

Wandering and dementia

A guide for care partners

Alzheimer Society

MANITOBA

Dementia Care & Brain Health

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Understanding wandering

Wandering

Wandering refers to a variety of behaviours that may result in a person living with dementia becoming lost. Wandering is a direct result of physical changes in the brain and:

- Is a common behaviour associated with dementia.
- May occur at any time of the day or night.
- May lead the person with dementia outdoors, which can expose them to dangers such as traffic or dangerous weather conditions.
- May occur on foot, by car or public transportation.



Reasons for wandering

Figuring out why a person living with dementia wanders can be difficult. It is important to remember that people living with dementia likely have a reason for going somewhere, even if we can't understand it. While every person living with dementia is unique, there are some common reasons to why they may wander:

- The person may be too hot or too cold in their current location.
- The person may be agitated due to medication side-effects, too much noise, or other forms of overstimulation.
- They may be in discomfort. For example, the person may be hungry, in pain, or in need of the toilet.
- The person may believe they need to leave the house in order to go to work, or take care of their children.
- They may not recognize their own home and may want to go somewhere that is more familiar.
- The person may be continuing a long-standing habit. For example, perhaps the person has always enjoyed long walks.

- New environments may increase disorientation.
 Moving to a new neighbourhood or a new home may increase someone's wandering risk.
- They may be experiencing delusions and hallucinations due to their illness or medication side-effects.
- They may be seeking relief from boredom.
- They may not have enough of an outlet for their energy.
- Restlessness or changing sleep patterns can lead to confusion between night and day.

Wandering can often occur at night.

The factors that may be contributing to the wandering behaviour of the person I am caring for are:

A note on language: We use the term 'wandering' in this resource as it is most commonly recognized and understood. However, this term is not always considered person-centred, as it suggests aimless or purposeless movement. You may see terms like 'exit-seeking' or 'wayfinding' used as alternatives in other resources.

Safety

The balance between risk and safety is delicate. While the act of wandering in itself is not a dangerous activity, it can become dangerous when the person living with dementia becomes disoriented or lost, or when the physical environment poses risks to their physical well-being. Busy streets with poorly marked crosswalks may increase the risk of a person becoming injured, for example.

Like all people, people living with dementia should have the opportunity to move about as freely as possible, but changes in the brain may mean that they aren't able to exercise the judgment and reasoning to do it safely.

The Alzheimer Society of Manitoba can assist people living with dementia and their families to explore practical strategies to minimize the risk of wandering and to be prepared if wandering does occur. For more information, call the First Link® Client Support Helpline at 1-800-378-6699 or 204-943-6622.



Reducing the risk of wandering

No one thing is going to prevent a person living with dementia from wandering. **Multiple strategies are recommended** to reduce the risk. The following are five key areas to consider.

1) Examine the immediate environment

Enable safe wandering

Like walking and other types of physical movement, wandering can often be a coping mechanism for people living with dementia. If the person is able to walk freely, in a safe and secure environment, the person can enjoy a healthy outlet for feelings of anxiety or restlessness.

- Consider using a technological device, like a bell that signals when a door is opened or sound-sensitive monitors to help keep track of where a person is in the home.
- Walking with a caregiver or a friend, or spending time outside in a secure area, may be a safe option for a person who tends to wander.

Provide visual cues

- Familiar objects, furniture and pictures can provide comfort and belonging.
- Leaving a light on in the hallway or placing an illuminated clock by the bed may help reduce disorientation at night.
- Labels on doors may help the person find their way around the home.





Reduce triggers

Many people living with dementia talk about "triggers" – something that can cause agitation, increased stress or more difficulty thinking. Understanding the person's triggers for wandering and how to manage them may help reduce wandering behaviour.

- Keep objects associated with the outdoors (car keys, jackets, shoes) out of the person's view.
- If possible, place door locks above eye level or where the person can't see them.
- Try disguising doors by decorating or covering them so they don't look like doors.
- Anticipate the times the person may wander or has wandered before, like approaching nightfall (often associated with sundowning).

Sundowning is when someone becomes confused, anxious, agitated or restless later in the day. It is a common symptom of Alzheimer's disease and other dementias.

2) Exercise

Exercise can help the person use up extra energy and may improve the person's sleep patterns.

• Consider involving the person in a regular exercise program.

The person's abilities, health and interests should be taken into consideration when choosing activities. If you have questions about your situation, speak to your doctor or health-care provider.

 Accompany the person on walks to provide stimulation. Go to a local shopping mall when the weather turns cold.



3) Develop meaningful activities

Everyone enjoys participating in meaningful activities where they can feel successful.

- Engage the person in an activity they might enjoy, like a cup of tea, a conversation or looking through a picture album.
- Involve the person in day-to-day household activities (peeling potatoes, setting the table, folding laundry, reorganizing a toolbox). Consider the person's past interests or skills when presenting activities.
- Try not to become upset or frustrated if these tasks are not done "right." The important thing is that the person living with dementia feels included and important.
- Try another activity if the person becomes bored or frustrated.
- Be flexible. Modify activities to adapt to the person's current abilities.

4) Keep records

Keeping an ongoing journal or record can help provide insight into reasons for the person's wandering behaviour. Understanding the person's wandering patterns and triggers can help you put strategies in place. Useful things to record include:

- Was the wandering dangerous?
- Why do you think the wandering occurred?
- How long did the behaviour last?
- What seemed to help the person relax or settle down?

5) Establish community connections

- If you haven't already, get in touch with our First Link® Client Support team for information, education and support by calling our Helpline at 1-800-378-6699 or 204-943-6622.
- Connect with your local community centre for socialization and support.
- Let others in your community know that the person living with dementia has a potential to wander. Ask friends, neighbours and local businesses to stay alert and call you if they think the person is disoriented. If it is possible, get the person with dementia's permission to do this first.

My strategies for reducing the person's risk of wandering are:

Wandering in long-term care

If the person living with dementia is moving to or currently lives in long-term care, you may want to consider the following:

- What is the care home's procedure when a wandering incident occurs?
- Does the care home have strategies to reduce the risk of wandering?
- Have you talked about reducing the risk of wandering as part of the person's care plan?



Becoming prepared

Fill out an identification kit now

An identification kit can help organize vital information about the person you are caring for. If the person goes missing, you will have valuable information on hand to assist police or RCMP.

- Fill out and print the identification kit on page 10-11.
- Keep the kit in a central location, for example, the refrigerator door, and make copies for other people that the person living with dementia may spend time with.
- Regularly check to ensure the information is current. For example, update the photo if the person's appearance changes.
- Keep two copies, one to give to police/RCMP in an emergency, and one for yourself.

Identification options

MedicAlert® Safe & Found – a 24/7 identification service

- The ID bracelet bears the authentic MedicAlert symbol recognized by emergency responders and is engraved with the wearer's critical medical information and the Emergency Hotline Number.
- The blue MedicAlert symbol on the face of the bracelet subtly indicates that someone is living with dementia, and first responders are specifically trained to understand the meaning of this conditionspecific ID.
- MedicAlert's 24/7 Emergency Hotline relays key medical information to emergency responders, including a MedicAlert subscriber's personal health record directly from the Subscriber Health Information Database (SHID).
- When called, the Emergency Helpline specialists immediately notify caregivers or family to let them know the situation and location of the member.

- MedicAlert offers a variety of service plan options when you register. At the end of your initial term, your subscription will automatically renew. When you initially subscribe to MedicAlert there is a one-time activation fee which helps cover the costs of setting up and reviewing your Personal Health Information Record before it becomes available to first responders.
- To learn more or to register, call 1-800-668-1507 or visit https://www.medicalert.ca/.



Customized identification

- Create a personal identification card which can be placed in a wallet or pocket.
- Consider writing or sewing identification labels into clothes.
- Generic bracelets can be purchased from some drug or jewelry stores and engraved by a jeweler.
- Engrave an existing piece of jewelry, such as a watch or pendant.

- Privacy and safety should be considered when deciding what information should be included on customized identification.
- A limitation of generic ID jewelry is that they are not connected with an emergency hotline service and may not be recognized by first responders (police, paramedics and fire rescue).



Identification kit

About the person living with dementia **Recent photo** First name: Last name: Nickname: Place a recent, good quality photograph clearly showing Date of birth: the person's head and shoulders here. Replace the photo with Gender: an updated version as needed. Language(s) spoken: Cell phone: Home address: **Wandering history Emergency contact person** Has the person wandered before? Yes No Name: Relation to person living with dementia: What are the person's favourite places to visit? Home phone: Cell phone: Where did the person used to work? Work phone: Home address: What transit routes has the person taken in the past?

Physical	descriptio	n	Medical information		
Height:	feet	inches	Medical condition(s):		
	metres	centimetres			
Weight:	lbs or	kgs	Allergies:		
Eye colour:			Current medication(s):		
Hair colour:					
Hair style:			Doctor's name:		
Ethnicity:			Doctor's phone number: ()		
Complexion:					
Identifyi	ng feature	2 S	Personal identification & locating devices		
Check all that apply:			Is the person wearing a form of identification? Describe what it looks like. Is it a bracelet or		
Hearing ai	d(s):	Visual aid(s):	necklace? What colour is it?		
Left _	Right	Glasses Contacts			
Dentures:		Walking aid:			
Upper	Lower	Cane Walker			
Wheelchair			Does the person have a locating device? Note the type and model and describe what it looks like.		
Other Location	(scars, birth on and desc	marks, tattoos). ription:			
			For people with access to a vehicle		
			License plate number:		
			Vehicle colour:		
			Vehicle brand and model:		

If an incident occurs

It's not easy to remain calm and think clearly when a person living with dementia is lost. Keep in mind that you are not alone and others are there to help. When a person living with dementia goes missing it is an **emergency** – the most important thing is to not delay your response. The following strategies may be helpful if the person living with dementia wanders away from home.

Step 1: Check common areas

- Try and get a sense of how long the person has been gone.
- Look inside the house, including the basement. Then check the surrounding outdoor area, including the front and back yards and any garages or sheds.
- If you live in an attached dwelling like an apartment building, check common areas and consider alerting the building manager.
- If you, or a neighbour, have a doorbell camera, or other type of surveillance device, check the footage for a time stamp of when the person left, what they were wearing and the direction they may have gone.

Places I'll check if the person I'm supporting goes missing:

- If you live in a rural or sparsely populated area, or it is late at night, do not search on your own. You may endanger yourself and complicate the search for police.
- Missing items may provide clues to the person's whereabouts. For example, missing grocery bags may mean the person is heading to the store or a missing transit pass may mean the person is taking public transit.

·		J	
		Phone:	

Step 2: Contact the police or RCMP

- Do not delay! Dial 9-1-1. Police and RCMP consider this an emergency that requires immediate assistance.
- Immediately inform police/RCMP the person is living with dementia and advise them if the person is wearing identification or a locating device.
- Share the information that is on the identification kit (page 10) with police/RCMP.

Step 3: Mobilize support

• Ensure that someone stays at home in case the person returns.

- If the person may be in a vehicle, share vehicle information with police/RCMP (license plate number, car model and make, colour.)
- If the person may be using public transit, share information about any transit routes they may have used in the past.
- If the person's credit cards are gone, inform police/RCMP and consider notifying credit card companies.
 Tracking credit card use may help to locate the person.
- Alert friends and neighbours that the person is missing.

People to call if the person I'm supporting wanders:

Phone:
Phone:
Phone:
Phone:



Reuniting

A person who has been found might be anxious or confused. Below are some communication strategies to help calm the person and reduce their stress.

1. Be prepared

If there is bad weather at the time of the person going missing, prepare them a change of clothing including underwear, socks. coat and shoes to bring with you (as appropriate to weather conditions).

2. Approach calmly

 Approach in a casual manner, and approach from the front to make sure the person can see you coming.

3. Provide reassurance

- Reassure the person about where they are and why.
- Talk about familiar things that may trigger a response to return home. For example, you might offer them a cup of tea or suggest that it is time to feed the dog.

4. Keep things in perspective

 It is natural to want to ensure that the person you are caring for doesn't go missing again. Come up with some strategies to reduce the risk of wandering and to prepare for a time when a wandering incident might happen again.

5. Ask for help

- After an emergency situation, you may need to re-evaluate the living situation of the person living with dementia.
- The Alzheimer Society of Manitoba is here to help. Call the First Link® Client Support Helpline at 1-800-378-6699 or 204-943-6622.

- If the person does not wish to return home immediately, walk a short distance with them while speaking calmly and normally.
- If they are determined to reach a particular location, consider taking them there or suggest that you will go there together a little bit later.
- Let them know that you have been worried about them, and will be happy to see them return home.
- Remember that neither you nor the person is to blame.
- Restraints should not be used to reduce the risk of future incidents, as they can create additional safety risks and have not been shown to reduce missing incidents.



Locating devices

Locating devices are electronic tools that can be used to follow a person's movements or identify a person's location. No device or system can guarantee that a person living with dementia will not become lost or that they will be found if they do; however, they may represent one part of an overall strategy to keep the person you support safer. Multiple strategies are recommended to help reduce the risks for wandering.

Methods of locating vary with the devices:

- Some rely on caregivers to receive a call or alert, then start a search.
- Some use a computer, telephone, cell phone, call centre operator or directly contact the police.
- Some send out an alert when a boundary is crossed (a predetermined, adjustable "geo-fence").

There is no one standard device that will work for every person living with dementia. New technology appears on the market daily. The table below highlights a few of the different types of locating technologies you may see on the market.

Device type	Applications	General features	Limitations
GPS (Global Positioning System)	 Built into some models of cars. Some use internet maps to allow tracking. Some allow user-defined safe boundaries (signal sent if person goes outside of the set boundaries). Assisted GPS (A-GPS) uses an assistance server (cellular tower) to reduce locating time. 	 Uses radio signals transmitted from satellites to electronic receivers to identify the location of a person wearing a transmitter within a few metres. Relies on battery power. But could use AC power, computers, internet connections, standard telephone service, cellular phone service and call centre operators. 	 Intended for use outdoors. Not able to pinpoint exact location, if satellite signal is affected (for example, under bridges, inside buildings, underground or underwater). Satellite signals may be affected by electrical interference, dense bush, or high rises. Needs to be charged frequently.
Radio frequency (Radio frequency modulation or homing device)	Wristband worn by person.	 Determines location using radio signals. Battery powered, lasts about 45 days. Works indoors and in wooded areas. Wearer has a unique radio frequency signal. 	 Limited range (usually less than five kilometres). Most effective indoors.

Device type	Applications	General features	Limitations
Cell phone	Newer technologies such as smartphones and tablets.	 By dialing 9-1-1, the lost person often activates a locating system. Cell phone allows for two-way communication with the lost person and caller. 	Relies on person carrying cell phone and knowing how to use it. Depends on cellular signal. GPS and locating applications are only available on newer models of cell phones.
BLE (Bluetooth Low Energy) *Apple AirTag	An AirTag sends out a secure Bluetooth signal that can be detected by nearby devices in the Find My Network. These devices send the location of an AirTag to iCloud, then you can go to the Find My app and see it on the map.	 Bluetooth low energy, or BLE proximity locators, use a low energy Bluetooth signal received by an internet connected device to locate a transmitter. Battery powered, last approximately one year. Your iPhone or Apple device will let you know when it's time to replace the battery. AirTags are water resistant. IOS 17 lets you share AirTag with up to five people. 	 Relies on person carrying the AirTag (i.e. attached to a keychain, placed in a wallet, sewn into a jacket pocket, etc.) Has to be connected to an Apple device (iPhone or iPad). Limited range makes it challenging to use in rural settings.

A repository of locating technology has been created at the University of Waterloo and can be found here: <u>Locator devices for people at risk of going missing | Aging and Innovation Research Program (AIRP) | University of Waterloo (uwaterloo.ca)</u>

In addition to locating technology, door cameras can be another strategy to be considered to reduce the risks of a person living with dementia becoming lost or going missing. Door cameras can mark a time and date the person left the house, assist in identifying what the person was wearing when they left, as well as potentially the direction they were walking. Consider a camera that can store video footage for 24-48 hours.

Ethical considerations

If you are deciding whether or not to use a locating device, consider the benefits, drawbacks and safety needs. For example, some people may think a locating device increases personal freedom and safety, while others may feel it is an invasion of privacy.

Making decisions can be difficult. To help make the choice, consider having a discussion with the person living with dementia. Have the discussion as soon as possible after the diagnosis in order to plan effectively for the future.

The Alzheimer Society of Manitoba is here to help support you in navigating these conversations. Call the First Link® Client Support Helpline at 1-800-378-6699 or 204-943-6622.

Before you decide whether the use of a locating device is right for the person you support, you may want to consider the following questions.

su	pport, you may want to consider the following questions.
•	What effect, if any, will there be on personal dignity? How important is this?
•	During their life, what value has the person living with dementia placed on their freedom and independence versus their safety and security?
•	How do these values influence the decision to use a locating device?

• Are there legal issues to consider if the person is no longer able to have input into the decision?

• When is a good time to start using a locating device?

Deciding on a device

It can be challenging to find a locating device that meets your exact needs. Fill out this check sheet for each device you are considering and compare. Salespersons or others using the device may be able to help you answer the questions.

Device			
Device type:	Device name:		
Manufacturer:			
Affordability			
Price of device:			
Other costs (monthly fees, service calls, repla	cement batteries):		
Is this device covered by an alternative fundi	ng source (insurance, service club)?	O Yes	No
Ease of handling/use			
What level of technology are you comfortab	le with?		
How often does the battery need recharging	and/or replacing?		
Does the technology require other equipmer	nt such as a computer, internet or cell	O Yes	No
phone? If yes, what?			
Can the device be easily removed, lost or for	gotten by the person?	O Yes	No
Service			
Is a trial period offered?		Yes	No
How long is the warranty period?		O	
What does the warranty cover?			
Is there a policy for upgrading if needs chang available? Is there a "loaner" unit that can b		O Yes	No
Depending on the technology that the tracking effective outdoors than others. Will the location both? Will the device be used in a rural or	ting device be used indoors, outdoors	O Yes	No

Reliability		
Is the device durable?	O Yes	No
Has this device been tested for use in various weather? (ex., winter weather, rain, etc.)	O Yes	ONo
Can the device get wet (i.e., can it be worn 24/7 and when the person is showering)?	O Yes	No
Is this device intended for use in the service area where it will be used (i.e., outdoors vs indoors, urban vs rural)?	O Yes	No
Is this device endorsed by:		
Policing services?		
Search and rescue units?		
Facilities caring for persons with dementia?		
Does this device incorporate:		
a geofence? (technology that will trigger a response when a device leaves a pro-	e-set area)	
a panic button?		
two-way communication?		
Will this device work if the person:		
is immersed in water?		
is out of a specific range?		
is away from a pre-determined area or leaves a building?		
Will this device provide an alarm when the person:		
removes the device?		
falls?		
is near water?		
is immersed in water?		
is out of a specific range?		
is away from a pre-determined area or leaves a building?		

Specific considerations

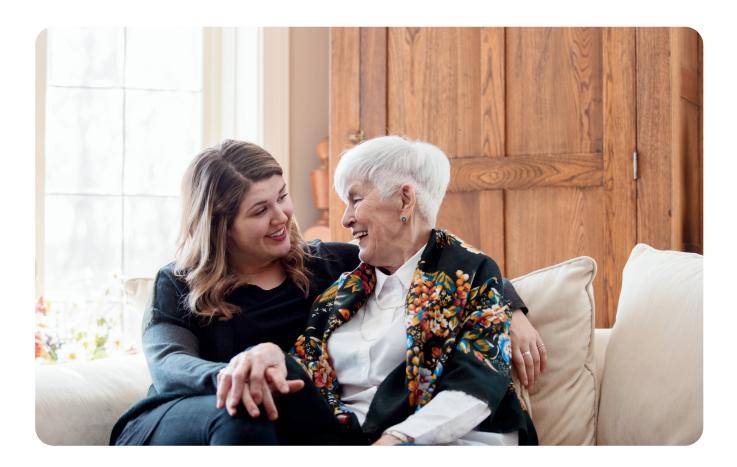
For the caregiver

•	Who needs to locate/track the person (e.g. agency, call centre, police, caregiver)?
•	Is two-way communication needed with the person who is lost?
•	Are special skills, knowledge, or training needed to use device?
•	Is the system flexible to changing needs (e.g. going on vacation)?
•	Is a map required?
•	Does the caregiver need to have knowledge of the area covered?
For	the person who may get lost
•	Is the device acceptable to the person wearing it?
•	Does the device need to be attached/carried by the person?
•	Is the device comfortable to wear?
•	Does it matter what the device looks and feels like (e.g. weight, size, appearance)?
•	Does the person need to identify his/her own location?

Resources page

The Alzheimer Society of Manitoba is dedicated to helping people build the knowledge, skills and confidence to live well with dementia. The Society is available to answer questions and help you find the professional assistance you need.

- Visit our website to find an Alzheimer Resource Centre in your area: www.alzheimer.mb.ca
- Call the First Link® Client Support Helpline, a province-wide service for people living with dementia, their caregivers, family and friends. Call toll-free: 1-800-378-6699 or 204-943-6622.



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Dementia Care & Brain Health

First Link® Client Support Helpline: 1-800-378-6699 <u>alzmb@alzheimer.mb.ca</u> | alzheimer.mb.ca