glasses		
Hearing aid		
Haircare • Professional style		
Makeup/shave		
In/out of chair		
In/out of bed		

Date: _____

Activity	Useful tips	Is help needed?
On the stairs		
Use of toilets		
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 Responsibility with money		
Walking <ul style="list-style-type: none"> • Habits, usual routines, ability to be independent 		
Preparing for bed		

Meal time - What do you like?

Breakfast: _____

Lunch: _____

Dinner: _____

Snacks: _____

Likes or dislikes: _____

What assistance, if any, is required with:

Cutting food: _____

Use of cutlery: _____

Hot and cold liquids: _____

Date: _____

Regular weekly activities calendar

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

Special considerations

The questions in this section are designed to be answered by your primary partner in care. Alzheimer's disease and other dementias progress over time. As the disease progresses, your abilities will change.

Unsafe walking (e.g. "wandering")

Does your family member walk outside in ways that are unsafe?

Yes No

What safety precautions do you use (ID bracelet, neighbours or family and community members)?

Do they become upset when returned home?

Yes No

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

Date: _____

Regular weekly activities calendar							
Month:	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

Night time restlessness

Does this occur? Yes No

If yes, are there safety precautions you use?

Restlessness

Does this occur at certain times of day? If so, what helps you?

What helps settle them?

Anger or agitation

Does this occur at certain times?

What usually triggers this?

Special
considerations

Date: _____

Anger or agitation

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

If they repeat themselves over and over, what responses help?

Hiding or hoarding articles

Are there places to check when your relative "stores" things?

Does anything need to be kept out of reach?

Special
considerations

Safety precautions

List any further information that is important for other partners in care: _____

Are any other safety measures being used?

Communication

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

Are there any other areas of concern and/or tips for care that comfort, reassure, or 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 partners in care when they are talking with your doctor. Caregivers should take this booklet to your appointments.

Anyone providing care can use these pages to record all of 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 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 a.m. I'm trying to keep her awake during the day. I think things are getting better.

Date: _____

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Date: _____

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