










Wandering and dementia

A guide for caregivers

Alzheimer Society
BRITISH COLUMBIA

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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 over-stimulation.
- 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 B.C. 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® Dementia Helpline at 1-800-936-6033 or contact your local Alzheimer Resource Centre.



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

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.



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?



All about me is a record-keeping tool which can be used to get to know the person living with dementia better.

Available online at www.alzheimerbc.org

5) Establish community connections

- If you haven't already, get in touch with your local Alzheimer Resource Centre for information, education and support or call the First Link® Dementia Helpline at 1-800-936-6033.
- 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.

- Fill out and print the identification kit on page 9-10.
- 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 in an emergency, and one for yourself.

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

First name:

Last name:

Nickname:

Date of birth:

Gender:

Language(s) spoken:

Cell phone:

Home address:

Wandering history

Has the person wandered before? Yes No

What are the person's favourite places to visit?

Where did the person used to work?

What transit routes has the person taken in the past?

Recent photo

Place a recent, good quality photograph clearly showing the person's head and shoulders here. Replace the photo with an updated version as needed.

Emergency contact person

Name:

Relation to person living with dementia:

Home phone:

Cell phone:

Work phone:

Home address:

Physical description

Height: feet inches
 metres centimetres

Weight: lbs or kgs

Eye colour:

Hair colour:

Hair style:

Ethnicity:

Complexion:

Identifying features

Check all that apply:

Hearing aid(s):

Left Right

Visual aid(s):

Glasses Contacts

Dentures:

Upper Lower

Walking aid:

Cane Walker

Wheelchair

Other (scars, birthmarks, tattoos).
Location and description:

Medical information

Medical condition(s):

Allergies:

Current medication(s):

Doctor's name:

Doctor's phone number: ()

Personal identification & locating devices

Is the person wearing a form of identification?

Describe what it looks like. Is it a bracelet or necklace? What colour is it?

Does the person have a locating device? Note the type and model and describe what it looks like.

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 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.

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

Phone:

Phone:

Phone:

Phone:

Step 2: Contact the police

- Do not delay! Dial 9-1-1. Police consider this an emergency that requires immediate assistance.
- Immediately inform police 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 9) with police.
- If the person may be in a vehicle, share vehicle information with police.
- 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 and consider notifying credit card companies. Tracking credit card use may help to locate the person.

Step 3: Mobilize support

- Ensure that someone stays at home in case the person returns.
- 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. Approach calmly

- Approach in a casual manner, and approach from the front to make sure the person can see you coming.
- If the person does not wish to return home immediately, walk a short distance with them while speaking calmly and normally.

2. 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.
- 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.

3. 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 where a wandering incidence might happen again.
- Remember that neither you nor the person is to blame.

4. 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 B.C. is here to help. Call the First Link® Dementia Helpline at 1-800-936-6033 or connect with your local Alzheimer Resource Centre.



Locating devices

Location 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.

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)	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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.
Radio frequency (Radio frequency modulation or homing device)	<ul style="list-style-type: none"> Wristband worn by person. 	<ul style="list-style-type: none"> Determines location using radio signals. Battery powered, lasts about 45 days. Works indoors and in wooded areas. Wearer has a unique radio frequency signal. 	<ul style="list-style-type: none"> Limited range (usually less than five kilometres).
Cell phone	<ul style="list-style-type: none"> Newer technologies such as smartphones and tablets. 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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.

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. You can also receive support from your local Alzheimer Resource Centre or by calling the First Link® Dementia Helpline at 1-800-936-6033.

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.

- 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, replacement batteries):

Is this device covered by an alternative funding source (insurance, service club)?	Yes	No
--	-----	----

Ease of handling/use

How often does the battery need recharging and/or replacing?

Does the technology require other equipment such as a computer, internet or cell phone?	Yes	No
---	-----	----

If yes, what?

Can the device be easily removed, lost or forgotten by the person?	Yes	No
--	-----	----

Service

Is a trial period offered?	Yes	No
----------------------------	-----	----

How long is the warranty period?

What does the warranty cover?

Is there a policy for upgrading if needs change or a new technology becomes available?	Yes	No
--	-----	----

Is there a "loaner" unit that can be quickly accessed?	Yes	No
--	-----	----

Reliability

Is the device durable? Yes No

Has this device been independently tested? Yes No

If yes, where and by whom did this testing take place?

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 pre-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 center, 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 B.C. 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.alzheimerbc.org.
- Call the First Link® Dementia Helpline, a province-wide service for people living with dementia, their caregivers, family and friends. Call toll-free: 1-800-936-6033 or 604-681-8651.



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Alzheimer *Society*
BRITISH COLUMBIA

info@alzheimerbc.org

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