



UNIVERSITY OF
WATERLOO

CASES OF PERSONS LIVING WITH DEMENTIA WHO GET LOST AND GO MISSING IN CANADA

May 2025



Public Safety
Canada

Sécurité publique
Canada



2. A friendly woman living with Lewy body dementia goes missing after walking out of her long-term care home

Personal information

Name: Sarah Stone.

Age: 70 years old.

Gender: Woman, pronouns are she/her.

Living situation: 150-bed long-term care home in Winnipeg, Manitoba.

Social support: Three adult children Mary, Lisa, and Kate, and a younger sister, Carrie.

Health: Lewy body dementia, Parkinson's disease, Type 2 diabetes, and anxiety disorder. Taking medications for these conditions listed above.

Interests: Travelling, walking, and doing outdoor activities such as biking.



Background

Sarah's current living situation

Sarah moved into a long-term care home after her husband passed away and she was diagnosed with Lewy body dementia. Before moving in, Sarah loved to travel and join community activities. She also volunteered at an assisted living home after retiring from teaching. She has not participated in recreation activities organized by the long-term care home.

Sarah's family

Sarah's youngest daughter, Kate, lives 30 minutes away from the care home. Kate is recently divorced, has three young children, and works full-time. Even though she is very busy, she still visits her mom once a week. Kate also has Power of Attorney, which means she can make financial and healthcare decisions for Sarah.

Sarah's younger sister, Carrie, lives about ten minutes away and visits three times a week. Carrie is not the main decision-maker, but she helps take care of Sarah and is listed as an emergency contact on Sarah's MedicAlert® file along with Kate.



The day of the incident

– Getting lost

1. Sarah goes missing

On an otherwise normal day at the long-term care home, Sarah seems more confused and upset than usual. The unit is noisy with door alarms and people talking in the hallways. Because there are not enough staff, the regular check that gets done at 2:00 pm is delayed. At 4:00 pm, a health care aide discovers that Sarah is not in her room. After looking in the other residents' rooms, the aide tells the nurse manager that Sarah is missing.

2. Code Yellow

The nurse manager initiates a “Code Yellow”, a procedure for when a resident is missing. This alerts all the staff to thoroughly search the building. They also call the police, the doctor, and Sarah’s emergency contacts. When the police get there Sarah is still missing, and they begin searching the surrounding neighbourhood.



The day of the incident

– Being found

Two hours after Sarah is reported missing, she is found on a highway about seven kilometers from the care home. She is walking in the rain, wearing her nightgown and slippers.

1. Arpit finds Sarah

Arpit, a community member who helps at a center for older adults, sees Sarah. He knows how to recognize someone living with dementia who seems lost. Concerned that Sarah is not dressed for the weather, Arpit approaches her and asks if she is okay and needs help.

2. Help is on the way

Sarah, shivering from the rain, says she is looking for her husband and cannot remember their home address. Arpit sees that Sarah needs help. He calls 911 right away.

3. Waiting for help

The 911 dispatcher tells Arpit to stay with Sarah until the police and paramedics get there. When they arrive, the officers see that Sarah matches the description of the missing person.



4. Returning to the care home

Sarah needs minor treatment from the paramedics and is then taken back to the care home.

After the incident

A few hours later, Kate and Carrie go to the care home after hearing what happened. It seems that Sarah walked out with some guests who were visiting another resident. The nurse manager sets up a meeting with Kate, Carrie, and the nursing staff. They talk about what happened, how to keep Sarah safe, and ways to keep Sarah from going missing again.



Resources

Do you know?

About 20% of people living with dementia go missing from long-term care homes.* ir.lib.uwo.ca/etd/7460

How to approach a missing person

If you see a person dressed inappropriately for the weather and think they may be lost, stop to ask if they need help.

- Speak slowly and calmly using simple language.
- Ask “yes” and “no” questions.
- Ask one question at a time and allow time to respond.
- If the person doesn’t understand what you’re saying, rephrase the sentence.
- Use non-verbal communication such as pointing in a certain direction to make things clearer and easier to understand.

Source: <https://www.alzheimers.org.uk/blog/what-to-do-find-someone-with-dementia-lost>



* Kowalski, Larissa, “Hiding in plain sight: A mixed methods analysis of older adults who are reported missing in two Canadian cities” (2020). Electronic Thesis and Dissertation Repository. 7460. <https://ir.lib.uwo.ca/etd/7460/>



Resources

Toolkit to manage the risk of getting lost and going missing for people living with dementia.

This toolkit contains strategies to help with the common concerns of people living with dementia and their care partners regarding the risks of becoming lost.

Emergency card

People living with dementia can carry an “In Case of Emergency” card. It has important information to help them if they go missing. This card was made by the **Calgary Missing Older adult Resource Network**, see page 16.

The Herbert Protocol

Important details about the person at risk can be gathered in The Herbert Protocol. This information can help first responders when someone is missing. Keep this information at home on your fridge and give it to care partners. Click this link to access the ‘**Resource Guide for Older Adults at Risk of Going Missing**’; fill out the form on pages 15-20.

Safety and leisure activities

Balancing leisure time with safety can be challenging. **The Canadian Guideline for Safe Wandering** provides strategies to promote safe wandering and manage the risk of getting lost when doing leisure activities.

Driving with dementia

It can be challenging to drive a car when the driver has a hard time remembering, navigating, and attending to the environment. This **Driving and Dementia Roadmap** includes safety considerations related to driving with dementia.

In Case of Emergency	
Full Name	_____
Date of Birth	_____ Blood type _____
Address	_____
Cell	_____ Work _____ Home _____
Current Meds	_____
Conditions	_____
Physician	_____ Phone _____
Allergy/additional info	_____
In Case of Emergency	
Emergency Contact #1	_____
Relationship	_____ Work Phone _____
Cell Phone	_____ Work Phone _____
Emergency Contact #1	_____
Relationship	_____ Work Phone _____
Cell Phone	_____ Work Phone _____
Additional Info	_____
_____ Last updated _____	

Locator devices

Locator devices help people living with dementia share their location with family in case they are lost. They may also help the police find people should they go missing. The **Alzheimer Society of Canada** shares more information about the purposes of locator devices. The **University of Waterloo Aging and Innovation Research Program** outlines features of locator devices, including cost and battery life.

What to do if you find a missing person

A missing incident is an emergency. Call police and ask the operator or service how you can help. **A video from Dementia Network Calgary** outlines a missing incident involving a person living with dementia and how to help.

Links

- **Toolkit** to manage the risk of getting lost and going missing for people living with dementia, made by the University of Waterloo. <https://uwaterloo.ca/managing-risks-of-disappearance-in-persons-living-with-dementia/toolkit-0>
- **“In Case of Emergency” card** made by Calgary Missing Older Adult Resource Network. See page 14. <https://missingseniors.ca/wp-content/uploads/2022/04/Resource-guide-for-people-at-risk-of-going-missing.pdf>
- **The Herbert Protocol** described by Calgary Missing Older Adult Resource Network. See pages 15-20. <https://missingseniors.ca/wp-content/uploads/2022/04/Resource-guide-for-people-at-risk-of-going-missing.pdf>
- **The Canadian Guideline for Safe Wandering.** https://canadiansafewandering.ca/#more_information
- **The Driving and Dementia Roadmap.** <https://www.drivinganddementia.ca/>
- **Locator device overview**, as described by the Alzheimer Society of Canada. <https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/ensuring-safety-security/tracking-devices>
- **Locator device features**, as described by the University of Waterloo Aging and Innovation Research Program. <https://uwaterloo.ca/aging-innovation-research-program/locator-devices>
- **What to do if you find a missing person.** Dementia Network Calgary’s video dementianetworkcalgary.ca/



For more information

Please contact:

Lili Liu, PhD, OT Reg (Ont.)

Professor, School of Public Health Sciences
Dean, Faculty of Health
University of Waterloo

519-888-4567 ext. 42126

lili.liu@uwaterloo.ca

Christine Daum, PhD, OT Reg (AB)

Research Assistant Professor,
University of Waterloo
cdaum@uwaterloo.ca



Public Safety
Canada

Sécurité publique
Canada