## **TOOLKIT TO** MANAGE THE **RISK OF GETTING LOST AND GOING MISSING FOR PEOPLE LIVING** WITH DEMENTIA







This Toolkit is for people living with dementia and their care partners to learn about the risks of becoming lost due to changing abilities caused by dementia. **Dementia is not one disease, but an umbrella term for a range of symptoms** that include difficulties with memory, thinking, problem-solving and language. There are many types of dementia, including Alzheimer's disease, vascular, Lewy Body, and frontotemporal.

This Toolkit was created by the University of Waterloo, in consulation with people living with dementia, care partners, and service providers. It was funded by Public Safety Canada.





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## SECTION 1: INTRODUCTION

## Introduction

Not everyone living with dementia will become lost while navigating alone. This Toolkit suggests strategies to help with common concerns of people living with dementia and their care partners regarding the risks of becoming lost.

Choose strategies that are helpful and you may consider ways to modify them to work best for you. The strategies in this Toolkit may not be helpful all the time for every person.





Read this Toolkit front to back or each section separately.

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### **Case studies**

Two case studies are included to offer a practical illustration of the strategies presented in the Toolkit.



#### **Mary and Ralph**

Mary (80 years old) and Ralph (82 years old) live in their single level bungalow in a large city. Ralph is living with Alzheimer's disease. Ralph got lost a few times this year due to changes in his abilities as a result of dementia.



#### **Arnold and Peter**

Arnold is 94 years old, and lives in long term care in a small town. He has vascular dementia and his son, Peter, is his care partner. Over the last few months, Arnold has lost his way trying to find his room and there have been multiple occasions where he has left the long-term home without anyone knowing. Last month Arnold went missing during one of his and Peter's community outings.

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## Lost or missing: What is the difference?

Any unexplained absence of an older adult is an emergency and requires the immediate involvement of police or emergency services.

#### Lost person

A **lost person** is someone who becomes lost from a **known** location. This could be the home, a coffee shop, grocery store, or washroom in the park. This gives emergency responders a place to start looking for the person. When the person is lost, call the police immediately and describe your situation to police.

#### "My mother who is living with dementia became lost from the grocery store."

#### **Missing person**

A **missing person** is someone who went missing at an **unknown** location. When the person is missing, call the police immediately and describe your situation.

"Mr. Akins left in his car and has not been seen since."

## Lost vs. missing person



#### **Mary and Ralph**

Ralph goes for a walk to relieve some tension caused by an argument he had with Mary and becomes lost on his way.

Ralph is a **lost person** because the place he was last seen is his home.

#### **Arnold and Peter**

When Peter and Arnold are out for coffee, Peter goes to the bathroom. When he comes out of the bathroom, Peter notices that his keys, Arnold and the car are no longer there.

Arnold is a **missing person** because it is unknown where Arnold drove the car.

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## SECTION 2: **PREPARING FOR AN EMERGENCY**

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## **Preparing for an emergency**

Create an Identification Kit,

such as the one available from the Alzheimer Society of Ontario, to save time in the event someone becomes lost or goes missing:

+ Alzheimer Society of Ontario's Identification Kit



Within the Identification Kit, consider keeping a list of locations the person living with dementia likes/liked to go (e.g., past home addresses, locations of former places of work, addresses of children, walking routes).

This information will be helpful for police if the person does become lost or goes missing.

## **Preparing for an emergency**



#### **Mary and Ralph**

Mary keeps Ralph's information in a folder by the door in case of an emergency. For example, when Ralph takes longer than normal to return from a walk, causing Mary to worry that he has become lost, she has what she needs to provide to emergency responders to start the search.



#### **Arnold and Peter**

Staff at Arnold's home meet yearly to review the processes when a resident goes missing. Both the facility and Peter, keep a completed copy of an Identification Kit for Arnold (an example is provided in the Resource Section of the Toolkit).

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# Responding in an emergency

What to do if a person living with dementia has become lost or is missing.

It is an emergency when a person living with dementia becomes lost or is missing.



**Call the police or emergency services in your area immediately** after determining that the person is lost or is missing. Be sure to state that the person is living with dementia. Answer the operator's questions with as much detail as possible and follow their instructions.



**Do a scan of the immediate area inside and outside** while waiting for emergency services to arrive. Look in places you wouldn't think the person living with dementia would go, such as in closets, or hedges/bushes on the property.



When the police arrive, they will **ask you specific questions**, some of which you may have answered on the phone with the emergency services operator. Be patient and repeat yourself if necessary.



You may be asked to provide documentation such as: the person's health card, driver's license or government issued photo ID, technology you use, such as location of door cameras, MedicAlert® information if applicable, locator devices (e.g., GPS devices) and a person's cell phone number. This documentation can be kept in an Identification Kit.

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## SECTION 3: **PREVENTING A MISSING INCIDENT**

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# Reduce the risk of becoming lost or going missing

No one strategy will prevent a person living with dementia from becoming lost or missing. **Multiple strategies are recommended** to reduce the risk.

Consider the options below to reduce the risks of becoming lost or going missing.



#### **Door cameras**

Door cameras can mark a time and date the person left the house. Consider a camera that can store video footage for 24-48 hours.

For more information on safety and dementia please see:

+ www.alzheimer.ca/safety



#### Locating technology

Locating technology can support independence of a person living with dementia. Check out resources below:

- + Alzheimer Society of Canada breaks down the information here: www.alzheimer.ca/ trackingdevices
- A repository of locating technology has been created at the University of Waterloo and can be found here: https://uwaterloo.ca/aginginnovation-research-program/locator-devices

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# Reduce the risk of becoming lost or going missing



#### **MedicAlert® Safe & Found Program**

MedicAlert, Canada's Public Safety Charity, runs Safe & Found – the country's National Wandering Registry. Medically-trained health professionals collect dementia-specific data such as wandering histories, places frequented, physical characteristics and health information pertinent to first responders involved in searching for a missing person. MedicAlert's world-recognized medical bracelet is also part of the program and is blue in colour for easy recognition hat the wearer is living with dementia.

### Consider registering with MedicAlert to have access to this service:

+ https://www.medicalert.ca/

## Living with dementia

People living with dementia may have difficulty with finding their way and **can become lost**, which can lead to an emergency.

We recognize many people may use the word wandering, but it can be stigmatizing and is non-specific to the situation. The words 'walking', 'moving about', 'leaving', 'removing oneself', or 'wayfaring', are preferred over the term 'wandering'.

A person living with dementia has the right to move freely in their home and in their community. This section of the Toolkit is from Dementia-Friendly Canada. Dementia friendly communities are places where people living with dementia and their families and care partners feel included and supported. This section offers strategies to help a person living with dementia, supporting their independence and their right to move about.



To learn more about dementia friendly communities visit:

+ https://alzheimer.ca/dementiafriendlycanada

# Strategies for a person living with dementia



Let a family member or friend know where you are going, and what time you expect to be back.

### Have a family member or friend check in with you daily if you live alone.

For example, a family member or neighbour can call you or send you a message in the morning and afternoon.



## Consider different strategies to help with navigation if wayfinding has become a challenge.

Try using locating technologies such as Google Maps, Apple Maps or other GPS devices. Other lower tech strategies include bringing your dog with you on walks, or keeping your home address with you so you can ask for directions if you become lost.



## Strategies for family and friends

**Physical activity can help** a person living with dementia feel more calm or less agitated.



#### Activities or hobbies that are familiar or

**enjoyable** can bring meaning and comfort to a person living with dementia. Such activities can include housework, gardening, yoga, or stretching. Here are some resources:

#### Stretch Lift or Tap Program (SLoT)

+ https://rgptoronto.ca/stretch-lift-tap/?\_ language=english#older-adults-and-caregivers



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#### SECTION 4: Image: Section 4: I

### Improving wayfinding in the home

People living with dementia may try to leave their home unexpectedly. This section suggests ways to adapt your home to be more dementia friendly.

When it is easier to navigate in the space, a person living with dementia may be less likely to become lost and go missing.

## There are many resources to help with improving wayfinding in the home:

- + https://www.brightfocus.org/alzheimers/ article/making-your-home-dementia-friendly
- + www.alzheimer.ca/dfc
- + https://alzswp.ca/support-groups-programsfor-the-care-partner/

## For location specific information from provincial Azlehimer Societies, please see:

- + Alzheimer Society of Ontario: https://alzheimer. ca/on/en/help-support/programs-services/ finding-your-way
- + Alzheimer Society of Manitoba: https:// alzheimer.mb.ca/living-with-dementia/ dementia-friendly-communities/#10135
- + Alzheimer Society of Saskatchewan: https:// alzheimer.ca/sk/en/help-support/programsservices/our-resources
- + Alzheimer Society of British Columbia: https:// alzheimer.ca/en/help-support/dementiaresources



## Lighting

Use uniform overhead lighting to reduce shadows, avoiding lighting or surfaces that cause glare for older adults. Consider adding lighting in dark areas of the home such as hallways, closets, or corners.



Ensure the lights are not too bright for someone entering from a dark room as this can cause the person to become disoriented while eyes adapt to the brightness.

Task lighting can help people living with dementia to focus on a specific activity, e.g., reading.

Adjust the lighting to match the time of day or use natural lighting.

#### For more information on safety, dementia and lighting for cognitive impairment please see:

- + https://alzheimer.ca/nb/en/aboutus/our-resource-centres/makingdementia-inclusive-resource-centre
- + https://ocfch.org/hand-in-hand/light

#### **Technology and adaptive lighting**

Motion sensor lights automatically light up a dark area when there is movement. Ensure these lights are not disorientating, e.g., become too bright too quickly. Dimmers can be used to adjust brightness and accommodate natural lighting.

Touch lamps can be helpful when light switches are hard to find.

Lights with timers can help signal what time of day it is. For example, they can turn on in the morning and turn off at night.





## Lighting



#### **Mary and Ralph**

Ralph often becomes agitated in the evenings when the sun is setting. Mary was unsure of the cause of Ralph's agitation at first. She then realized that shadows, similar colours, and small font are especially difficult for Ralph to see, which was causing confusion. Mary adapted their home to support Ralph's declining vision and dementia progression, by installing motion sensor lights in the hallways and putting lamps in the living room to reduce the number of shadows.

## **Colour contrast**

Age-related vision changes can cause challenges when things have low contrast. This can become worse with dementia.

#### **Strategies**

- Use colour contrast to help a person locate an object or a room. For example, a black toilet seat on a white toilet, or a red door with white walls.
- + Use the same colour to camouflage objects or rooms.
- + Use multiple strategies. For example, use colour contrast for toilet seat in addition to a sign with an image of a toilet on the door to help a person with dementia find the bathroom.





## **Pattern contrast**

Patterns such as on wallpaper, rugs, and furniture can cause confusion for a person living with dementia. For example, patterns with small details can appear to move, and polka-dots can look like holes in the walls or floors.

#### **Strategies**

- + Use solid colours instead of patterns.
- + Avoid bold patterns such as stripes, dots, or florals.
- + Use furniture covers to cover patterned furniture.





## Reflections

Textures, such as shiny floors and mirrors, can cause confusion for people living with dementia. For example, shiny floors can appear as water and persons living with dementia may not recognize their reflections in mirrors.

## Some low-cost strategies adapt the home are:

- + Cover mirrors with paper or other matte materials.
- + Remove or cover mirrored décor.
- + Reduce polish on shiny surfaces to minimize glare.
- + Add neon tape to the floors to emphasize direction, edges of the wall and floor and increase contrast.



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## SECTION 5: OTHER STRATEGIES

### Familiarity as a strategy to enhance independence for people living with dementia

Familiar spaces can promote independence for people living with dementia as they can enhance memory and wayfinding in the space.

**Familiarity** is a feeling that happens when a person is around things, places, or people that help with recognition, trigger memories and sense of identity.

People living with dementia may experience **false familiarity**, which is when a person has a sense of familiarity without having any prior experience with objects, spaces and people.

If **false familiarity** occurs when a person is walking or visiting a new place, they may become lost and disoriented.



## Enhancing familiarity: Strategies for people living with dementia

People living with dementia and their care partners can benefit from routines, frequently visiting the same locations, and regularly engaging in meaningful activities.



#### If you enjoy walks and exploring your

**community**, consider taking the same route every time to enhance familiarity. This will also help people locate you if you become lost.



**Choose activities you enjoy doing regularly.** Familiarity with the task can reduce stress if memory becomes a concern.



Find places that you enjoy being in and visit them regularly.



Familiarly in a space can help a person feel safe.

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These strategies can help promote familiarity and a sense of comfort for people living with dementia.



## Enhancing familiarity: Strategies for care partners

Encourage the person living with dementia to **take familiar routes.** Increase your familiarity with the routes by going with the person living with dementia.

Knowing a person's routes can help locate them if they become lost or missing.



While at home, encourage the person living with dementia to do **meaningful and familiar activities.** 

The familiarity can reduce stress or confusion for the person living with dementia and help with independence.



Consider **activities** that the person living with dementia has enjoyed in the past.

The person's familiarity with the tasks and objects can help them gain independence in the activity.



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# Strategies for promoting familiarity



### Arnold and Peter

To establish feelings of familiarity, Peter and Arnold go to the same coffee shop, take the same routes, and do the same activities during their outings. Arnold also enjoys visiting the same museum he used to take Peter to when his son was a child.

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### Entering unknown spaces and becoming disoriented

People living with dementia may become disoriented in new or unfamiliar spaces and become lost. In this process, people living with dementia may enter a room, home, or other location that may not belong to them, is unsafe, or is restricted.

There are ways to modify the environment to reduce the number of paths to certain locations. This can help people living with dementia navigate their environments more easily and independently. Please see next page for suggested strategies.





## **Strategies**



People living with dementia may need extra clues in their environment to navigate to where they want to go. Enhance paths to areas of high use, such as the bathroom, bedroom, kitchen, or living room by adding signs with arrows, lights, or both. We have included examples of signs at the end of this Toolkit under 'Resources'.



For restricted access areas or for those that are unsafe, use door murals that disguise the door as a cabinet or bookshelf, place caution tape across the door, or place large curtains in front of the door. *These strategies may not work for everyone as certain murals can lead to greater disorientation. Consider the different ways the person you are supporting may react to different images such as a fake bookshelf.* 



- More information on how to make your home dementia friendly is included in the previous section:
- + Adapting the home for people living with dementia.



## Wayfinding



#### **Mary and Ralph**

Mary helped Ralph navigate around the home by placing labelled pictures on the doors of important rooms. For example, the bathroom has a picture of the toilet, and the bedroom has a picture of the bed on the door.



#### **Arnold and Peter**

To help Arnold navigate in the long-term care home, Peter hung photos of Arnold in his room and put the label "Arnold's room" on the door. Care staff have put directional signs to the bathroom and the dining room to help Arnold and other residents find their way.



**Unmet physical** care needs and the risk of becoming lost for people living with dementia: **Strategies for** care partners

One reason a person living with dementia may leave a home or environment suddenly is because the person is trying to satisfy a need or want but become lost in the process.



People living with dementia can benefit from receiving support to satisfy their needs, which could reduce their risk of becoming lost. These strategies are intended to help care partners learn how to best support the person living with dementia.

## **Strategies**

#### **Using the toilet**

- + People living with dementia may need support for basic hygiene and personal care including using the toilet.
- + A person living with dementia may need a prompt to remember to use the toilet.
- The person may need support using the toilet but may not communicate this need. Ask the person living with dementia if the person needs support.
- If incontinence becomes an issue, consider incontinence products so that the person is comfortable if an accident occurs. Incontinence products include urinary pads, briefs such as Depends or Tena, and incontinence underpads that can be placed on the bed or chair.



## **Strategies**

#### **Hunger and thirst**

People living with dementia may have difficulty interpreting signs of hunger or thirst leading to either over- or under- eating and not drinking enough fluids. Below are some helpful strategies to increase the person's hydration and nutrition.

- Create a schedule for when meals and snacks are available and make it readily visible on a white board or sheet of paper posted on the fridge for the person living with dementia to see.
- + Offer fluids throughout the day, not just with meals and medications.
- + Encourage and gently remind the person to drink or eat.

- + Sit and have a drink or meal with the person living with dementia.
- + For variety, include solid or semisolid foods with high water content, such as fruits and vegetables like watermelon or cucumber.
- + If you are concerned about the person with dementia overeating, try offering smaller portions, then they can have several "helpings" without being denied.

#### For more information about providing support with hydration and meals:

- + https://dementiawellnesscanada.com/healthy-eating-for-plwd/
- + https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/providing-day-day-care/meal-time
- + https://www.albertahealthservices.ca/assets/about/scn/ahs-scn-srs-aua-dehydration.pdf


## **Strategies**

#### **Pain and discomfort**

- People living with dementia may have difficulty communicating that they are in pain. Signs of pain can include changes in mood, personality, or behaviour, such as becoming easily upset or emotional and withdrawing from social activities.
- + Explore potential sources of pain, for example, a toothache, a stomach ache, arthritis, or headache.

#### **Unmet psychological and social needs**

- People living with dementia have the same psychological and social needs as people without dementia. People with dementia add value and purpose to everyday activities when included and engaged in the world around them.
- People living with dementia often experience grief, whether it be the loss of someone or something (recently or from the past), such as their driver's license, home, abilities, or independence. Their grief needs to be acknowledged and validated during these circumstances.



### For more information, please see:

- + Finding Suitable Activities for people living with dementia, from Alzheimer Society of Canada.
- + See next page for strategies to engage in meaningful activities.



## Engaging in meaningful activities: Strategies for care partners

- + Reduce distractions that can cause a person living with dementia to become frustrated, confused, or frightened, which can prompt the person to leave the area and become lost.
- + Ensure that assistive devices are clean and have charged batteries. For example, ensure hearing aids are working at comfortable volume, and glasses are clean with an updated prescription.
- + Break down an activity into small steps and assist with difficult tasks. Allow the person to be independent, finishing the tasks they can, even if it takes extra time.
- + Encourage the person and offer positive feedback.
- + Offer verbal prompts to help with the memory of the person living with dementia remember the next step of the activity.
- + If the person becomes upset, stop the activity, and try again later.
- + Relate the activity to the person's past occupations, hobbies, interests, or passions.



Listening to music, dancing, or creating art, can provide positive feelings for some people living with dementia.

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## **Engaging in meaningful activities**



#### **Mary and Ralph**

Ralph sometimes becomes agitated when he doesn't understand verbal instructions while trying to complete a task. To reduce Ralph's stress, Mary has learned some tips to effectively engage a person living with dementia, which helps the activity run more successfully.

For example, Mary breaks down simple tasks to 1-3 steps and will often show Ralph what to do so he can follow her.

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#### **Arnold and Peter**

Arnold is bored when Peter isn't there to visit and he is often found pacing the hallways. Arnold liked fixing cars when he was younger, so the care staff created a "mechanic station." Now, Arnold spends a lot of his time meaningfully engaged with tools rather than pacing the hallways.

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## SECTION 6: USEFUL RESOURCES

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This section provides ready to print resources discussed in this Toolkit. Please find below the table of contents for these resources:

- + Additional Contact Information see page 42
- + Alzheimer Society of Ontario's Identification Kit see page 43
- + Signage see page 48



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# Additional contact information

If you have questions or would like further information on the Toolkit, visit: Managing risks of disappearance in persons living with dementia (MRDPD)

+ www.uwaterloo.ca/mrdpd

Minimisation des risques de disparition des personnes atteintes de démence (MRDPD) + www.uwaterloo.ca/mrdpd-fr



Alzheimer

Society ONTARIO



Search is an emergency **DO NOT DELAY** Call 911 if a person living with dementia is missing

#### **IDENTIFICATION FORM**

#### **BASIC INFORMATION**

First name:	Last name:			
Former last name(s):				
Nickname(s) – please circle those preferred:				
Address:				
City:	Postal			
Phone #:	Cell #:			
Date of birth:	Sex:	Ethnicity:		
Date of birth: Language(s) spoken – please list and indicate fi		Ethnicity:		
		Ethnicity:		
Language(s) spoken – please list and indicate fi		Ethnicity:		
Language(s) spoken – please list and indicate fi Birthplace – address if possible/known:	irst language:			

#### **2** APPEARANCE & PHYSICAL DESCRIPTION

Height:	Weight:	Shoe size:		
Eye colour:	Hair colour:			
Hair style (i.e. curly, straight, bangs, etc.):				
Facial hair (describe the style if applicable):				
Complexion:	Dominant hand: 🗅 Left	🖵 Right		
Distinguishing features – please check all that apply and provide further details:				
🗅 Scars 🗋 Tattoos 📑 None 📮	Other:			
Speech habits/idiosyncrasies (i.e. accent, talks with a stutter, etc.):				

#### **B** HEALTH AND WELLNESS

Hearing aids or difficulties?  Yes No Wear glasses or contacts? Yes No			
Dentures: 🗅 Upper 🕒 Lower 🗅 None			
Mobility: 🗅 Uses cane 🗅 Uses wheelchair 🗅 Uses walker 🗅 Uses scooter			
Other (please describe):			
No assistive device in use			
Risk factors: 🛛 Suicidal 🔍 Confused 🔍 Frustrated 🖓 Depressed			
Uther (please describe):			
Smoker? 🛛 Yes 🖵 No Frequency:			
Type(s) (cigarettes, cigars, etc.): Brand(s):			
Drinks alcohol? 🛛 Yes 🗳 No Frequency:			
Type(s) (wine, beer, spirits, etc.): Brand(s):			
Medical conditions and history:			
Heart attack - date: Stroke - date:			
🗅 Congestive heart failure 🗅 Diabetes 🕒 Pacemaker 🕒 Asthma 🕒 Irregular Heartbeat			
Seizures High blood pressure Chronic obstructive pulmonary disease (COPD)			
Mental health and related behaviors Cancer - diagnosis date:			
Currently having chemotherapy/radiation			
Surgeries or procedures in the last five years? If so, please list:			
Allergies – please list, including any food allergies or sensitivities:			
Medications - please list: Self-prescribed medications			
(i.e. vitamins, herbs, dietary supplements) – please list:			
Result of not taking medications:			

OHIP #:	Version:			
Family doctor's name:	Phone #:			
Do you have a Do Not Resuscitate Form (DNR) in place? UYes UNO				
If so, where is it?				
Is a tracking device in use? 🗆 Yes 🗅 No 🛛 Is there a Power of Attorney (POA)? 🖵 Yes 🗅 No				
If so, who is the POA?				
Name:	Phone:			
Email:				

#### **4** PERSONALITY AND LIFE

Personality – please describe:
Habits – please describe:
Spiritual and cultural needs – please describe:
Favourite possessions, including any pets – please describe:
Favourite/significant places - please list:
Triggers that could cause distress - please list/describe:
Best way to calm down - please list/describe:

Best way to communicate - please describe:			
Person who knows them best is a: 🕒 Famil	liy member: 🛛 Friend: 🗳 Other:		
Name:	Phone #:		
Email:			
Are there any next of kin? 🛛 Yes 🖓 No			
If yes, please list:			
Name:	Phone #:		
Email:			
Name:	Phone #:		
Email:			
Name:	Phone #:		
Email:			
Name:	Phone #:		
Email:			
Name:	Phone #:		
Email:			
Important life moments - dates and significance:			
Typical mode(s) of travel – please check all that a	apply		
Driving Walking Cycling Public Transit Other:			
If a driver – please complete:			
License plate #:	Vehicle colour:		
Vehicle make and model:			

5 LIFE IN THE PAST	
Previous addresses – please list and indicate time of residency:	
Destruisess of events whereast introduces the event indicate where	
Past places of employment – please list/describe and indicate when:	
Been lost or gone missing before? 🛛 Yes 🗳 No	
If "Yes", how many times? 🖸 1-3 📮 4-6 📮 7-9 📮 10+	
Where have they been found? Please list:	
Date of completion:	
Care partner name: Relationship:	
Phone #: Email:	



- Register the person living with dementia with a registry some communities have Project Lifesaver, or a Vulnerable Persons Registry – for those that don't, there is MedicAlert<sup>®</sup> Safely Home<sup>®</sup>
- Label clothing with name and care partner's phone number
- Save scent (swab with a cotton ball the armpit and put in sterilized container) for use by dogs in search and rescue
- Use a locating device. You can compare devices at tech.findingyourwayontario.ca
- Camouflage doors to deter leaving
- Provide a safe, clutter-free space to pace
- Put this form in a Ziploc bag and place in freezer for safe keeping—leave a note on the fridge to indicate this form is there
- Use Finding Your Way's Incident Response and Post-Incident checklists when the person living with dementia goes missing

Funded by:



## Signage

For more information on signage, see:



Poster 1: Toilet









**Poster 5: Keep Out** 



**Arrow Left** 













For more information on signage, see:



For more information on signage, see:



For more information on signage, see:



For more information on signage, see:



For more information on signage, see:



For more information on signage, see:



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For more information on signage, see:



## Acknowledgements

The University of Waterloo would like to give a special thanks to the Alzheimer Society of Canada, Alzheimer Society of Saskatchewan, Alzheimer Society of British Columbia, Alzheimer Society of Ontario, Alzheimer Society of Southwest Partners, Alzheimer Society of Nova Scotia, Calgary Missing Older Adult Resource Network (CMOARN), SAR-1, and Centre de recherche sur le vieillissement Université de Sherbrooke for their ongoing support and for making the current version of this toolkit possible.





