

Wandering and getting lost: a review of at home strategies you can use to manage the risks



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Webinar presentation for the Alzheimer Society
London and Middlesex

May 29, 2020



Learning objectives

During this webinar you will:

1. *Discover* what wandering behaviour is
2. *Learn* about the risks that are associated with wandering and getting lost
3. Be able to *identify* strategies you can use to manage the risks

Our research team



Lili Liu



Antonio Miguel
Cruz



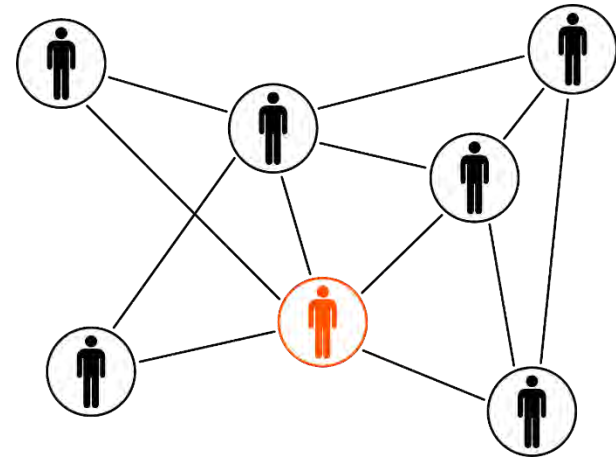
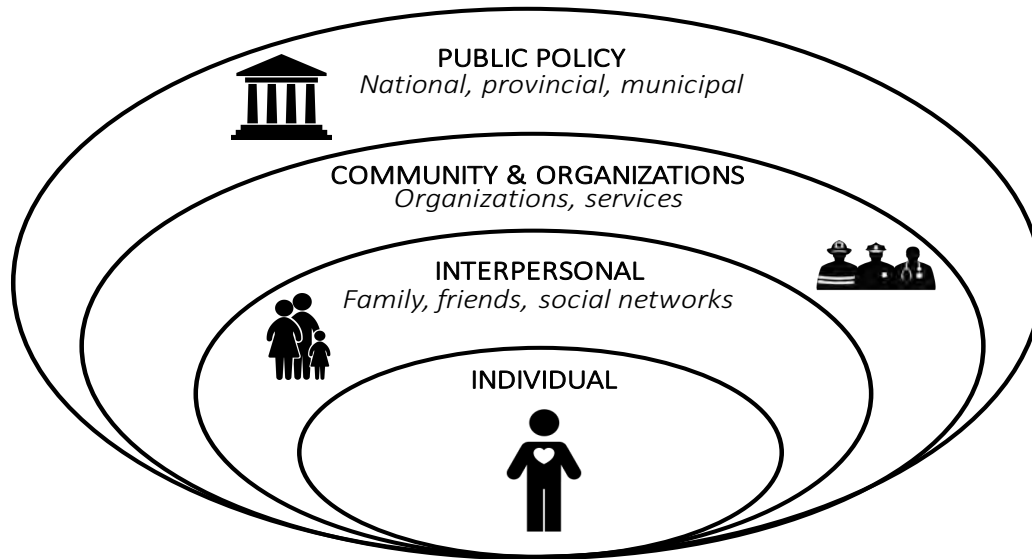
Christine Daum



Noelannah
Neubauer

Our values and beliefs about research

- Multiple perspectives from diverse stakeholders are needed to understand the problem
- Multiple solutions are needed to have impact and make change



For people with dementia, every step counts.

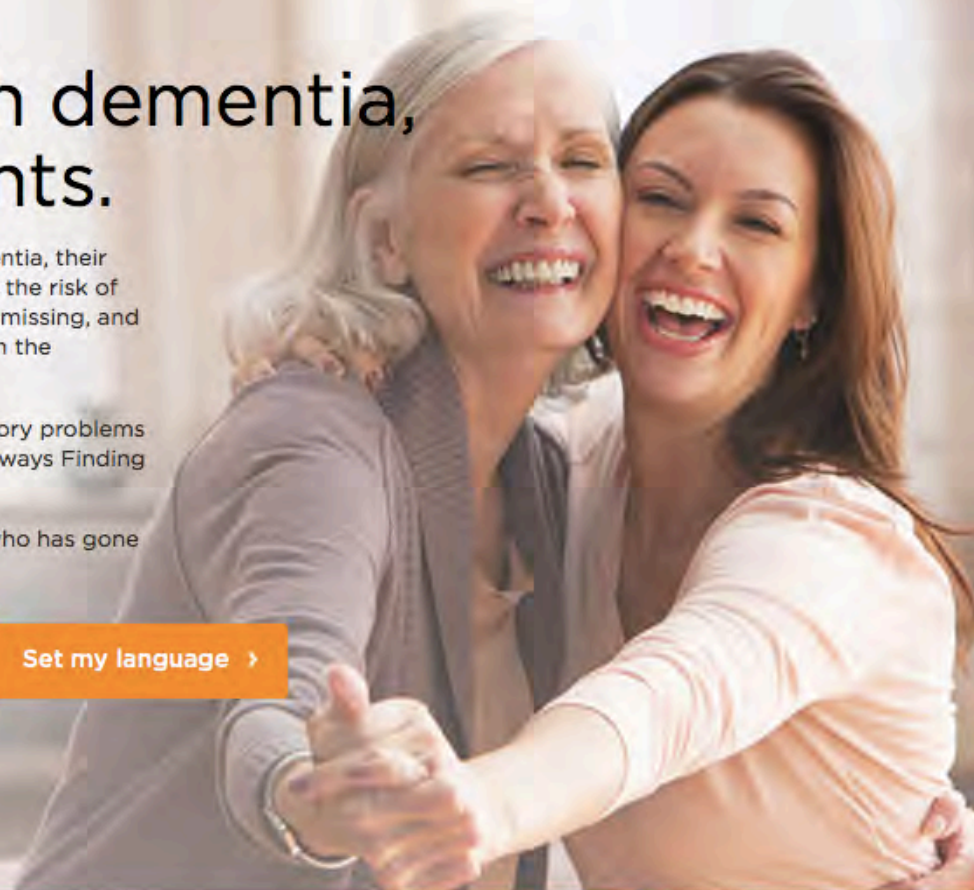
Finding Your Way[®] helps people living with dementia, their families, caregivers and communities to recognize the risk of going missing, be prepared for incidents of going missing, and ensure that people with dementia can live safely in the community.

60 percent of people with dementia-related memory problems become lost at some point. Below, we outline the ways Finding Your Way can help.

Important: If you know someone with dementia who has gone missing, please call **911 immediately**.

[Download the new Resource Guide! >](#)

[Set my language >](#)



2016 Locating Technology Forum

Neurodegenerative Disease Management



- Programs such as Finding Your Way® increase awareness about the risk of missing person events.
- An evidence-based guideline of strategies co-developed with stakeholder to manage critical wandering would enable care partners to make informed decisions when choosing interventions, and will provide a basis for tailoring a specialized program of care.

UPDATED: Missing vulnerable Richmond Hill senior found safe

Honorito Sanson, 78, may have been be confused, police say

NEWS Apr 17, 2020 by Lisa Queen Richmond Hill Liberal

KITCHENER News

Missing man with dementia found thanks to Project Lifesaver: police

Two years after Shin Noh disappeared, Coquitlalm family seeks answers

JEREMY DEUTSCH, TRI-CITIES NOW 09.10.2015 |



Missing Burlington senior located in Fort Erie

Police in London, Ont., seek public's assistance in locating missing 84-year-old man



BY ANDREW GRAHAM · SBO CPPL

Posted April 27, 2020 4:27 pm

Human remains found in Mulmur Township confirmed to be missing Caledon senior

Northumberland OPP continue search for missing elderly woman in Roseneath

UPDATE: Senior missing in freezing, snowy weather in Toronto found

Man, 82, found alive near airport during heavy snowfall

What are the stats?

Percentage and trend of missing persons calls that are persons with dementia

Region	Range	Frequency	Trend
North	30-50% of missing persons calls	N/A	Drastic increase
East	30-50% of missing persons calls	N/A	Steadily increasing
South Central	27-33% of missing persons calls	N/A	>1% increase per year
South West	10% of missing persons calls	N/A	Steadily increasing
Central	30-50% of missing persons calls	2-3 calls/ 12 hour shift	Increased. One department has doubled within the last 5 years
Toronto	N/A	5-7 calls/ 24 hours	Increased slightly

Is the prevalence underestimated?

People with Dementia Who Go Missing: A Qualitative Study of Family Caregivers Decision to Report Incidents to the Police

Karen Shalev Greene*, Charlotte L. Clarke**, Francis Pakes and
Lucy Holmes***

Abstract Walking and exercising are an important part of living well with dementia. People with dementia may have an inability to recognize familiar places, find a familiar location, or become disoriented and are more likely to become missing. The aim of this article is to identify what factors influence family caregivers of people with dementia reporting them missing to the police. We used a qualitative approach based on semi-structured interviews of 12 family caregivers of people with dementia in UK. We identify four factors that inhibit family caregivers from reporting a missing person incident to the police and three factors that prompt family caregivers to call the police. We discuss implications for improved policy and practices by law enforcement agencies, social services, health services, and non-government organizations.

Why are so few reporting these cases to the police?

- Feeling of embarrassment and guilt
- Fear of disapproval or judgement by the police
- Fear of negative reactions by the person with dementia
- Distrust of police and desire to protect their relative

Lived experiences

Do you have any experiences related to someone with dementia that “wandered” or was lost and went missing

How does this topic make you feel?

What are the causes?



What are the risks of getting lost?

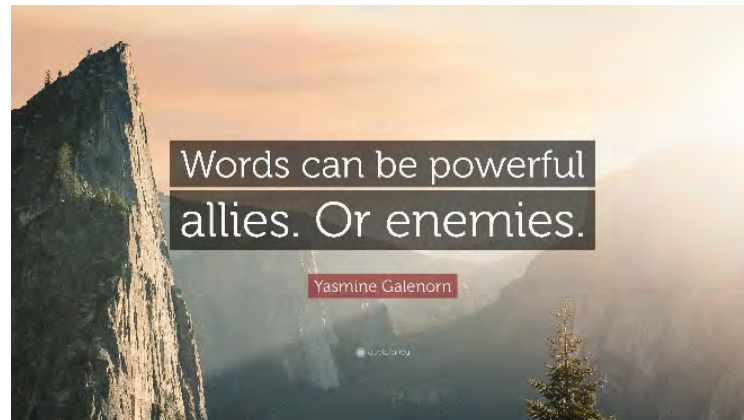




What are the risks
of restricting
wandering?

Wandering terminology: To use or not to use?

- Challenge assumption that dementia-related wandering is “aimless behavior”
- Confusion between “wandering” and “getting lost”
→ *critical wandering*
- Stigma attached to using “wandering” around the world → *wayfinding*



From restricting to promoting safe wandering

“Any human being wants to go for a walk and doesn’t just want to sit still. No one wants to be trapped inside. It’s not that you’re exit seeking, you just want the freedom to go and do whatever you want to.”

- *Occupational Therapist*

“We assume they’re not sleeping but maybe their past job was a night supervisor. Sometimes they are in their mind reliving their past when we see them moving around. We need to try to identify what that could be.”

- *Registered Nurse*



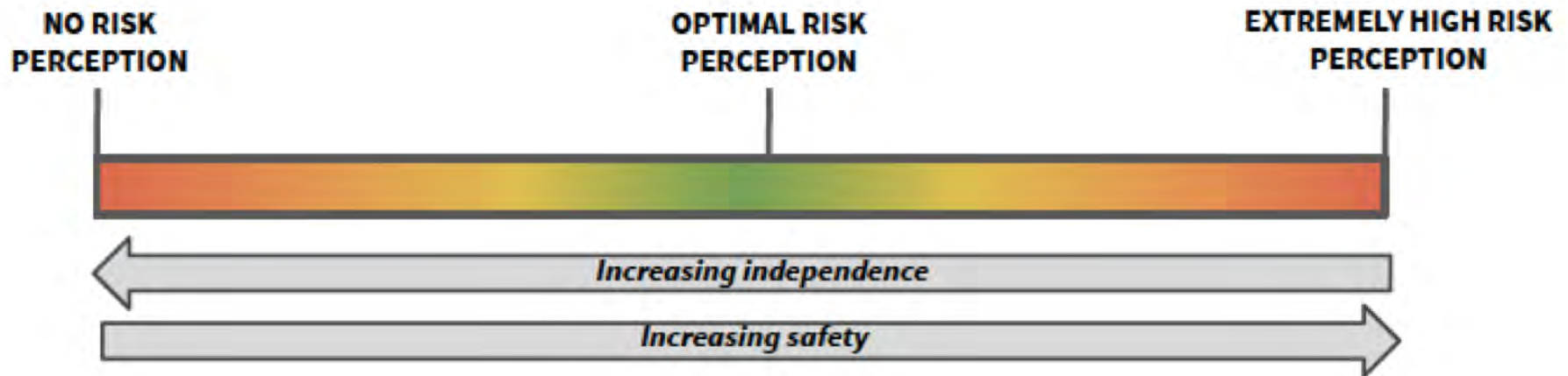
From restricting to promoting safe wandering

“Sometimes I like to walk out and about aimlessly. I’m just happy to be outside. At times though I forget where I am and that’s when I start to panic.”

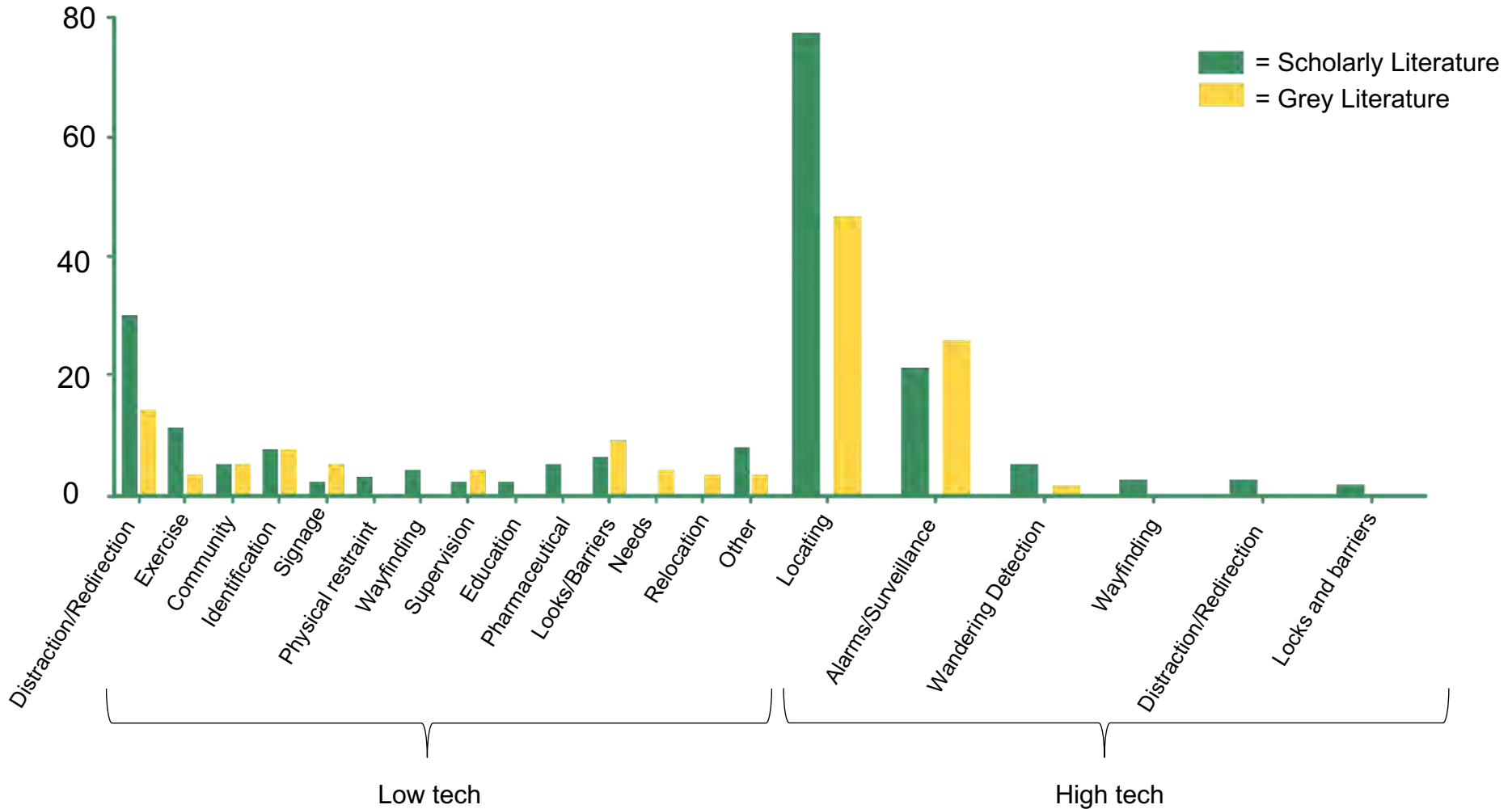
- *Person Living with Dementia*



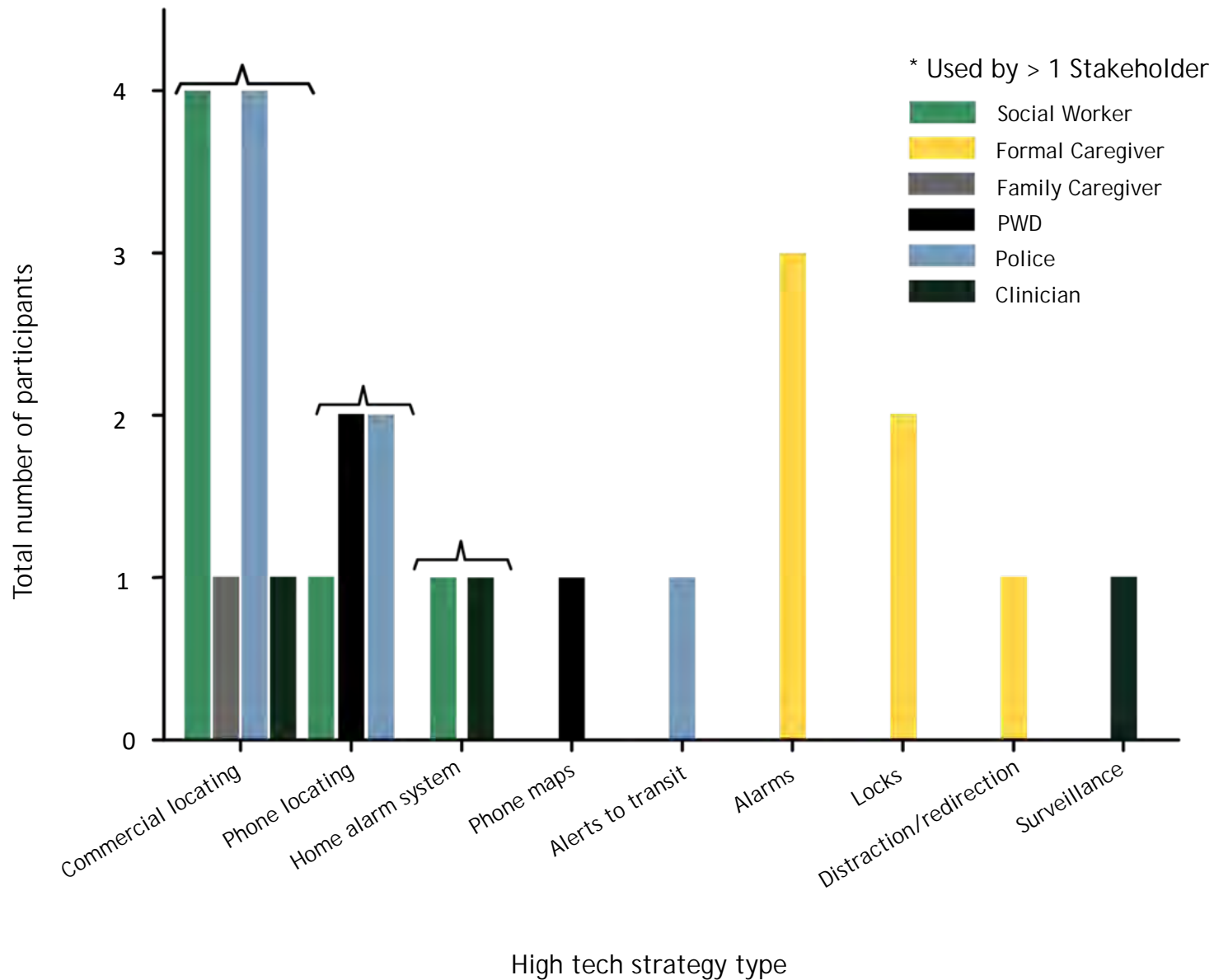
Goldilocks Principle on Dementia and Wayfinding



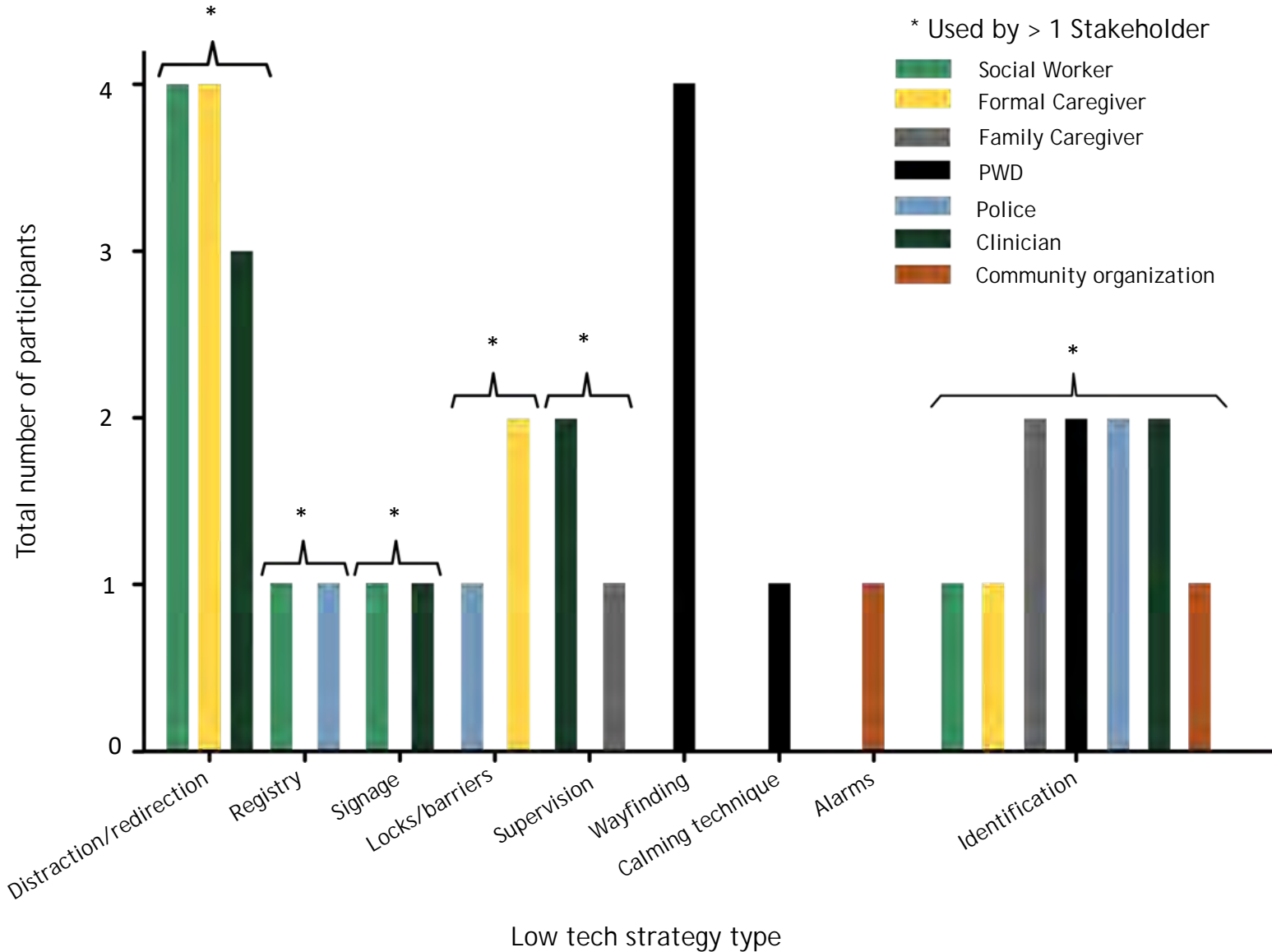
Number of wander management strategies that were high (n=183) and low (n=142) tech



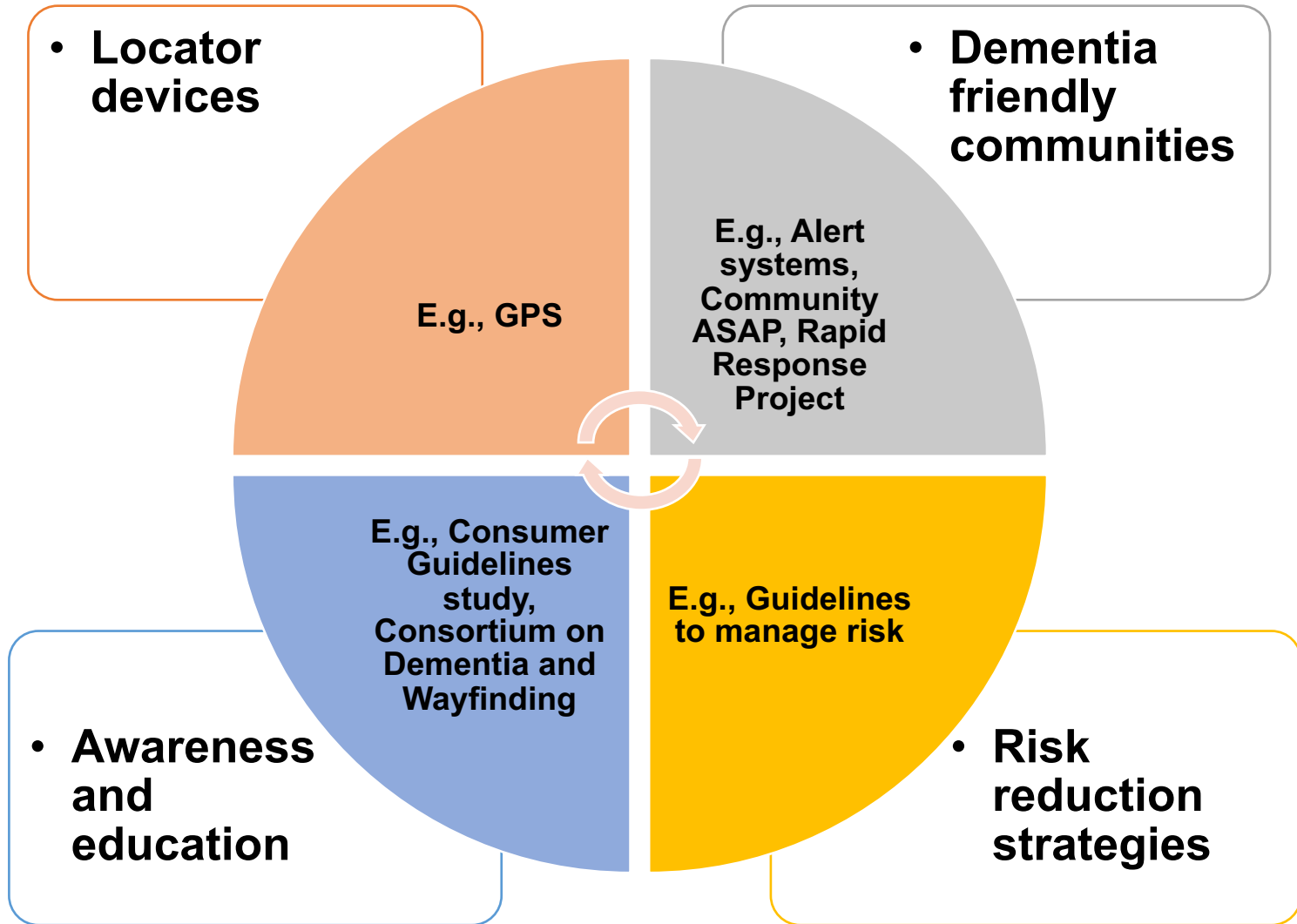
Wander-management high tech strategies used among stakeholders.



Wander-management low tech strategies used among stakeholders.

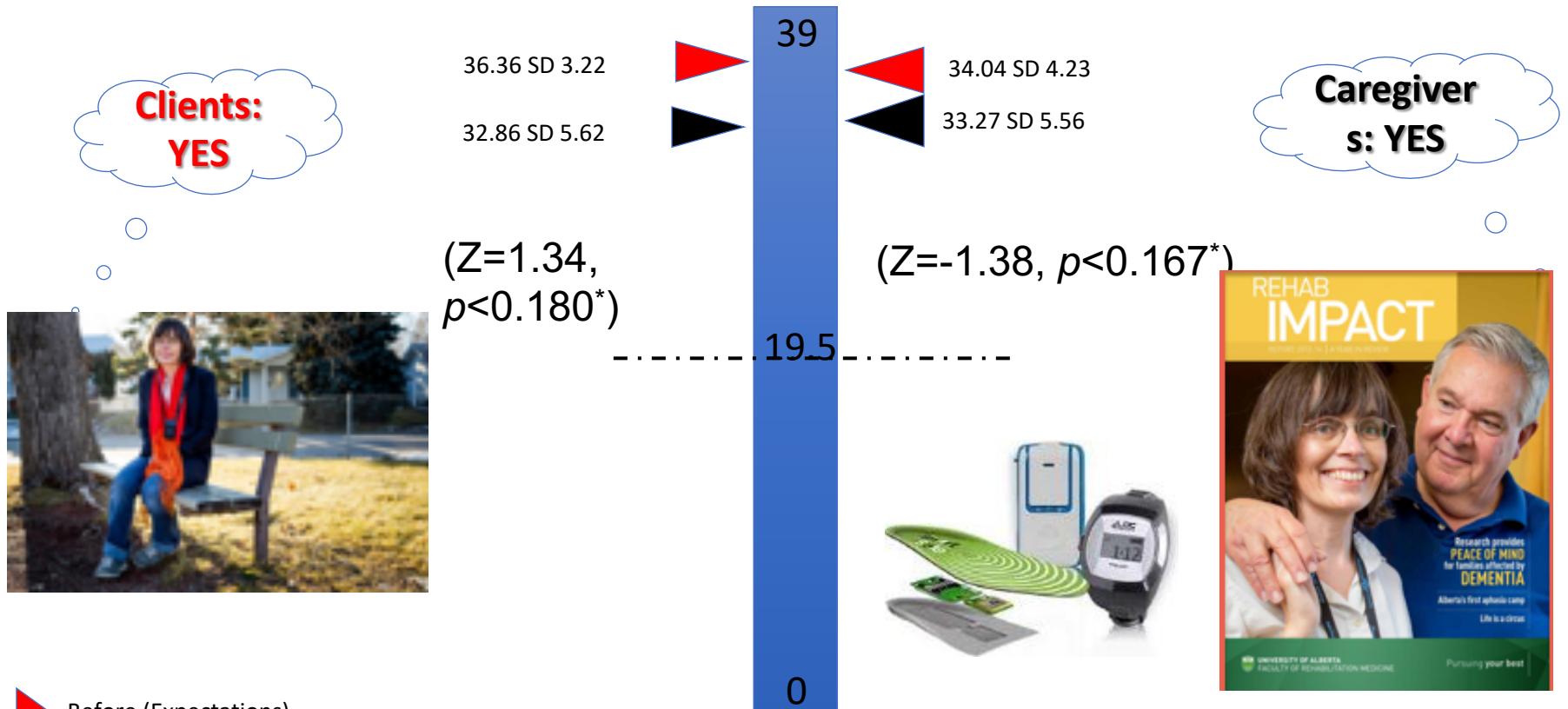


Approaches to address the issue



GPS locator device study

Dyads' expectations about GPS device met?



▶ Before (Expectations)

◀ After (Actual use)

* Wilcoxon signed-rank pairs test statistics

Participant feedback:

It gave freedom and peace of mind

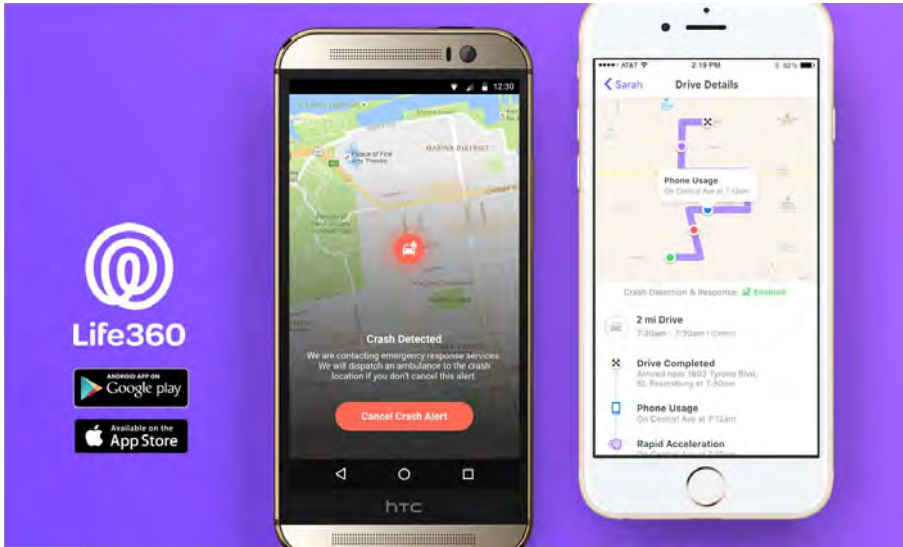
Provided a sense of security



Gave me comfort to know where he was at all the time

Peace of mind that if he got mixed up or lost that we would have a way of locating him





Technology Products Repository



[VIEW PRODUCTS](#)

[ADMIN/VENDOR ACCESS](#)

Products List

Search



PrimeMobile™
SafeTracks GPS Canada Inc.

[VIEW](#) [+ COMPARE](#)



BlueBeacon™
SafeTracks GPS Canada Inc.
(SafeTracks™)

[VIEW](#) [+ COMPARE](#)



**S911 Lola Mobile Personal
Emergency Response
System**
Laipac Technology Inc.

[VIEW](#) [+ COMPARE](#)



GoSafe
Philips Lifeline

[VIEW](#) [+ COMPARE](#)



**GPS Guardian Connect
Integrated with MedicAlert**
MedicAlert Foundation Canada

[VIEW](#) [+ COMPARE](#)



Helpline: At Home System
Nortek/Linear

[VIEW](#) [+ COMPARE](#)

Alarms and surveillance



Distraction/redirection



Distraction/redirection



Be prepared for a lost event

Alzheimer
Society
ONTARIO



Search is an emergency
DO NOT DELAY
Call 911 if a person living
with dementia is missing

IDENTIFICATION FORM

1 BASIC INFORMATION

First name:	Last name:	
Former last name(s):		
Nickname(s) - please circle those preferred:		
Address:		
City:	Postal:	
Phone #:	Cell #:	
Date of birth:	Sex:	Ethnicity:
Language(s) spoken - please list and indicate first language:		
Birthplace - address if possible/known:		
Current living arrangements:		
<input type="checkbox"/> Alone <input type="checkbox"/> With family <input type="checkbox"/> Facility <input type="checkbox"/> Other (please describe):		

2 APPEARANCE & PHYSICAL DESCRIPTION

Height:	Weight:	Shoe size:
Eye colour:	Hair colour:	
Hair style (i.e. curly, straight, bangs, etc.):		
Facial hair (describe the style if applicable):		
Complexion:	Dominant hand: <input type="checkbox"/> Left <input type="checkbox"/> Right	
Distinguishing features - please check all that apply and provide further details:		
<input type="checkbox"/> Scars <input type="checkbox"/> Tattoos <input type="checkbox"/> None <input type="checkbox"/> Other:		
Speech habits/idiosyncrasies (i.e. accent, talks with a stutter, etc.):		



When a person with dementia goes missing

Take a deep breath and try to stay as calm as you can even though it is not easy. You are not alone. Others are there to help you. Going through this checklist will help you bring the person with dementia home quickly and safely.

Call the police – 911 – search is an emergency – DO NOT DELAY!

1. Immediately tell police that the person has dementia.
2. Try to get a sense of how long since you last saw the person.
3. Give police the **information** you have assembled in the “**Identification Kit**” – including a recent photograph.
4. Let the police know about any medical conditions or medications the person is taking.
5. Tell the police where you think the person may go.
6. Let them know if the person is registered with any registry program such as **MedicAlert® Safely Home®**, **Project Lifesaver®** or has any **identification or locating devices** on them.

Mobilize support

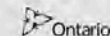
1. Make sure someone stays at home in case the person returns on their own.
2. Alert friends, family and neighbours that the person is missing.



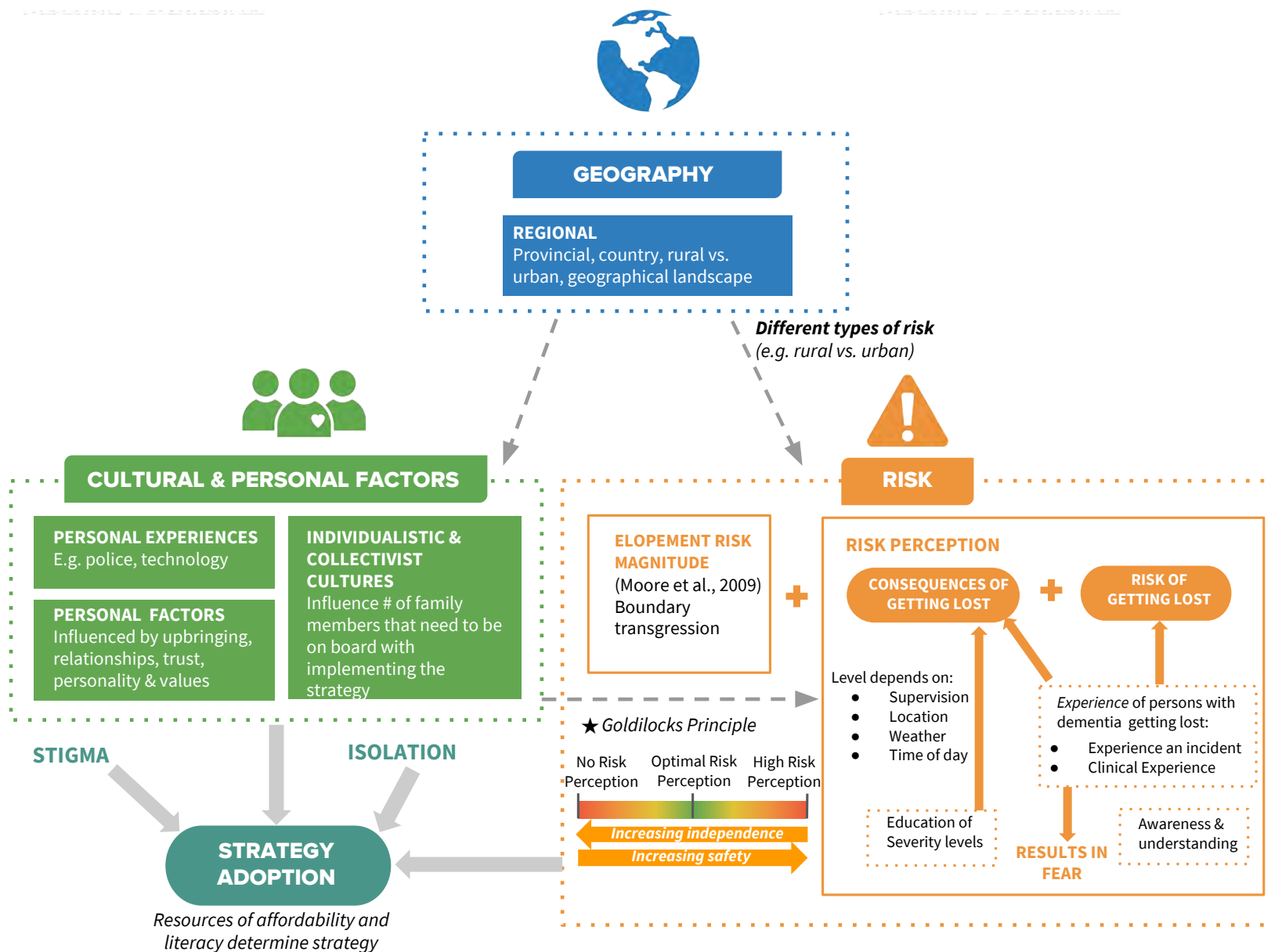
For local Alzheimer Society contact information, call 2-1-1
Visit: FindingYourWayOntario.ca

www.alzheimersociety.org









Funded by



Conceptual model



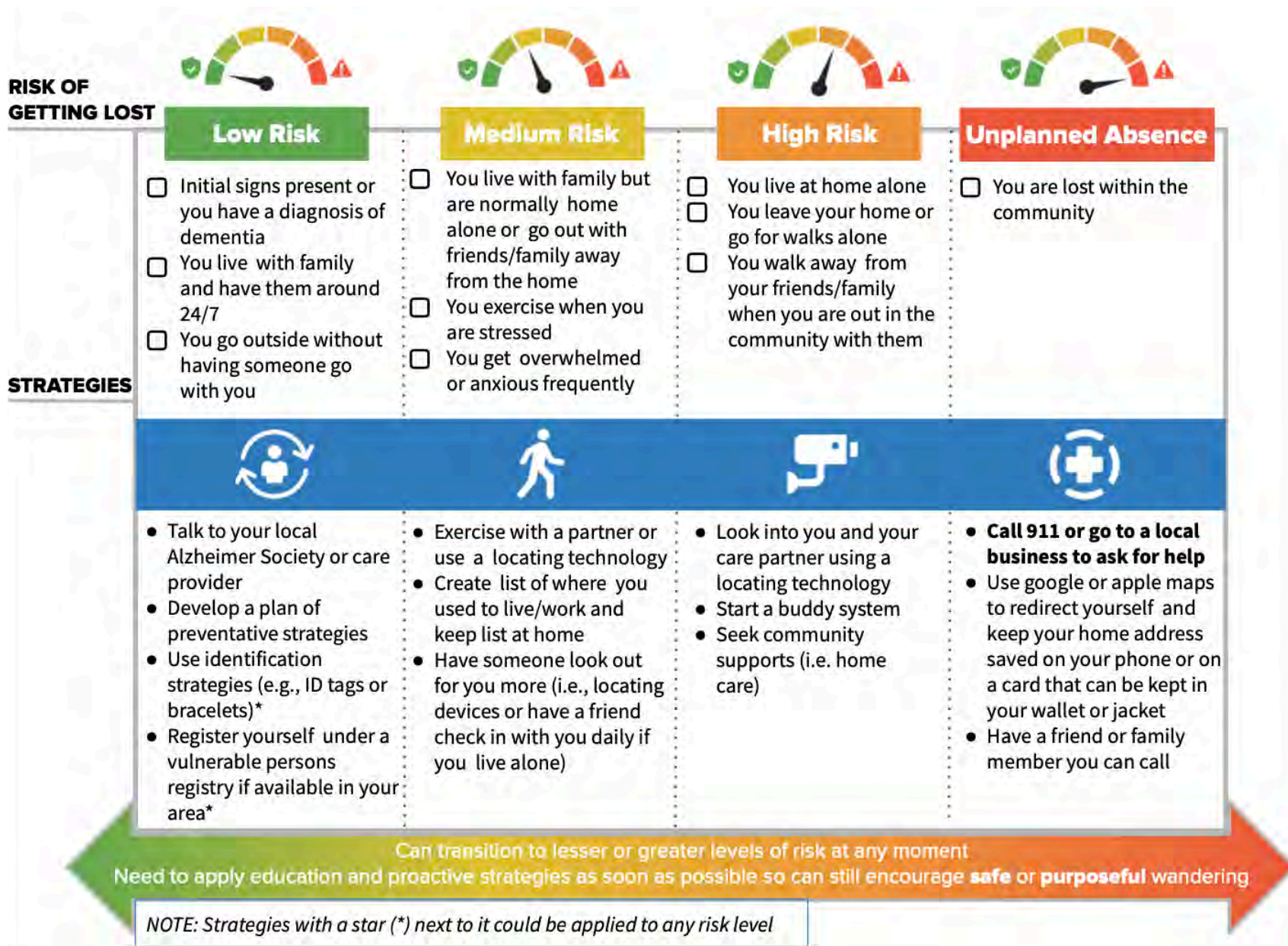
Canadian Guideline for Safe Wandering: Community Version

	 Low Risk	 Medium Risk	 High Risk	 Unplanned Absence
RISK OF GETTING LOST	<ul style="list-style-type: none"> <input type="checkbox"/> Initial signs present or diagnosis of dementia <input type="checkbox"/> No history of getting lost <input type="checkbox"/> Lives with family and is supervised 24/7 <input type="checkbox"/> No interest in going outside home without having someone accompany them 	<ul style="list-style-type: none"> <input type="checkbox"/> Limited supervision at home <input type="checkbox"/> History of exercising as a means of alleviating stress <input type="checkbox"/> Regularly engages in outdoor/community activities <input type="checkbox"/> Becomes frequently overwhelmed or anxious <input type="checkbox"/> At a stage where identify themselves in their earlier years. Talks of going to work or wanting to go home <input type="checkbox"/> Regularly states intent to leave home 	<ul style="list-style-type: none"> <input type="checkbox"/> Regularly goes for walks alone <input type="checkbox"/> Lives at home alone <input type="checkbox"/> In the later stages of dementia, they may frequently walk away from care partner when out in the community <input type="checkbox"/> Pattern of preparing to go outside (i.e., putting coat and shoes on, grabs bag/purse) 	<ul style="list-style-type: none"> <input type="checkbox"/> Lost within the community <input type="checkbox"/> Is missing, has eloped, has lost one's way exterior to care
STRATEGIES	 <ul style="list-style-type: none"> • Education and awareness • Developing a plan of preventative strategies • Talk to physician ASAP • Watch for signals seen in medium and high risk • Register under a vulnerable persons registry if available* • Identification strategies (e.g., ID tags/ bracelets/kit)* 	 <ul style="list-style-type: none"> • Distraction/redirection strategies • Exercise with a partner or use a locating technology • Add list of where used to live/work • Increased supervision (i.e., day programs, locating devices or buddy system for those that live alone) 	 <ul style="list-style-type: none"> • Locating technologies • Alarms/surveillance • Locks and barriers • Buddy system • Seek community supports (i.e. home care) • Relocation 	 <ul style="list-style-type: none"> • Call 911 immediately • Search and rescue methods • Community involvement,

← Can transition to lesser or greater levels of risk at any moment
 Need to apply education and proactive strategies as soon as possible so can still encourage **safe** wandering →

NOTE: Strategies with a star () next to it could be applied to any risk level*

Canadian Guideline for Safe Wandering: PWD Version



List of available strategies

Low Risk

- Keep a list of people to call on for help
- Education and awareness
- Finding Your Way Program (<https://findingyourwayontario.ca>)
- Alzheimer Society (<https://alzheimer.ca/en/on>)
- Register participant with Vulnerable Person Registry (if available) or with an identification program
- MedicAlert (<https://www.medicalert.ca>)

Medium Risk

- Distraction/redirection strategies:
- Providing meaningful activities (i.e. chores, task, ect.) or play music that they grew up to
- Install signs to assist in way-finding
- Have person with dementia exercise with a partner or use a locating technology (<https://tech.findingyourwayontario.ca>)
- Keep a list at home of the places the person with dementia used to live and work
- Increase supervision (i.e., day programs, locating devices or a buddy system for those with dementia that live alone)

High Risk

- Keep car keys out of sight
- Avoid busy places that are confusing and can cause disorientation
- Increase supervision (i.e., day programs, Tracking devices or being connected to a care worker for those that live alone)
- Install locks or alarm systems on the exit door or window to know when it is opened *Disclaimer: locks should ONLY be implemented when the care partner is at home for safety reasons such as fire risk, ect.*
- Consider locating technologies such as Commercial GPS (<https://tech.findingyourway.ontario.ca>) or GPS devices available on your phone (e.g. Find My Friend App or Google maps)
- Install door murals (painted camouflaged exit doors), place mirrors or curtain in front of the exit door
- Ensure someone has descriptors readily accessible of the person with dementia (i.e. photo, locations they like to go to, ect.)
- Place identification information on items of clothing, or objects they regularly use (i.e., walker, wallet)
- Discuss long term care options

Unplanned Absence

- Call 911 immediately DO NOT wait 24-48 hours to alert the police. The police want to know right away about the missing person even if you find them soon after. The longer you wait to call the greater the risk they are at for being found seriously injured or deceased
- Notify the community to keep a look out for the missing person

Face and content validity study

"I thought this is what we need- we needed sort of a way of guiding people through a conversation to help them decide what they need and so I was really excited about it."

- Social Worker

"When someone's first diagnosed it gives them something to take home and look at and read and process - and it helps us be proactive in our own care. I was so afraid because they were talking about me going into a facility so that created a lot of stress for me."

- Person living with dementia



General Impression of the Guideline

“The reference to technology options in the guidelines we have found positive; learnt about resources that we didn't previously know about!”

“It's very simple and easy to read. It's - it's really easy for people to use. I like the suggested strategies. They're fantastic.”



Methods of using the guideline

“That I find I’m utilizing a lot now because it's just such a handy handout to give to our care partners.”

“This is a really good tool to gauge the risk people may experience, it seems to be an option in all conversations, not just time the clients are bringing it up.”

“During our Care partner Support groups and First Link sessions we purposely presented the sheets to increase awareness...”

“...with new staff coming in, I can also see it as a training tool”

RAPID RESPONSE PROJECT

- Purpose was to develop a best police practice resource for lost persons with dementia
- Advisory committee
- Resource launched on findingyourwayontario.ca





Family and Care Partner Support & Information

Knowing the risks is important, but people living Alzheimer's and other dementias and their families can still live well in the community. If you are living with dementia, or are caring for a person with dementia, Finding Your Way® has information and resources to help you be prepared for incidents of going missing.

[Reduce the risks >](#)



First Responder Information Centre

We all have a responsibility to help people living with dementia to be safe in their community. However, first responders should be extra prepared to help. Visit our **NEW** First Responder Information Centre to learn about accessing dementia training, search programs available in Ontario, how to communicate and interact with people living with dementia and more.

[First Responder Info Centre >](#)

findingyourwayontario.ca

Push for a Silver Alert in Canada



E-1588

PETITION TO THE GOVERNMENT OF CANADA

Whereas:

- There are over 550,000 Canadians living with dementia and this number will double by 2030;
- 60% of people with Alzheimer's will wander at least once during their disease. Wandering is common as the disease progresses;
- Silver Alert is a public notification system to quickly help find seniors who wander because of Alzheimer's disease and related dementias;
- A Silver Alert would provide information to media outlets and activate an emergency alert system through law enforcement agencies; and
- The Provinces of Alberta and Manitoba have established a Silver Alert, through an amendment to their Missing Persons Amendment Act.

We, the undersigned, **citizens of Canada**, call upon the **Government of Canada** to develop a National Silver Alert strategy for all Canadian provinces and territories.

National Silver Alerts for missing persons with dementia could save lives

Recent cases in Victoria, where the missing person died, fuels support for such a system

Oct. 30. 2019 3:45 p.m. / LOCAL NEWS / NEWS

National Post View: Ontario shouldn't have shelved its plan for a 'Silver Advisory' system

A public alert system would make it possible for more seniors to live at home with their families, rather than in institutions

Manitoba MLA to table bill calling for Silver Alert to help find missing seniors

System for seniors modelled off of Amber Alert to find abducted children

Erin Brohman · CBC News · Posted: Mar 02, 2017 5:00 AM CT | Last Updated: March 2, 2017

U.S. has Silver Alert for missing seniors -- why not Canada?

BY NEWS STAFF

POSTED APR 5, 2016 1:06 PM EDT LAST UPDATED APR 5, 2016 AT 1:13 PM EDT

change.org

Start a petition My petitions Browse Membership



Create a Silver Alert system to help find vulnerable people


12,922 have signed. Let's get to 15,000!



Alert Systems

C-ASAP

Missing Person Details



John Doe
Johnny

Reported Missing

Details

Reported missing at: 9:47 a.m.
8205 114 St NW Edmonton AB

Seen John Doe? Call 911



**Purple
Alert**



Purpose: To identify the concerns associated with release of personal information in Community ASAP.



Interviewed: Persons living with dementia, care partners, service providers, first responders, industry members.

Highlights of findings:

Disclosure of personal information puts people at risk of being taken advantage of.

The risk is that the volunteers would prey upon this person if he/she is found and returned home, identified to have dementia. They are already vulnerable to scammers, to people who would be able to redirect them and take advantage of them. (Service provider 1)

Privacy may be comprised, and in turn, autonomy too.

I was tired of people almost panicking about where I was and what I was doing. It was like I had no privacy anymore, and our privacy needs to be respected. We're still humans. And yes maybe at 80 your privacy should be a little less important, but for the younger onset it's a huge importance. (Person living with dementia 12)



Release of information may result in stigma.

There is stigma around it. So even if when the person is found, the story it's a happy ending... that disclosure has happened, that they are living with dementia, and so people talk. (Service provider 17)

Permanency of data released in the public realm.

Do I want my data out there and it's forever out there, so after I pass away my data still gonna be around there? (Service provider 17)

*One person with dementia is one person with dementia.
(Service provider 2)*

Ultimately, “**safety** trumps privacy”.

Release whatever it takes to find them. (Person living with dementia 3)

I don't have concerns because safety trumps privacy...bring her (home) safe. (Care partner 15)

Yet, different stakeholders have a varying perspectives on the balance between safety and privacy.

Authentic, ongoing consent is paramount.



International Consortium on Dementia and Wayfinding



Calgary February
2019



Edinburgh March 2019



Liverpool July 2019

- Persons living with dementia
- Care partners
- Industry
- Researchers
- Academics
- Students
- Community organizations (Alzheimer associations)
- Health professionals
- First responders (police, search & rescue)

Current consortium members



ICDW Summer Series 2020

Thursdays at 10am EST from **June 18 – July 30, 2020**

- **June 18:** ICDW intro and networking
- **June 25:** Policing perspective
- **July 2:** Technology perspective
- **July 9:** Lived experience – PWD
- **July 16:** Lived experience – Care partners
- **July 23:** Research perspective
- **July 30:** Final discussion and networking



Website: <http://icdw.org>

Recommendations

1. More research on the effectiveness of wander-management strategies
2. Awareness campaigns that emphasize the shared lived experiences of involved stakeholders
3. Shift away from reactive strategies to mitigate the risks associated with getting lost
4. Integrate tailored strategies addressing the factors highlighted in the conceptual model
5. Prioritize knowledge translation practices that transcend beyond traditional academic strategies

Next steps



Proposed AGE-WELL 2.0 Projects

How to get involved

- Participate in the online silver alert forum
- Join the International Consortium on Dementia and Wayfinding
- Join a Community Advisory Committee
- Sign up for one of our studies



CONTACT INFORMATION

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