

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

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AGING AND INNOVATION RESEARCH PROGRAM



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Website

Managing risks of disappearance in persons living with dementia (MRDPD) www.uwaterloo.ca/mrdpd

Managing the risks of going missing among persons living with dementia by building capacities of SAR personnel, first responders, and communities

- *Public Safety Canada* - The Search and Rescue New Initiatives Fund \$2,147,140 CAD, *three years* (April 2021 to March 2024)
- Lili Liu, Antonio Miguel Cruz, University of Waterloo
- Build capacities, partnerships and coordination of search and *rescue personnel, first responders, and communities* to manage risks of going missing in persons living with dementia



Types of Community Partners

- Indigenous territories
 - Kahnawà:ke Mohawk Territory (Quebec) and Peguis First Nation (Manitoba)
- Local and provincial police from ON and AB
- RCMP
- Search and rescue organizations
- Fire services
- Ambulance and paramedic services
- Community organizations such as:
 - Alzheimer Societies across Canada
 - Advocacy groups including Calgary Missing Older Adult Resource Network
 - Judicial bodies including Ministry of Justice Attorney General Saskatchewan
- Medic Alert

Website & Videos

<https://uwaterloo.ca/mrdpd>



[English Video \(Overview\)](#)

- [Home | Managing risks of disappearance in persons living with dementia \(MRDPD\)](#)

[French Video](#)

- [Home | Minimisation des risques de disparition des personnes atteintes de démence \(MRDPD\)](#)

SAR NIF FORUM
TORONTO NOV 26, 2022

DEMENTIA FRIENDLY FIRST RESPONDERS



COLLOQUE SAR NIF
TORONTO le 26 NOV, 2022



FOUR INITIATIVES

1. Dementia-friendly resources for first responders
2. Prevention and safety-focused toolkit
3. Best practice guide for conducting “Return Home Discussions”
4. Analyze existing data in police, search and rescue, Medic Alert, and interRAI (long term care data) to understand missing persons incidents and lost person behaviour specific to persons living with dementia in Canada

Toolkit for communities

Printable, accessible, research-based, with tip sheets and resources

Target audiences:

- People living with dementia
- Care partners and caregivers
- First responders, front-line staff
- Indirect audience: General public



Deciding on content: What topics and why?



Goal:

Strength-based approach to preventing missing incidents among people living with dementia



Phase one:

Internet scan: Determine what resources exist and at what quality



Phase two:

Focus groups and four revision rounds with internal team and external partners

Community Engagement



▪ **Community engagement:**

- People living with dementia
- Partners in care
- Search and rescue experts
- Service providers
- Researchers

Received feedback by:

- One-on-one meetings
- Focus groups
- Large community forums

Toolkit overview

Case studies

Pre-emergency (prevention)

- Improving wayfinding, strategies to promote comfort and safety in the community and long-term care settings
- A mix of high and low-tech strategies

During emergency (action)

- What to do when a person is missing



CONTENTS

- 1 Introduction** page 4
- 2 Preparing for an emergency** page 9
- 3 Preventing a missing incident** page 13
- 4 Improving wayfinding in the home** page 19
- 5 Other strategies** page 26
- 6 Useful resources** page 40

TOOLKIT WALK THROUGH

1

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.**



1

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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- 1 **Introduction**
- 2 **Preparing for an emergency**
- 3 **Preventing a missing incident**
- 4 **Improving wayfinding in the home**
- 5 **Other strategies**
- 6 **Useful resources**



SECTION 2:

PREPARING FOR AN EMERGENCY



Table of Contents

2

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.



High tech

- 1 Introduction
- 2 Preparing for an emergency
- 3 Preventing a missing incident
- 4 Improving wayfinding in the home
- 5 Other strategies
- 6 Useful resources



SECTION 3:

PREVENTING A MISSING INCIDENT

←
Table of Contents

3

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

←
Table of Contents



Locating technology

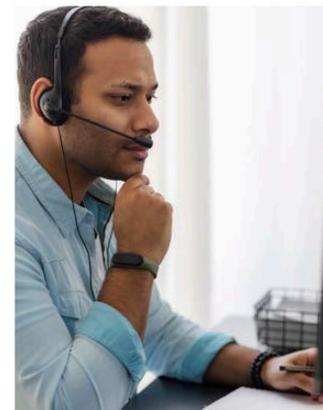
Locating technology can support independence of a person living with dementia. Check out resources below:

- 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/aging-innovation-research-program/locator-devices>

Proactive strategies | 14

3

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 that the wearer is living with dementia.

Consider registering with MedicAlert to have access to this service:

→ <https://www.medicalert.ca/>

←
Table of Contents

Proactive strategies | 15

3

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.

Low tech

3

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>



- 1 Introduction
- 2 Preparing for an emergency
- 3 Preventing a missing incident
- 4 Improving wayfinding in the home
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SECTION 4:

IMPROVING WAYFINDING IN THE HOME

Lighting



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

Colour contrast

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

Strategies



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.



- Enhancing familiarity
- Disorientation and spatial navigation
- Wayfinding in the home
- Unmet physical care needs
 - Hunger and thirst
 - Using the toilet
 - Pain and discomfort
- Unmet emotional needs
 - Meaningful activities

- 1 Introduction
- 2 Preparing for an emergency
- 3 Preventing a missing incident
- 4 Improving wayfinding in the home
- 5 Other strategies
- 6 Useful resources



←
[Table of Contents](#)

SECTION 5:
OTHER STRATEGIES

- 1 Introduction
- 2 Preparing for an emergency
- 3 Preventing a missing incident
- 4 Improving wayfinding in the home
- 5 Other strategies
- 6 Useful resources

SECTION 6:
**USEFUL
RESOURCES**

←
Table of
Contents

- Identification kit example created by Alzheimer Society Ontario
- Signage examples such as arrows, toilet icons

Printable signs

For more information on signage, see:

→ [Making a Dementia-Inclusive Resource Centre Alzheimer Society of New Brunswick](#)



Resources | 59

Toolkit next steps

- Dissemination of both French and English versions
- Toolkit to be uploaded to project website: www.uwaterloo.ca/mrdpd



Greater SARNIF project next steps

- Current funding completion March 2024
- In process of applying for additional funding to continue and expand on work



Preparing for the future

- SAR Personnel and First Responders will encounter increasing number of incidents involving persons living with dementia
- Capacity building can begin during training, on the job, or through professional development
- Responsibility lies with all members of a community, including care partners, businesses, pedestrians, and across the lifespan
- Use resources co-created with community stakeholders to enhance the capacity of police, SAR and communities to prevent missing incidents among persons with dementia

Special thanks to our partners and participants



Public Safety
Canada

Sécurité publique
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Centre de recherche
sur le vieillissement
Research Centre
on Aging



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Our greatest impact happens together.