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# Caring for People with Dementia who Wander in the Community

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With thanks to Professor Elizabeth Beattie



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## In this presentation

- Provide an overview of dementia-related wandering in the context of the community
- Discuss the outcomes associated with wandering
- Discuss findings of our literature review exploring interventions to promote safe walking for people with dementia in the community
- Discuss some recommendations for practice
- Launch the Walking Safely e-learning module

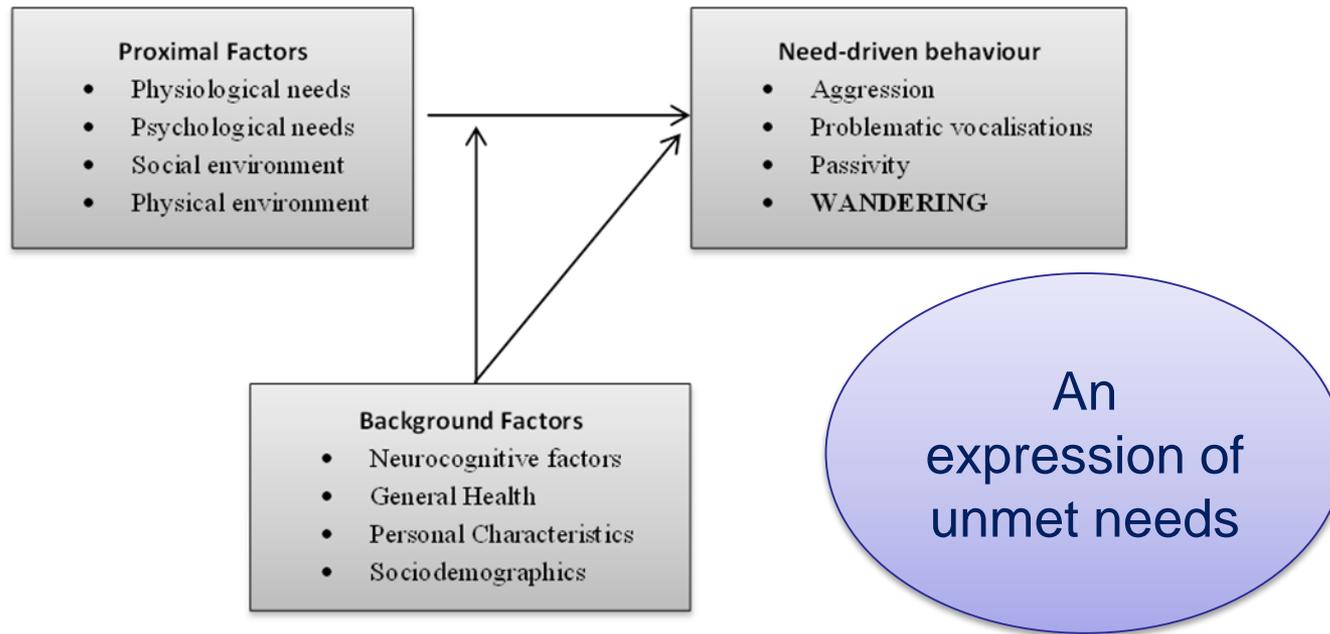


## Dementia-related wandering

*'A syndrome of dementia-related locomotion behaviour having **frequent, repetitive, temporally-disordered** and/or **spatially-disorientated** nature that is manifested in **lapping, random and/or pacing patterns**, some of which are **associated with eloping, eloping attempts or getting lost unless accompanied.**'*  
(Algase et al., 2007. p.696)



# Need Driven Dementia Compromised Behaviour Model (Algase et al., 1996)





# Who is more likely to wander?

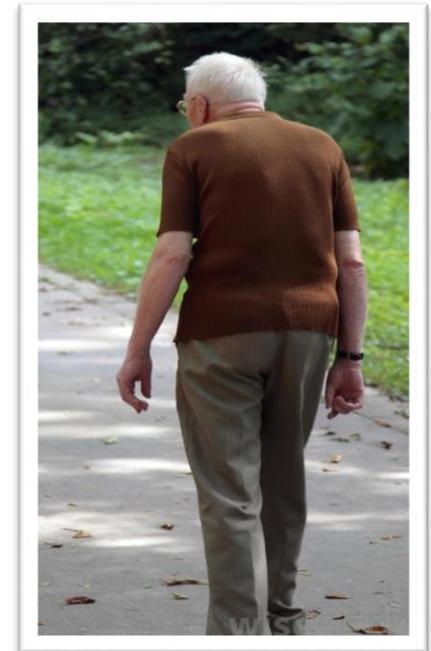
People with dementia who have:

- More sleep disturbances
- Extraverted personality
- Diagnosis of Alzheimer's disease
- More advanced dementia

Also:

- Relatively younger men
- Independent mobility

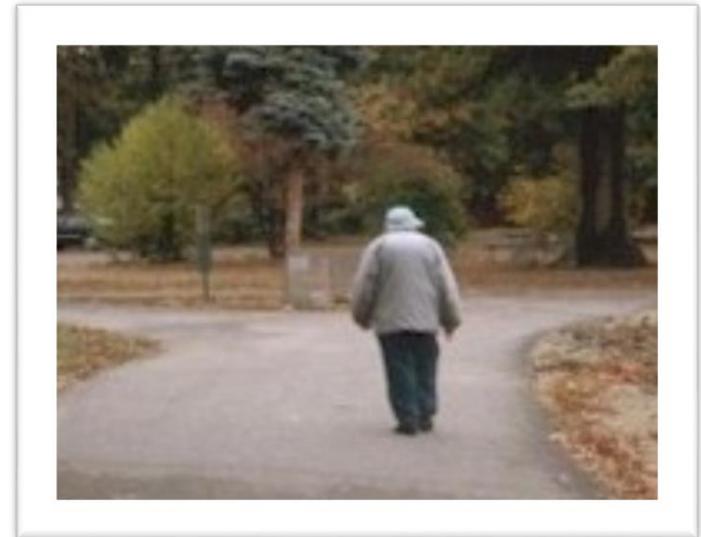
**However first wandering event can occur in early dementia**





# Wandering in the community

- **Prevalence**
  - Klein et al., 1999: **17.4%** (n=638)
  - Logsdon et al., 1998: 24% had wandered but not in the past year; 12% wandered regularly (n=193)
  - Nagaratnam et al., 1998: 27% (n=90)
  - Hope et al., 1994: **63%** (n=104)
- **Characteristics** (Hope, 2001) (n=104)
  - Increased walking (16%)
  - Attempting to leave home (10%)
  - Being brought back home (13%)
  - Trailing (14%)
  - Checking (14%)
  - Aimless walking (21%)
  - Pottering (19%)
  - Inappropriate excessive walking (10%)





## Outcomes associated with wandering

Characteristic of wandering	Impact on person with dementia who wanders
<ul style="list-style-type: none"> <li>Persistent repetitive walking</li> </ul>	<ul style="list-style-type: none"> <li>Malnutrition/dehydration, exhaustion, weight loss, increased risk of falls</li> </ul>
<ul style="list-style-type: none"> <li>Ineffective patterns of ambulation</li> </ul>	<ul style="list-style-type: none"> <li>May never achieve goal → frustration, incontinence, becoming lost in familiar places</li> </ul>
<ul style="list-style-type: none"> <li>Walk day and night</li> </ul>	<ul style="list-style-type: none"> <li>Sleep deprivation/exhaustion, disturb others</li> </ul>
<ul style="list-style-type: none"> <li>Meal time impulsivity – repeatedly leaving the dinner table</li> </ul>	<ul style="list-style-type: none"> <li>Malnutrition/dehydration, weight loss</li> </ul>
<ul style="list-style-type: none"> <li>Spatial disorientation/ eloping behaviour</li> </ul>	<ul style="list-style-type: none"> <li>Become lost if unsupervised, death</li> </ul>



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## Risky Wandering

= Walking beyond safe limits



Target of interventions



Promote safe walking



# Identify the risks of Wandering

## Revised Algase Wandering Scale (RAWS)

- Two versions of RAWS
  - Long Term Care
  - Community Version

## The Revised Algase Wandering Scale-Community Version (RAWS-CV)

- Measures
  - Type and frequency of wandering behaviour
  - Manifestations of the behaviour → potential for adverse outcomes

# RAWS-CV

Consists of 39 items with 6 subscales:

Persistent Walking (14 items)

Repetitive Walking (7 items)

Eloping Behaviour (8 items)

Spatial Disorientation (4 items)

Negative Outcomes (4 items)

Mealtime Impulsivity (2 items)

## Revised Algae Wandering Scale (RAWS) – Community Version

Please circle the number beside the statement which best describes your family member's current ability or behaviour. Use the following scale: 1=never or unable; 2=seldom; 3=sometimes; 4=usually; 5=always.

	1 Never/ unable	2 Seldom	3 Sometimes	4 Usually	5 Always
<b>A. Persistent Walking (PW)</b>					
1. He/she does a lot of spontaneous walking.	1	2	3	4	5
2. He/she goes to many different places while walking.	1	2	3	4	5
3. He/she gets up and walks during the night.	1	2	3	4	5
4. He/she walks around restlessly.	1	2	3	4	5
5. He/she walks around between awakening and breakfast.	1	2	3	4	5
6. He/she walks about aimlessly.	1	2	3	4	5
7. He/she travels many different routes while walking.	1	2	3	4	5
8. He/she walks around between lunch and dinner.	1	2	3	4	5
9. He/she often changes direction or course while walking.	1	2	3	4	5
10. He/she walks around between breakfast and lunch.	1	2	3	4	5
11. He/she walks for an odd or inappropriate reason.	1	2	3	4	5
12. He/she walks around between dinner and bedtime.	1	2	3	4	5
13. He/she walks without an apparent destination.	1	2	3	4	5
14. He/she walks during inappropriate times.	1	2	3	4	5
<b>B. Repetitive Walking (RW)</b>					
15. He/she walks intensely between two places.	1	2	3	4	5
16. He/she paces up and down.	1	2	3	4	5
17. He/she walks back and forth between two places in a repetitive way.	1	2	3	4	5
18. He/she walks in one continuous direction.	1	2	3	4	5
19. He/she goes repeatedly to the same location(s) while walking.	1	2	3	4	5
20. He/she repeatedly travels the same route while walking.	1	2	3	4	5
21. He/she walks in a continuous route, as if on a track.	1	2	3	4	5
<b>C. Eloping Behavior (EB)</b>					
22. He/she runs off.	1	2	3	4	5
23. While walking alone, he/she walks beyond intended destination.	1	2	3	4	5
24. He/she attempts to go outside.	1	2	3	4	5
25. He/she stands at the outdoor wanting to go out.	1	2	3	4	5
26. He/she attempts to find or go to familiar locations, even unrealistic ones.	1	2	3	4	5
27. He/she attempts to leave his/her own area.	1	2	3	4	5
28. He/she gets lost outside the house.	1	2	3	4	5
29. He/she enters private or unauthorized areas.	1	2	3	4	5
<b>D. Spatial Disorientation (SD)</b>					
30. He/she cannot locate own room without help.	1	2	3	4	5
31. He/she cannot locate bathroom without help.	1	2	3	4	5
32. He/she gets lost inside the house.	1	2	3	4	5
33. He/she cannot locate dining room without help.	1	2	3	4	5
<b>E. Negative Outcomes (NO)</b>					
34. While walking alone, he/she has fallen down.	1	2	3	4	5
35. He/she has been found with some major injury.	1	2	3	4	5
36. He/she has been found with some minor injury.	1	2	3	4	5
37. While walking alone, he/she bumps into obstacles or other people.	1	2	3	4	5
<b>F. Mealtime Impulsivity (MI)</b>					
38. He/she walks off during meals.	1	2	3	4	5
39. During meals, he/she tries to leave the table or walks away.	1	2	3	4	5

40. He/she is a wanderer.
1. Definitely not ( )
  2. At times ( )
  3. Yes, but it is not a problem ( )
  4. Yes, and it is a problem ( )



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# What carers have told us about managing wandering in the community

Study Aim:

1. Explore the carers experience of caring for a person with dementia who wanders in the community
2. Examine strategies used to manage wandering

Interviewed 30 carers of people with dementia who wander and live at home.

*Investigators: Prof. Elizabeth Beattie, Dr. Margaret MacAndrew, Ms. Hazel Bucher, Dr. Christine Stirling, Dr. Marguerite Bramble*

## Negative outcomes of wandering – Part A care recipient

For person with dementia (yes response)	Frequency (%)
Has become lost while walking (n=26)	17 (65%)
Has been returned home by others who were concerned (n=28)	16 (57%)
Others have had to search for PwD (n=28)	10 (36%)
Problems sitting at the table for meals (n=28)	6 (21%)
Has had a fall (n=28)	9 (32%)
Has broken a bone due to a fall (n=27)	7 (26%)
Is anxious about going outside alone (n=28)	11 (39%)
Is anxious they will not be able to find his/her way back home (n=27)	9 (33%)
Feels they are not as capable as they were (n=28)	19 (68%)
Feel that the relationships they had with others has changed in some way (n=28)	22 (79%)

## Negative outcomes of wandering-Part B carer

For the carer (yes response)	Frequency (%)
Increased anxiety and concern for your relative (n=27)	25 (93%)
Concern that they may not be able to cope in the future if the behaviour worsens (n=27)	24 (89%)
Criticism from family and friends about how you are managing the situation (n=26)	8 (31%)
Negative changes in how family and friends relate to you and the person you care for (n=26)	11 (42%)
Sleep issues related to anxiety (n=26)	17 (65%)
Sleep issues related to the night walking habits of the person you care for (n=26)	16 (62%)
Day time fatigue related to loss of sleep (n=26)	18 (69%)
Reduced social activity outside the home (n=26)	22 (85%)
Inability to take a holiday away from home (n=26)	21 (81%)
Feeling of sadness or depression (n=26)	20 (77%)
Feeling of resentment (n=26)	13 (50%)



# Strategies used

- Provided constant supervision
- Received help to maintain surveillance
- Walked with the person with dementia
- Used removable devices to block access to areas
- Moved furniture to block access to areas Locked or blocked doors
- ID bracelet
- Used alarm system, GPS tracking
- Used a surveillance system
- Restricted movement using external measures

Containment  
Engagement



## The stories fueling their fear

“The police bought her back twice and the vice principal from the school over here bought her back another time.”

“You *don't know what's gonna happen to her* and you wonder *who is she gonna end up with.*”

“Ah well, uhm, left the door open and she'd vanished and showed up with one of the neighbors I think the first time.”



## Act to minimise risk

“It is after she has kept getting up and I have kept telling her not to get up. She has done it about five times. In the end, I have *just tied her up* so maybe between one and two hours...”

“.....at night time we secure the place and there’s *no way out*, normally.”

“I’ve got to take him up there, give him directions as he goes - he can’t find the toilet or the bedroom or anything like that.”

“In the night I *give her a sleeping tablet*. ... For seven hours it [works]. Usually she doesn't call before four in the morning.”

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# Running out of options

- Dedicated to keep person with dementia at home as long as possible
- Belief that becoming lost is inevitable
- Impossible to always be there
- Not sure what to do next
- Going to aged care is inevitable
- I've tried everything



## Reports of becoming lost in the news

- Review of newspaper articles reporting a person with dementia as missing (2011-2016)
- 130 reported cases of people with dementia in Australia becoming lost.

**Table 1. Gender by outcome for cases where people were found (n=92).**

Gender	Found Well	Found Injured or Unwell	Found deceased	Total
Male	65% (43)	12% (8)	23% (15)	66
Female	46% (12)	38% (10)	15% (4)	26

Investigators: Dr Schnitker, Dr MacAndrew, Ms Shepherd, Prof Beattie



# Where people went missing from

**Table 2.** Location from where the person went missing. N=92

Where missing from	No. found	Found alive	Found deceased
Home	43	33	10
Aged care facility	26	22	4
Holiday place	3	2	1
Hospital	7	4	3
Visiting	3	3	0
Shops or market	1	1	0
Not stated	9	8	1
<b>Total</b>	<b>92</b>	<b>73</b>	<b>19</b>



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# What is the current state of evidence about strategies to manage wandering in the community?





## Why a review was needed

- Focused mainly on people living in RACFs
- No updates since 2009
- Previous reviews inconclusive → ????  
Effectiveness of non-pharmacological interventions to reduce risky wandering not known → few evidence based resources to help community dwelling carers
- Aim: *What is the current evidence around the use of Non-Pharm interventions to reduce risky aspects of wandering?*

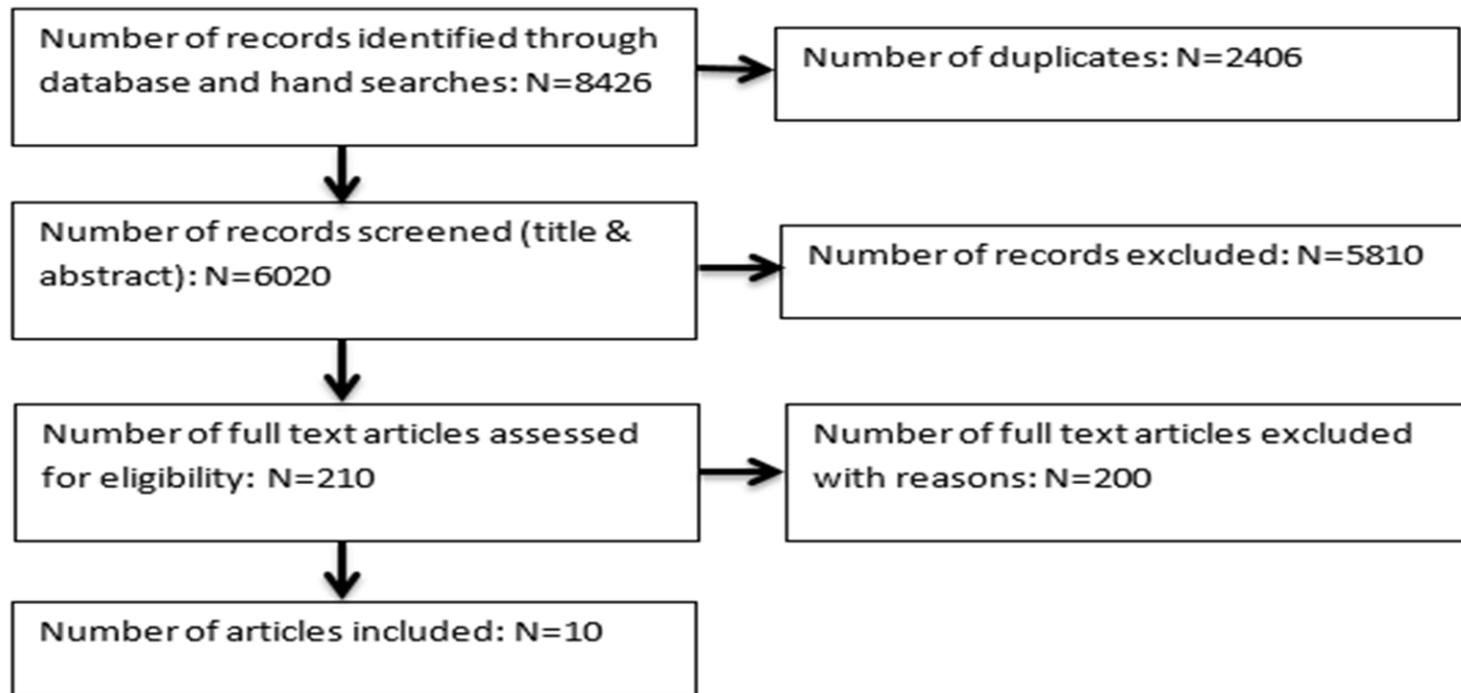


# Inclusion Criteria

- *Participants:* any type or severity of dementia, living in the community, exhibiting wandering behaviour or at risk of outcomes associated with wandering behaviour
- *Interventions:* non-pharmacological interventions aimed to reduce characteristics of wandering
- *Studies:* any type of study design reporting quantitative data on relevant outcomes
- *Outcomes:* any measure of wandering behaviour or other outcome relating to risky wandering
- *Very broad criteria* → *some evidence is better than none!!*



Figure 1: Review flowchart for selected studies



(Schmitker, Beattie, MacAndrew, Shepherd (unpublished))



# Categories of findings

## INTERVENTION TYPE

## OUTCOMES MEASURED

- external stimulation through engagement in activity or massage (4 studies) →
  - 'smart home' technologies (3 studies) →
  - environmental modification/ visual barriers (3 studies) →
- repetitive and frequent ambulation
  - Ineffective pattern of ambulation
  - night-time events (injuries & exits)
  - boundary transgression/exits

# External Stimulation: studies

Intervention	Characteristic of wandering targeted	Findings
Multisensory stimulation (MSS) (light, sound, touch and smell ( <i>Baker et al, 2003</i> ))	<b>Repetitive walking</b> - Used a general behaviour tool – single item characterised as wandering	No significant differences between MSS group (n=65) & activity group (n=71)
Colouring in V's listening to music ( <i>Lancioni et al, 2011</i> )	<b>Repetitive walking</b> - Observed amount of walking around the common room and number of times he left the activity table	Participating in preferred activities rather than no activity at all reduced wandering (n=1)
Engaging activity V's social activity V's watching & listening activity V's physical activity ( <i>Woodhead et al, 2005</i> )	<b>Ineffective patterns</b> - Daily Record of behaviour – 2 items: paced up and down & followed you around	Engaging activity (discussion groups, reality orientation, singing, drama, arts, crafts) showed significantly more decline in the 'Restless Behaviours' (n=94)
Relaxing massage ( <i>Rowe &amp; Alfred 1999</i> )	<b>Ineffective pattern</b> – 2 items from CMAI	Non-significant reductions in CMAI scores including 'pacing and walking' & 'searching and wandering' (n=14)



# Promote safer walking: studies

## 1. Smart Home Technology

*(Evans et al, 2011; Orpwood et al, 2008; Rowe 1999)*

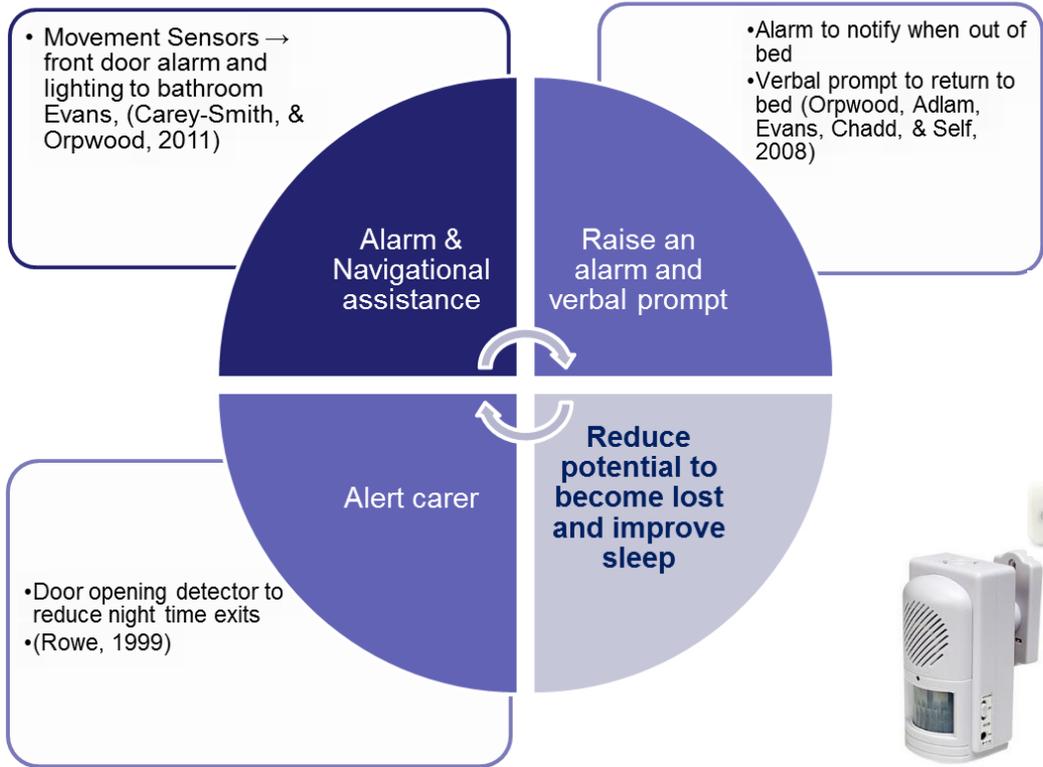
## 2. Environmental modifications

*(Feliciano et al. 2004; Padilla et al. 2013; Moore 2014\*).*

*\* Only study to measure wandering status at baseline*



# Smart Home Technology





## Visual Barriers

- Strip of cloth matching colour of door (Feliciano, Vore, LeBlanc, & Baker, 2004) → ↓entry into room
- 8 strips of black tape placed 25cm from the exit door and 4 strips placed on the glass door (Padilla, Gonzalez, Agis, Strizzi, & Rodriguez, 2013) → Nil effect seen
- a neutral-coloured canvas cloth covering the entire interior surface of the monitored door and attached to the door using a combination of Velcro and double-faced tape. (Moore, 2014) → ↓exit attempts
- Staff redirecting most effective



# Summary of evidence

	External Stimulus						Promote Safer walking		
Characteristics of wandering / outcome targeted	Multisensory Baker 2003	Music Choi et al 2003	Cognitive intervention Padilla 2013	Engaging activity Lancioni 2011 Woodhead 2005	Massage Rowe 1999	Exercise Woodhead 2005	Barrier Feliciano 2004	Smart homes (ext alarms + lighting) Evans 2011 Orpwood 2008 Rowe 1999 Rowe 2009	Environmental barriers Padilla 2013 Moore 2014
Improve Navigation								X	
Reduce Boundary transgression (exiting and entry to out of bounds areas)							X	X	X
Repetitive walking	X		X	X	No effect				
Restless behaviour				X					
Night time walking								X	
Disturbed Sleep								X	
Risk of Injury								X	
Carer stress								X	

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## What is missing

- Impact of using Safely Home Programs
- Efficacy of GPS tracking – have qualitative evidence regarding barriers and facilitators to use but no evidence about efficacy to reduce adverse outcomes
- Exercise and music programs



## Limitations & implications

- Broad inclusion criteria; low methodological quality
- Wandering not measured in a robust or validated way
- BUT potential direction for future research:
  - Low cost & acceptable interventions
  - Understanding the person with dementia's needs & preferences
  - Larger samples needed using validated wandering assessment tools
  - Quantitative studies using GPS tracking systems in the community needed



# Recommendations

- Robust research to test efficacy of low cost acceptable non-pharmacological interventions to reduce risky wandering in the community
- No evidence regarding impact of Safely Home Programs to reduce adverse outcomes of wandering
- Need to understand underlying need
- Accurate assessment to identify type and intensity of wandering
  - Is there risk associated with the behaviour
  - Can it be reduced/eliminated
  - Use of appropriate interventions
- Education for professional and family carers to improve early identification of risky wandering and targeted intervention to minimise risk



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# Launch e-learning tool



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Centre now Dementia Training Australia  
([www.dementiatrainingaustralia.com.au](http://www.dementiatrainingaustralia.com.au))



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