

A BY US FOR US GUIDE

Safety When Out and About

An inspirational guide for people living with dementia and care partners

SERIES 2

Introduction

It's easy to get lost – everyone has done it. We can get turned around and distracted or confused in a large crowd or busy traffic. Anyone can be fooled by a faulty memory, or streetscapes that only seem familiar... “I was sure it was down this way!”

People living with dementia are like anyone else, but with extra challenges. Memory changes or reduced ability to solve problems can increase the risk of getting lost, or make finding your way more difficult. Sometimes these issues can settle in like a fog, especially if we're fatigued. At other times the sun is shining brightly and we're on our way.

This guide was researched and written by people living with dementia and their care partners. We know how important it is for people living with dementia to be independent, active, involved and socially engaged. We also understand that to be safe, secure and confident it is important to plan ahead with strategies to reduce the risk of getting lost. We gathered feedback from people living with dementia and their care partners through a series of focus groups and online questionnaires. Their tips and strategies for staying safe in the community are contained in this guide.

Communication underlies many of the tips in this guide. People living with dementia need to be honest and open about how they are feeling, unafraid to ask for help, and considerate of concerns that others may have. Care partners need to listen, and support with agreed upon solutions. By working together and planning ahead, you can both be more confident in “being out and about”.

– Mark & Maggie Weidmark
Members of the By Us For Us Development Team

Potential for getting lost

While it is important for people living with dementia to remain independent and active outside of the home, it is also important to take precautions to avoid getting lost.

There are many reasons why someone could potentially lose their way. The following are just a few:

- ✓ Busy or unfamiliar environments can cause a person living with dementia to become disoriented.
- ✓ Anxiety and overstimulation can affect concentration. Once concentration is reduced, those living with dementia can easily become distracted and unable to pay attention to potential safety hazards.
- ✓ Poor communication between partners can result in confusion, anxiety and preventable emergencies.
- ✓ Keeping the diagnosis private can result in family members and neighbours being unaware that a person has dementia. They will not be attentive to the signs that a person is in trouble when they encounter each other out and about in the neighbourhood.
- ✓ Not asking for help or acknowledging that help is needed can put a person living with dementia in a dangerous and potentially life-threatening situation.
- ✓ Lack of awareness and understanding can result in family members, support workers, and volunteers not knowing what support is needed in order to help keep the person living with dementia as safe as possible.

Areas of concern

Some other areas of concern with regards to safety and finding one's way in the community are:

- ✓ Travelling in unfamiliar places.
- ✓ Travelling in rural areas where Global Positioning Systems (GPS) and other mobile devices are not as reliable.
- ✓ Using public washrooms.
- ✓ Using public transit.
- ✓ Navigating buildings with similar designs that are difficult to tell apart without landmarks.
- ✓ Going out after dark when tired, stressed or in a hurry.

Technology and assistive devices

Technology and assistive devices are being used more and more to support the continued independence of people living with dementia. Making use of such things as a Global Positioning System (GPS) and other locating device technology, and medical/personal identification programs are beneficial for both those living with dementia and their care partners. Consider the following benefits of technology and assistive devices:

- ✓ Prevent or reduce the chances of becoming lost.
- ✓ Give peace of mind to care partners, knowing there are safeguards in place that will allow a person living with dementia to maintain their freedom and independence.
- ✓ Like insurance, it is there when you need it.
- ✓ Can be customized to ensure that the device works for you and your care partners.
- ✓ Can locate an individual, connect to first responders, or help a person find their way.

“I always use a GPS when I am out of the house.”

(Person living with dementia)

Technology and assistive devices continued

Tips for staying safe using technology and assistive devices

Assistive devices

- ✓ MedicAlert® Safely Home® bracelet (See the Resources section of this guide for more information about this program).
 - Register for the program when you are diagnosed.
 - Put the bracelet on as soon as you get it and do not take it off.
 - Members of the MedicAlert® Safely Home® program have access to the hotline number that is engraved on the bracelet when in Canada or in the U.S.A.
- ✓ Wearable sensors that can be worn on a foot can help detect movement and alert a designated care partner.
- ✓ Door or window chimes can be installed to alert a care partner if a window or door has been opened.

Locating device technology

- ✓ Cell phone
 - Pre-program phone numbers of care partners or friends to call in an emergency.
 - If safe, use a lanyard to hang a cell phone around your neck as a visual cue to use it in case of an emergency.
 - If you have a smartphone, use it to take notes, create voice memos, or take pictures of landmarks.

Technology and assistive devices continued

✓ Global Positioning System (GPS) technology

- Attach a personal Global Positioning System locator to a key chain or attach to the wrist to assist in locating an individual in the case a missing incident occurs.
- Program a destination into a hand-held or car-mounted Global Positioning System to get audio and visual instructions to help get you to a location.

✓ Walkie-talkies

- Use to keep in touch with your care partner in large buildings that are difficult to navigate, like grocery stores.

Practice using new technology and make sure you are comfortable with them before going out. Make sure battery-powered devices are always charged.

Although technology and other assistive devices are very useful, cost may be a concern for some. It is important to talk with others, such as the Alzheimer Society or a pharmacist, about other possible strategies for staying safe when out and about.

Strategies for people living with dementia

In order to stay safe in your community or when away from your home, consider the following strategies:

Have your ID and important information with you at all times

- ✓ In your wallet or purse, carry personal identification (e.g., MedicAlert® Safely Home® card), emergency contact information, home address, and any important medical information, such as prescriptions and medical conditions.
- ✓ Carry your health card and add a sticker on it that says you have dementia.
- ✓ Carry a card designed for people living with dementia to help get support and understanding from the public (See the Resources section of this guide for an example of this card and where you can get one).
- ✓ Consider wearing personal identification around your neck on a cord or lanyard.

“I use the same roads most of the time and only go from place A to place B.”

(Person living with dementia)

Strategies for people living with dementia continued

Carry memory aids

- ✓ Small memo book (3 x 5 inches) to jot down information or reminders:
 - Landmarks you pass that will help you remember your route home.
 - Location of your car in a parking lot.
 - Directions to where you want to go.
- ✓ Map of the area or neighbourhood; be sure to circle your home address, put a star beside your destination, or trace your bus route/driving route.

Stick to a routine and maintain consistency

- ✓ Walk at the same time every day.
- ✓ Take familiar paths and visit familiar places.
- ✓ Use the same entrance when entering large buildings (e.g., hospitals, shopping malls, community centres).
- ✓ Leave a courtesy note to inform your care partners about your planned route or schedule.

Strategies for people living with dementia continued

Use visual reminders

- ✓ Put a sign on your door to help you stop and think before stepping outside. “Are you tired today?” If the answer is YES, reduced alertness could put you at higher risk of getting lost.
- ✓ Change the look of the sign occasionally, so you don’t ignore it.

Be aware of your surroundings

- ✓ Pay attention to landmarks or other visual cues when out on your own.
- ✓ Cross roads at designated crosswalks, intersections, or pedestrian islands.
- ✓ Walk at a time of day when traffic is not too busy.

Take precautions when travelling

- ✓ Carry a card with important information about your stay:
 - Hotel address and room number.
 - Phone number you can be reached at while you’re away.
 - Policy numbers of medical travel insurance.
 - Dates of stay.

Strategies for people living with dementia continued

- ✓ If you're going to be away for an extended period of time (e.g., temporary address in Florida during the winter), write down your temporary address and carry it with your personal identification.
- ✓ Plan travel routes ahead of time so you will be more prepared and have a better understanding of where you're going.
- ✓ If you are out and getting tired, consider using mobility devices, such as a wheelchair. They prevent you from getting overtired, which reduces the risk of becoming confused and disoriented. These devices are typically available in airports, shopping malls, grocery stores, amusement parks, etc.

Be open to receiving support

- ✓ Talk to your family/friends if you have concerns; share how you are feeling in that moment.
- ✓ Ask for directions if you become lost and need help finding your way.
 - Look for a trusted person, such as a police officer, postal worker, bus driver, business owner, etc.
- ✓ If you're taking public transit, tell the bus driver where you'd like to get off the bus and ask them to announce your stop.

Strategies for people living with dementia continued

- ✓ Ask yourself if it is a good day to go out alone.
 - If needed, walk with a friend, or bring your dog along if your dog can lead you home in case you have difficulty finding your way back.

While these strategies can help you stay safe in the community, it is important to have a plan in place in case you lose your way.

If you become lost

- ✓ Stay calm; remain where you are and don't panic.
- ✓ Rely on familiar landmarks to get you back on track.
 - Rely on the position of the sun during the day.
 - Look for the unique outdoor lighting on your house at night.
- ✓ Refer to your small memo book or assistive device to help re-trace your steps.

“At this stage the GPS solves my problems. When I can no longer drive, I will use buses and I can ask the bus driver if I can't understand the bus stop signs.”

(Person living with dementia)

Strategies for care partners

There are many ways that care partners can support people living with dementia to stay safe while maintaining their independence in the community. Below are some suggestions.

Plan ahead

- ✓ Inform your neighbours that the person you are supporting is living with dementia. Give them a picture of your partner with contact information on the back. Share with them how they can recognize if your family member is possibly disoriented and needs support.
- ✓ Keep a recent photo at home and in your wallet or purse so it is available in case the person you are supporting goes missing.
- ✓ Help fill out important personal information on emergency cards and information sheets.
- ✓ Post emergency contacts and other important information on your fridge or somewhere accessible in case of emergency.

“I make sure the staff (on train, plane, in hotel or resort) are aware that he has dementia.”

(Care partner)

Strategies for care partners continued

- ✓ Carry a “Carer Emergency Card” that states you are a care partner and lists back up emergency contact information in the event that you are not able to care for the person living with dementia. This provides first responders with information that there may be a person that needs support at another location (See the Resources section of this guide for an example of this card and where you can get one).
- ✓ Make arrangements to return at an agreed upon time when going out.
 - Discuss alternate arrangements that could be made if you’re running late.

Use safety measures

- ✓ Encourage the person living with dementia to activate a Global Positioning System tracking feature on their cell phone so you can monitor their location in case they go missing.
- ✓ Install unique lighting outside your home to make it more identifiable in the dark.
- ✓ Continually look for new devices as technology is rapidly evolving.

Strategies for care partners continued

Involve the person living with dementia in decision-making

- ✓ Let the person living with dementia help plan the route or decide where to go.

Pay attention to details

- ✓ Notice what the person living with dementia is wearing (e.g., type of clothing and colour) and, if possible, take a picture before they go out on their own.

Use family washrooms

- ✓ Use family washrooms when in the community or wait outside public washrooms in case your partner living with dementia needs assistance.

“I stand outside of public washrooms and wait for him to come out. I would not hesitate in getting staff or a gentleman to go back in and see if he is okay if he was taking an unreasonable amount of time. This has not happened yet.”

(Care partner)

Strategies for care partners continued

Explore transportation options

- ✓ Contact your local public transit service provider to get information on bus routes in your area.
- ✓ Plan routes and coordinate schedules ahead of time to ensure familiarity with the system.
- ✓ Check with your local public transit service provider to see if they offer reduced fares for care partners. Some companies offer “companion cards” that provide a discount for the care partner.
- ✓ If the service is offered in your area, register for accessible transit for the person living with dementia.
- ✓ Ensure that drivers (e.g., friends, family members, taxi drivers) know the correct address of where the person living with dementia is going.

Take precautions when travelling

- ✓ Give the person living with dementia time to familiarize themselves with their new surroundings.
- ✓ Take extra care to stay close to the person living with dementia.
- ✓ Inform the hospitality staff that the person you are travelling with has dementia.

Strategies for care partners continued

Stay close

- ✓ Hold hands in large crowds if the person living with dementia is not feeling safe:
 - If you are not comfortable holding hands, maintain contact in another way, like holding on to the person's jacket
- ✓ Let the person living with dementia lead the way when walking together in crowded or vast spaces.



For more tips while travelling, refer to the By Us For Us guide: **Living Safely.**

“When I have an appointment, Jack comes with me. I do not leave him in the waiting room unless he feels comfortable with the staff at the desk.”

(Care partner)

Strategies for care partners continued

While these strategies can help the person living with dementia stay safe when out and about, it is important to have a plan in place in case they lose their way.

- ✓ If they have not returned by a mutually agreed upon time, start searching. Make sure to start by looking inside and outside your home, in case they returned without saying anything (e.g., went directly to a basement workshop or to the garden).
- ✓ Arrange for someone to be at your home while you are out searching in case the person returns.
- ✓ Search in familiar areas first and ask the neighbours if they have seen the person living with dementia.
- ✓ Ask security staff for assistance if you are in a large building or ask if they could make an announcement over the Public Announcement system (if available).
- ✓ Show an updated photo of the person living with dementia to those who are helping with the search.
- ✓ Call 911 immediately and report that the person living with dementia is missing. Let them know if they are registered with MedicAlert® Safely Home® or other programs.

“Safety is all about planning ahead.”

(Harry Gutoskie, Care partner)

Working together

It is important for people living with dementia and care partners to work together when planning for safety. People living with dementia should be involved in decision-making and care partners should listen to their concerns. Below are a few strategies that can be used together to help maintain safety when out and about.

Plan ahead

- ✓ Have a conversation about safety early on to develop strategies that will help keep the person living with dementia safe; gradually adjust the strategies as needed.
- ✓ Consider registering for the MedicAlert® Safely Home® program (See the Resources section of the guide for more information).
 - Start wearing the bracelet as soon as you receive it and be sure to keep it on at all times.
- ✓ Introduce yourself and your care partner to neighbours; make them aware that you have dementia so they can be another helpful resource in the community.
- ✓ Connect with your local Alzheimer Society to learn about the Finding Your Way™ program (See the Resources section in this guide for more information).

Building safer, dementia friendly communities

In order to ensure the safety of people living with dementia, we need to work together to create a broader awareness about what living with dementia is like. We can all be advocates by sharing our experiences and encouraging others to share theirs as well. As stated by Brenda Hounam, personal advocate and spokesperson, “You only have to tell one person in order to be an advocate.”

Through public awareness and educating others about the dementia, the stigma associated with it will start to fade. Once our communities realize that people living with dementia can continue to live well, they can become more supportive. The more support in the community, the more dementia-friendly it will become. Don't be afraid to open up - the more we talk about what we need to live safely with dementia, the wider our circle of support becomes.

“Neighbours know in case they ever were to see him out wandering. So far, he has not wandered, but it could happen. Extra eyes are a good thing and it is a good feeling knowing that others in the community care.”

(Care partner)

In summary

Below is a table of the common concerns and strategies that have been presented in this guide so you can access them easily. We have purposely left the last half of the table blank so that you can add your own concerns and strategies to the list.

Common Concerns	Strategies
Finding your car in a parking lot	Make a note of where you parked your car in your small memo book. Use landmarks (e.g., trees, light posts, shopping cart stations) to help you remember row numbers, or make note of how close it is to a major store.
Using public washrooms	Look for family/accessible washrooms.
Getting around using public transit	Look for landmarks to remind you of your stop, or travel with a companion. Tell the bus driver where you'd like to get off the bus and ask them to announce your stop.
Going out after dark	Look for unique lighting on your house or in the window of your home.
Finding your way in a shopping mall	Consider using a walkie-talkie to communicate with your companion.

In summary continued

Common Concerns	Strategies
Walking alone	Consider using Global Positioning System technology.
Taking a different route to the store	Leave a courtesy note with your care partner about the alternate route you are taking that day.
Navigating busy and crowded spaces (mall, airport, grocery store)	Stay close to your companion - hold hands, place your hand on their shoulder, or hold on to their arm or jacket.

Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

Resources

Alzheimer Society of Canada

Toll-free telephone: 1-800-616-8816

Email: info@alzheimer.ca

Website: www.alzheimer.ca

First Link[®] is for people living with dementia and their care partners. It offers information about dementia and links people living with dementia and their care partners directly to programs and services in their communities.

Website: www.firstlinkontario.ca

Finding Your Way[™] offers practical advice on how people living with dementia can stay safe while staying active. It shows how to best deal with the risk of going missing.

Website: www.findingyourwayontario.ca

MedicAlert[®] **Safety Home**[®] can help people living with dementia if they become lost. Critical information and a hotline number are engraved on a MedicAlert[®] bracelet that's worn by the person living with dementia. Should the person go missing, first responders are trained to look for the bracelet and call the MedicAlert[®] 24-hour emergency hotline to access personal and medical information.

Website: www.medicalert.ca/safely-home

Ontario 211 is a 24 hour a day, 7 days a week hotline and website for Canadians needing information about community, social, non-clinical health and related government services. The information is available in over 100 languages.

Telephone: 2-1-1

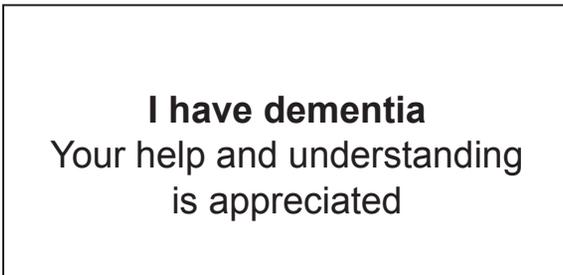
Website: www.211ontario.ca

World Health Organization

Website: www.who.int

Identification Cards can be used by people living with dementia to show to others that they may need help and understanding. Care partners can also carry an identification card to indicate they support someone that may need help in case they are not available. Examples are included below and templates are available on the Schlegel-UW Research Institute for Aging website: www.the-ria.ca.

Identification Card for People Living with Dementia Example



Care Partner Emergency Card Example

<div style="background-color: red; color: white; text-align: center; padding: 5px;">ATTENTION!</div> <div style="text-align: center; padding: 5px;">CARER EMERGENCY CARD</div> <p style="text-align: center; font-size: small;">Someone relies on me to look after them. PLEASE READ THE INFORMATION ON THIS CARD in the event of my illness or an accident.</p> <div style="background-color: black; color: white; text-align: center; padding: 2px;">I AM A CARER:</div> <p>My name is: _____ Address: _____ Tel: _____</p> <div style="background-color: black; color: white; text-align: center; padding: 2px;">I CARE FOR:</div> <p>Name: _____ Address: _____ Tel: _____</p> <div style="background-color: black; color: white; text-align: center; padding: 2px;">EMERGENCY CONTACT #1:</div> <p>Name: _____ Address: _____ Tel: _____</p>	<div style="background-color: black; color: white; text-align: center; padding: 2px;">EMERGENCY CONTACT #2:</div> <p>Name: _____ Address: _____ Tel: _____</p> <div style="background-color: black; color: white; text-align: center; padding: 2px;">EMERGENCY CONTACT #3:</div> <p>Name: _____ Address: _____ Tel: _____</p> <div style="background-color: black; color: white; text-align: center; padding: 2px;">ABOUT THE PERSON I CARE FOR:</div> <p>_____ _____ Medication: _____ _____</p> <div style="background-color: black; color: white; text-align: center; padding: 2px;">IMPORTANT PHONE NUMBERS:</div> <p>Doctor: _____ Fire, Police, Ambulance: _____ Other: _____</p> <p style="font-size: x-small; text-align: center;">This card was adapted from the Carer Emergency Card produced by The Princess Royal Trust Fallick Carers Centre</p>
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We also suggest that you check for other local, national and international resources.

Endorsements

From a personal perspective, I know that I want my friends and family to always feel safe and I know there are many ways to do this. This brochure is a great resource as it helps in providing suggestions for people to consider. Not all ideas work for everyone, we all have unique situations. I love having choices. While working at the Alzheimer Society of Ontario, I know that there is little awareness of missing incidents in our communities and many people do not know where to seek help. Our Finding Your Way™ program has tools to help inform people living with dementia and their care partners about the risk of getting lost or going missing, and helps all of us prepare for such incidents, if they occur. Please visit www.findingyourwayontario.ca to learn more. Congratulations to the whole team for their hard work on this brochure.

Cathy Conway

Alzheimer Society of Ontario

MedicAlert® Foundation Canada, the Alzheimer Society of Ontario, and the Murray Alzheimer Research and Education Program actively work to educate, empower, and promote safety for Canadians living with dementia. MedicAlert® is proud to be a collaborative partner alongside organizations that mirror our passion in developing tools to better service those impacted by dementia. The By Us For Us guide has, within it, comprehensive material that will, without a doubt, contribute to the well-being of those finding their way and bringing them safely home.

M Alfieri Catherine Horlock

Director Member Experience, MedicAlert® Foundation Canada

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Creator of the By Us For Us Project: Brenda Hounam

The development team

Brenda Hounam, Harry Gutoskie, Ron Hopewell,
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Alzheimer Society
ONTARIO

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About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:

www.the-ria.ca

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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Phone: 519-904-0660

Email: info@the-ria.ca

Website: www.the-ria.ca

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Murray Alzheimer Research
and Education Program