



# After a missing person with dementia is found

*A guide to conducting return discussions  
for first responders and service providers  
in Canada*

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## 1. INTRODUCTION

### What is this guide and who is it for?

This is a guide for return discussions by first responders and service providers with persons living with dementia who have been found after a missing incident. This guide provides stakeholder-informed suggestions and recommendations for how to conduct a discussion with persons living with dementia who have been found. This guide includes questions for both the person who was missing and care partners in order to identify services or strategies to prevent future missing incidents. ***Users of this guide should adapt the recommendations to fit their resources and situations.***

### Background information

Persons living with dementia are at risk of getting lost and going missing.<sup>1,2</sup> After a missing incident, there is an increased risk of a repeat missing incident.<sup>3</sup> A discussion with a returned missing person after a missing incident can help the person and care partners identify factors that led to a missing incident and identify ways to support the person. These discussions can be called return home interview, return interview, follow-up discussion, or return discussion. In this guide we use the term ***return discussion***.

### How was this guide developed?

This guide is based on a review of the literature and informed by interviews with first responders and service providers as well as focus groups with stakeholders who work with people living with dementia.<sup>4</sup> In a review of academic publications and grey literature, we learned that in the United Kingdom, return home interviews are conducted with children.<sup>5</sup> We did not find literature on return home interviews with older adults living with dementia. Nevertheless, in focus groups, 11 first responders (police, search, and rescue) and 9 service providers (e.g., social workers) stated that the principle of return interviews or discussions should be applied to older populations at risk of going missing. Return discussions can help identify factors related to a missing incident, connect persons to community supports, suggest safety strategies, maintain mobility, and support care partners.

### Case scenario

This return discussion guide includes a case scenario to illustrate how the recommendations could be used in practice. The full case scenario is in Appendix 1.

## 2. PREPARING FOR THE RETURN DISCUSSION

### Who may conduct a return discussion?

Currently, return discussions are not a regular or consistent part of services in Canada. A return discussion could be done by first responders or service providers (see Table 1 for examples). First responders and service providers are suggested because it is likely that these professions are already involved in a missing incident, whether in the search for or the follow up with the missing person.

Table 1. Examples of first responders and service providers (vary with jurisdiction)

<b>First responders</b>	<b>Service providers</b>
Police	Community organization employees
Fire service personnel	Social workers and system navigators (e.g., case manager)
Paramedics	Care facility staff (e.g., residential, long-term care, retirement home)
Search and rescue personnel	Nurses

First responders or service providers who have training and experience working with persons living with dementia would be best suited to conduct return discussions. Police units focused on older adult safety, victim services, or community organizations oriented towards supporting older adults are examples of possible teams of first responders or service providers that already work with persons living with dementia. First responders and service providers are encouraged to work together to offer discussions to returned missing persons living with dementia, either within or across organizations.

Some communities that have system navigators, or persons who follow the individual diagnosed with cognitive impairment, through the continuum of services. System navigators could facilitate the discussion or be involved in the follow up, as they understand local systems, resources, and services available to support the returned missing person.

Police and other first responders may not be able to conduct discussions with returned missing persons due to time and resource constraints. Also, some families may be intimidated or fearful of police thus be reluctant to participate in a discussion with members of law enforcement. Regardless of the type of personnel conducting the discussion, it is important to establish rapport with the person living with dementia and put the person at ease. Effective return discussions provide relevant information that identifies circumstances leading up the missing incident and the gaps in supports.

Questions pertaining to a missing incident could also be self-administered, by the returned missing person or a care partner. A self-administered questionnaire may be useful in cases where a return discussion with a facilitator is not possible or in cases

where individuals and families prefer a self-managed approach. More details are available in Section 3 of this guide.

#### KEY TAKEAWAY

Discussions conducted by trained and experienced persons would help families be at ease after the missing person with dementia returns home.

## Who may be included in the discussion?

When possible, the returned missing person should be involved in the discussion as this person may be able to share what led to the missing event. The care partners can also be included in the discussion if the person living with dementia consents. Care partners include family and friends, neighbours, health care professionals, and employees of a facility where the person with dementia resides. Each person provides a perspective on the circumstance surrounding a missing incident. For example, family and friends may have been present before a missing incident and would be able to provide information on the events leading up to the incident. Involvement of key persons in the discussion could create the best understanding of the missing incident, the needs of a person living with dementia, and service gaps.

Arrange to speak alone with the returned person who may want to share information in private. Discussion providers can be alert to possibilities of home issues including abuse. In a long-term care facility, it may also be useful to interview facility staff individually to gain an understanding of the incident and how future incidents can be prevented. Further, there may be situations where an individual does not have any partners in care. In these situations, the returned missing person should be interviewed, and the discussion could focus on how to provide meaningful support to the person.

Ultimately, the autonomy of persons living with dementia and their care partners should be respected. Where capacity exists, consent should be given freely. This is important during the discussion process, which may include referrals for future support. When offering a returned missing person and care partners a discussion, the provider can emphasize that the discussion is intended to support them. The discussion is not an extension of police information gathering, rather the focus is to understand their needs and how support could be implemented to improve their quality of life.

#### KEY TAKEAWAY

All effort should be made to include the returned missing person living with dementia in the discussion, although in some cases this may not be possible. The inclusion of close family or friends (e.g., family or friends who also act as partners in care) is also valuable.

## Timeline for conducting a return discussion

Discussions should be conducted as soon as possible after the missing person is found. However, the timeline should be flexible to allow time for the immediate medical needs of the person living with dementia to be met. For example, a missing person may be taken to hospital immediately to care for injuries. Timeline flexibility also allows time for the person living with dementia and family to settle immediately after a missing incident. A missing incident can be a traumatic event for the person with dementia and family and this should be considered when developing a timeline for conducting a discussion.

## Location of a return discussion

Discussions could be conducted in-person or online. For either mode, it should be made as simple as possible for participants to engage in a discussion.

In-person	Online
<p>If conducted in-person, the location should be selected by the persons participating in the discussion. This could be in a home, an office, or a neutral location (e.g., a quiet location of a coffee shop, with privacy). A discussion in-person facilitates rapport. Also, the discussion provider can assess the wellbeing of the returned missing person living with dementia, particularly if the discussion is conducted in a home environment.</p>	<p>An online discussion format includes landline telephones, mobile phones, or a computer. Discussions should be online when the participant(s) prefers a virtual platform, has access to technology, and can use the technology. Virtual discussions may be appropriate for rural or remote communities or when other challenges prevent the participant(s) from travelling. There may be individuals who prefer not to discuss the incident in-person.</p>

Table 2. In-person and online locations for return discussions

### KEY TAKEAWAY

Ideally, a discussion is conducted in-person at a location agreed upon by all discussion participants to facilitate rapport building and provide the ability for the discussion provider to assess the person living with dementia's wellbeing. When meeting in-person is not an option, discussions could be done via telephone or video-call.

## 3. CONDUCTING THE RETURN DISCUSSION

A return discussion is a conversation between the returned missing person, care partners, and the return discussion provider who facilitates a conversation that builds trust. The discussion provider would preface the conversation by creating an understanding of three things: (1) the missing incident is not a fault of the returned missing person nor the care partners, (2) missing incidents can happen regardless of the preventative strategies in place, and (3) the person living with dementia is at risk of going missing again.

### Topics of return discussion

When conducting a discussion with a returned missing person living with dementia, first responders and service providers should consider the following three topics.

#### 1. Safety and well-being

Ask questions about the safety and wellbeing (physically, mentally, emotionally) of the person living with dementia. It should be determined if the person requires medical attention.

#### 2. The missing incident

Ask questions about the events that occurred leading up to the person's missing incident, the events that occurred during the incident, and how the person returned (e.g., found, returned independently).

#### 3. Offering support

Ask about the support the person already has in place (e.g., informal caregiving support), what supports could benefit the person going forward (e.g., home care services, door alarms, GPS technology), and what community supports the person and care partners would like referrals to.

### Questions

Based on these three topics, specific questions could be asked by different discussion providers.<sup>†</sup> Questions can be divided to suit the needs of both returned missing persons and providers. Questions can also be directed at care partners on behalf of the person with dementia who is not able to respond.

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<sup>†</sup>These questions could also be self-administered in situations when it is not possible to (or the individuals choose to not) involve a discussion provider. Self-administered questionnaires may enable individuals to provide information about their missing incident sensitively, in their own time. Information reported in the questionnaire will be used to identify needs and help to mitigate further missing episodes. The questionnaire can be shared with a care partner or used personally as a reflection tool to assist in creating a safe environment.

### **Physical safety and wellbeing**

1. Do you require any immediate medical attention?
2. How do you currently feel physically?
3. Do you feel safe in your home environment?
4. Do you feel comfortable in your home environment?

### **Mental safety and wellbeing**

5. How do you currently feel mentally?

### **Emotional safety and wellbeing**

6. How do you currently feel emotionally?

### **Pre-missing incident**

7. Do you remember getting lost?
8. What were you doing before you got lost?
9. Where were you before you got lost?
10. Who was with you before you got lost?
11. Were you wearing any technology when you got lost?
12. Were you using any technology when you got lost?
13. What do you think caused you to get lost?

### **During the missing incident**

14. Did you get injured during your missing incident?
15. How did you feel during your missing incident?
16. What happened during your missing incident?
  - Where did you go?
  - What mode of transportation did you use?
17. Did you ask anyone for help?
  - Why?

### **Post missing incident**

18. How did you return home?
19. How did you feel when you returned home?
20. Was this the first time you got lost?
21. How many times have you been lost before?
22. When was the last time you were lost?

### **Support**

23. What support do you currently receive from community support services? Do we have your consent to disclose details of your missing incident and details from our current discussion with your support services?
24. What support do you currently receive from your family and friends?
25. What other support would you like to have? Would you like to be referred to any community support services?

**Note to the return discussion provider:** this is where you can suggest supports you think the person living with dementia could benefit from and ask for opinions on your suggestions.



## Barriers

Some barriers may be encountered during return discussions. These barriers can be classified by type (see Table 3).

Barrier	Type
	<b>Organization and System</b>
Lack of standardized protocol	First responders may have standardized approaches to follow for finding a missing person living with dementia, however, after the person is found, the literature tells us that there is not a standard or regular protocol for any service provider in Canada.
Privacy legislation	Provincial and Federal privacy laws and organizational policies can inhibit organizations from sharing information, such as whether a missing person has dementia. Also, without the permission of the person living with dementia, police cannot publicly share that a person has a cognitive impairment. The fear of breaching privacy legislation limits how much information is shared, and who the information is shared with.
Siloed system	First responders and service providers work with many other organizations and services. While there is a strong desire to collaborate, internal policies and processes sometimes prevent their ability to share information. The result is people not receiving the information they require to develop and implement programs.
	<b>Discussion Provider</b>
Scope of practice	Among first responders and service providers, it may be unclear who has responsibility for following up with a missing person after they have returned home. Specifically, first responders and service providers work within boundaries of responsibility. These boundaries can be physical (e.g., geographical) or less visible (e.g., scope of a community service). Either boundary places restriction on what the person is able or allowed to do to support the returned missing person living with dementia.
Competing priorities	Conducting discussions requires resources, including time and funding for each participating organization. Competing resources within an organization's current scope may create barriers to conducting all the essential elements of discussions or including them in organization or service policies.
Limited training and experience	For first responders and service providers, training and education, and in-the-field experience vary. Not all employees receive training and education on how to follow up with returned missing persons, including what community support services to refer them to. Organizations and services may have many training and education topics to be covered, some of which may

	be mandatory or prioritized. There may also be a finite amount of time available for training and education.
	<b>Discussion Participant</b>
Physical health	A person living with dementia may require immediate medical attention. This could be a barrier to conducting an interview if the person is unable to participate due to medical or health reasons.
Stress	A missing incident is stressful for persons living with dementia and their care partners. After a missing incident, the persons affected may need time to rest and recover. The stress experienced during and after a missing incident could be a barrier to conducting a discussion.
Unwilling to participate in a discussion	A returned person living with dementia and care partner may be reluctant to participate in a discussion, resulting in them declining the invitation, or refusing to share certain information about the missing incident. Returned missing persons who have dementia may be fearful of consequences, especially if they do not trust the discussion provider to keep the information they share, private. A returned person and care partner's decision to not participate in a discussion should be respected.

Table 3. Types of barriers

## 4. PRACTICAL CONSIDERATIONS

### System Navigation

Return discussions may require partnership and collaboration between groups within a community. For example, a group of service providers may have the experience and resources to conduct interviews but may need to collaborate with local search and rescue or police services to identify cases where a return discussion may be appropriate. These partnerships and system wide changes can be difficult to implement. Additionally, each community has its own set of systems and community organizations. As such, this guide can only provide suggested steps for communities to implement return discussions. However, the following prompts may aid in understanding what steps need to be taken in your community.

These considerations were developed through one-on-one semi-structured online interviews with 11 first responders (e.g., police officers) and 9 service providers (e.g., social workers) from Canada and the United Kingdom. We explored the interview approaches used by first responders and service providers after missing persons living with dementia were found and returned home.

1. What similar services currently exist in your community?

They may have different names or different target populations, but connection with an existing service may help.

2. Where does information about relevant missing cases reside?

Is the information with the police service, or a community group like the Alzheimer's Society, or both?

3. Who currently has resources (people, finances, etc.) to administer return discussions?

Can you partner with them?

4. If no resources currently available, what resources are needed?

Can you partner with another group to pool resources?

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## 5. APPENDICES

### Appendix 1

#### Case Scenario 1

This is the story of Sam who was diagnosed with dementia 5 years ago, at the age of 60. Sam lives in the rural Village of St. Jacobs, Ontario (approx. population of 2000), a 10-minute drive away from Waterloo city centre (approx. population 150,000). Sam lives in a two-storey retirement residence, in the heart of the Village, with his spouse. Sam and his spouse have two adult children who live in Waterloo.

Yesterday, Sam went for a walk in the downtown of St. Jacobs. Sam's spouse began to get concerned after Sam did not return after two hours. Sam's spouse called their adult children, who alerted the local police service and the retirement residence staff. Thankfully, Sam was found by police three hours after he was reported missing. Sam has now returned home to the retirement residence. Sam and his family are thankful Sam is safe, but they are worried Sam will go missing again. What could you, as a first responder or service provider, do to support him, and his partners in care, and prevent a future missing incident?

There are a few options for who could conduct a discussion with Sam; 1. The local police service has a unit focused on older adult safety. This unit is knowledgeable about the community support services available to Sam and his family, and 2. The local Alzheimer Society or another local community organization that specializes in supporting older adults in the Region of Waterloo and may already provide direct supports to older adults and their families.

When Sam was found and returned home by local police, the attending officers had a brief conversation with Sam and his family. The officers asked for Sam's consent to refer him and his family to you, a service provider, who will follow up with them and offer a discussion. You receive Sam's case, including the contact information for Sam and one of his adult children.

Sam is included in the discussion as he was the person who experienced the missing event firsthand. Sam understands that he was missing, and he can recall the event. Sam's spouse and adult children are also included in the discussion as Sam lives with his spouse and has a close relationship with his adult children. Sam's consent is sought before any other person is involved. Sam and his family also think it would be good to include retirement residence staff who have an existing relationship with Sam. Finally, Sam requests that his family physician be informed about his missing incident and be included in the discussion.

Upon being returned home from being missing, Sam is extremely upset and scared. Sam's spouse and adult children are also upset and worried about Sam's

wellbeing and safety. Sam's adult children decide to host their parents at their home in the city for a few days to allow Sam time to rest among family.

You, as a service provider, receive Sam's referral 24 hours after Sam was returned home by local police. The following morning, you reach out via telephone, first to Sam and then to one of their adult children and leave a message for both. The next day, you hear back from one of Sam's adult children and schedule a discussion for the following afternoon (i.e., 4 days after Sam returned home from being missing).

When scheduling the discussion, you, as a service provider, discuss discussion modes with Sam and their adult children. They say they would prefer to have an in-person meeting at Sam's residence in the retirement home.

You, as a service provider, arrive at Sam's retirement residence. When you walk into the building, you notice there is no staff at the front desk, however, Sam's spouse is there to greet you and walk you to their residence. When you walk into their residence, you notice the kitchen is cluttered with takeout containers.

You start the discussion checking in with Sam and his family by asking how they are doing. Then you move on to ask about Sam's missing incident. You give each family member time to contribute to the recounting of events. You learn that Sam just couldn't remember his way home. Sam didn't know how to use the new smartphone his adult children had gifted him for Christmas and was too embarrassed to ask a stranger for help, so he just continued to walk around in hopes that he would remember how to get home.

Sam and his family fear he will get lost again. You suggest Sam and his family install a locating app on Sam's phone to allow Sam's location to be seen at all times. You also suggest Sam and his spouse attend the free smartphone literacy classes offered by the local community centre every week. You also suggest that until Sam is feeling more confident, his spouse accompanies Sam on his daily walk.

Now that you addressed the main cause of the missing incident, you ask Sam and his family if there are any other areas in their lives that they want more support in. You mention you noticed the takeout containers and ask if this is an area they would like support. You suggest that Sam and his spouse sign up for the retirement residence's dining program, which provides three meals a day to residents. You also refer Sam and his family to the local Alzheimer Society for ongoing support as their needs change.

## Appendix 2

### Resources

#### *Education for interviewers*

1. [ALZeducate \(Alzheimer's Society of Ontario\)](#)
2. [Alzheimer Society of Canada](#)
3. [Managing Risks of Disappearance in Persons Living with Dementia](#)
4. [Aging and Innovation Research Program](#)
5. [Champlain Dementia Network](#)
6. [Self-administered return home interviews](#)

#### *Resources for persons living with dementia and their partners in care*

1. [Alzheimer Society of Canada](#)
2. [Managing Risks of Disappearance in Persons Living with Dementia](#)
3. [Aging and Innovation Research Program](#)
4. [Canadian Guideline for Safe Wandering](#)
5. [DREAM Resources for People Living With Dementia](#)
7. [Caregiver's Guide to Understanding Dementia Behaviors](#)
6. [Missing People United Kingdom](#)
7. [Toolkit to manage the risk of getting lost and going missing for people living with dementia](#)
8. [Self-administered return home interviews](#)

#### *Local Resources*

Take some time to investigate what other resources exist in your community.