

safety when out and about

An inspirational guide
for persons with early-stage memory loss
and their partners in care

A By Us For Us[®] Guide

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!”

Persons living with dementia are like anyone else, but with extra challenges. Memory loss 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 partners in care. 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 partners in care 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. Partners in care 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.
- **Memories of a past job or a former home** can cause a person living with dementia to leave the safety of their current home in search of a memory from the past.

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 GPS and other mobile devices are not as reliable.
- Using public washrooms.
- Using public transit.
- Navigating buildings with similar designs that are non-descript and 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 Global Positioning Satellite (GPS) and other locating device technology, and medical/personal identification programs are beneficial for both those living with dementia and their family care partners. Consider the following benefits of technology and assistive devices:

- Prevent or reduce the chances of becoming lost.
- Give peace of mind to family members, 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 your family.
- 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

tips for staying safe using technology and assistive devices

Assistive device:

- MedicAlert® Safely Home® bracelet (See Additional 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 USA.
- Wearable sensors that can be worn on the foot can help detect movement and alert a designated partner in care.
- Door or window chimes can be installed to alert family members if a window or door has been opened.

Locating device technology:

- Cell phone:
 - Pre-program phone numbers of family members 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, make voice memos, or take pictures of landmarks.
- Global Positioning Satellite (GPS) technology:
 - Attach a personal GPS locator to a key chain or wear it on 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 GPS to get audio and visual instruction and help you get to the location.

- Walkie-talkies:
 - Use to keep in touch with you partner in care in large buildings that are non-descript, like grocery stores.
- Practise 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 possibly 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 a form of dementia.
- Consider wearing personal identification around your neck on a cord or lanyard.
- Carry a card designed for people living with dementia to help get support and understanding from the public (See Additional Resources section of this guide for an example of this card and where you can get them).

“I use the same roads most of the time and only go from place A to place B.” — Person living with dementia

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 family members about your planned route or schedule.

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.

- Get a keychain engraved with your temporary address and important information if you're going to be away for an extended period of time (e.g. temporary address in Florida during the winter).
- 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 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.
- 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 do 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.

"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

- Refer to your small memo book or assistive device to help re-trace your steps.
- Tell someone that you have lost your way, especially if you feel unsafe; accept that it happened and come up with strategies to prevent it from happening again.
- If you are carrying a cell phone, call home or another trusted person.
- Take a picture with your phone and send it to a family member to help find you.

There is space at the end of this guide to write down some of your own strategies.

strategies for partners in care

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

Plan ahead:

- Inform your neighbours that the person you are supporting is living with dementia. Bring a picture of your family member living with dementia and your contact information and 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.” — Partner in care

- Carry a “Carer Emergency Card” that states you are a partner in care and lists emergency contact information in the event of your illness. This provides first responders with information that there may be a person living with dementia that you are responsible for, that needs support at another location (See Additional Resource section in this guide for more information).
- 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 GPS 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.

Involve the person with dementia in decision-making:

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

Pay attention to details:

- Notice what the person 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.” — Partner in care

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 partners in care; some companies offer “companion cards” that provide a discount for the partner in care.
- If the service is offered in your area, register for accessible transit for the person 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 *(also refer to the By Us For Us Guide – Safety for more tips while travelling):*

- Give the person 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.

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.

“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.” — Partner in care

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

- If he or she has not returned by a mutually agreed upon time, start searching. Make sure to start by looking inside and outside your home, in case the person 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 your family member.
- Ask security staff for assistance if you are in a large building or ask if they could make an announcement over the PA system, if available.
- Show an updated photo of the person with dementia to those who are helping with the search.
- Call 911 immediately and report that the person 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, Partner in care

working together

It is important for people living with dementia and partners in care 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 Additional 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 partner in care to neighbours; make them aware of the diagnosis 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 Additional Resources section in this guide for more information).
- Together, create a map of your neighbourhood and include any significant landmarks and places where you often travel. Make photocopies of the map and use a highlighter or pen to mark directions to and from a location. The front cover image of this guide is an example of a neighbourhood map.

“Even though it’s not a concern now it could be in the future - think of what might happen as the illness progresses.”

— Maggie Weidmark, Person living with dementia

building safer, dementia friendly communities

**Be brave
enough to
start a
conversation
that matters.**



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 disease, 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.” — Partner in care

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
<i>Finding your car in a parking lot</i>	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.
<i>Using public washrooms</i>	Look for family/accessible washrooms.
<i>Getting around using public transit</i>	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.
<i>Going out after dark</i>	Look for unique lighting on your house or in the window of your home.
<i>Finding your way in a shopping mall</i>	Consider using a walkie-talkie to communicate with your companion.
<i>Walking alone</i>	Consider using GPS technology.
<i>Taking a different route to the store</i>	Leave a courtesy note with your family member about the alternate route you are taking that day.
<i>Navigating busy and crowded spaces (mall, airport, grocery store)</i>	Stay close to your companion - hold hands, place your hand on their shoulder, or hold on to their arm or jacket.

additional resources

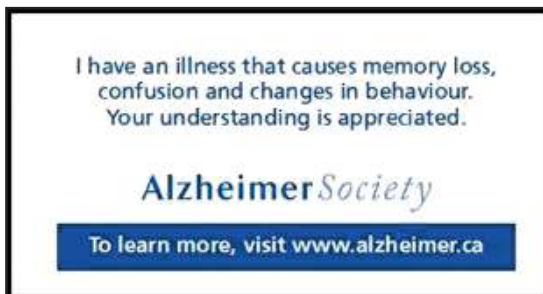
- **Finding Your Way™** is a program that offers practical advice on how people living with dementia can stay safe while staying active. It shows how to best deal with the risk of going missing. For more information visit www.findingyourwayontario.ca.
- **MedicAlert® Safety Home®** is a service that 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 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. For more information visit www.medicalert.ca/safely-home.
- **The Murray Alzheimer Research and Education Program (MAREP)** Living with Dementia: Resources for Living Well is a website that provides information and resources to persons with dementia and their family partners in care - information and resources to enable them to live well and help prepare for the road ahead. Visit the website at www.livingwithdementia.uwaterloo.ca.
- **First Link®** is for people living with dementia and their partners in care. It offers information about dementia and links people living with dementia and their partners in care directly to programs and services in their own communities. For more information visit www.firstlinkontario.ca.
- **The Alzheimer Society** has a locating device checklist and information sheet accessible in hardcopy via local offices or online at <http://goo.gl/d8TRsQ>.
- **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. When you don't know where to turn, call 2-1-1 or visit www.211ontario.ca.

- Below is an example of a “Carer Emergency Card” that partners in care can carry to indicate they support someone else that may need help, in case the partner in care becomes ill or is not able to communicate with a first responder. A downloadable version of this card is available online at uwaterloo.ca/marep.

ATTENTION!	
CARER EMERGENCY CARD	
Someone relies on me to look after them. PLEASE READ THE INFORMATION ON THIS CARD in the event of my illness or an accident.	
I AM A CARER:	EMERGENCY CONTACT #2:
My name is: _____	Name: _____
Address: _____	Address: _____
Tel: _____	Tel: _____
I CARE FOR:	EMERGENCY CONTACT #3:
Name: _____	Name: _____
Address: _____	Address: _____
Tel: _____	Tel: _____
EMERGENCY CONTACT #1:	ABOUT THE PERSON I CARE FOR:
Name: _____	_____
Address: _____	_____
Tel: _____	Medication: _____

	IMPORTANT PHONE NUMBERS:
	Doctor: _____
	Fire, Police, Ambulance: _____
	Other: _____
	This card was adapted from the Carer Emergency Card developed by The Prince George Social Network Centre.

- Below is an example of a personal identification card that people living with dementia can show to someone else to get help and understanding. A downloadable version of this card is available online at uwaterloo.ca/marep.



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 partners in care 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.

Catherine Horlock
Director Member Experience
MedicAlert® Foundation Canada

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FINDING Your Way™

*For people with dementia,
every step counts.*

Funding provided in part by:

Alzheimer Society
ONTARIO

 **Ontario**

we welcome your input

If you are a partner in care or have been diagnosed with early-stage memory loss and would like to comment on this guide or suggest topics for future guides, please contact MAREP at info@the-ria.ca.

Look for other guides in the following By Us For Us© series:

- Series 1 – Persons with dementia series
- Series 2 – Partnership series
- Series 3 – Family partners in care series

To order additional copies of this guide, contact:

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www.the-ria.ca/marep