

Staying Safe 'Going Out': The Experience of Being Missing for People Living with Dementia

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The global impact of dementia

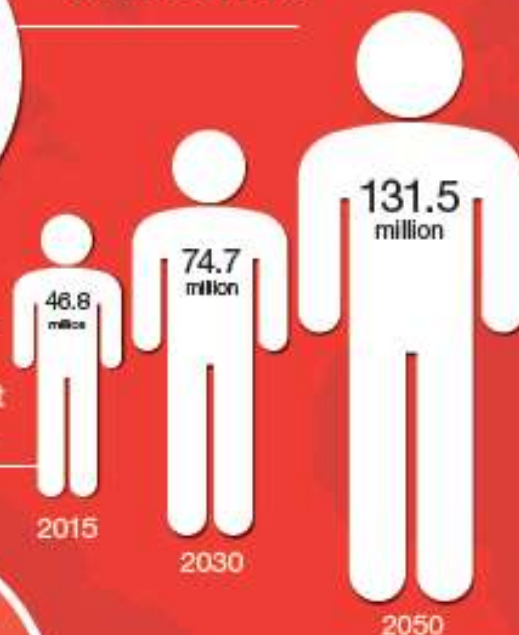


Around the world, there will be 9.9 million new cases of dementia in 2015,

one every
3 seconds

46.8 million people worldwide are living with dementia in 2015.

This number will almost double every 20 years.



68%
2050

Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.



2015

2018

The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion. By 2018, dementia will become a trillion dollar disease, rising to

US\$ 2 trillion
by 2030

If global dementia care were a country, it would be the

18th largest
economy

in the world exceeding the market values of companies such as Apple and Google



Google
\$368
billion

(source: Forbes 2015 ranking)



This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.



**Alzheimer's Disease
International**

The global voice on dementia

The World Alzheimer Report 2015 was independently researched by King's College London and supported by Bupa.



**Why is dementia a
LEPH concern?**

Background



Out of doors mobility is an important part of living well with dementia (Bantry White & Montgomery, 2015).



Poor topographical memory leads to **poor navigation** and increased risk of getting lost (McShane *et al.*, 1998). Therefore, people living with dementia are **at risk of becoming lost** even in familiar environments (Rowe & Bennett, 2003).



The individual may or may not feel like they are lost.



Despite their elevated risk, the majority of people with dementia who go missing are found **safe and well**. Concern about missing leads to **preventative measures**.



High complex cases have a **high mortality and morbidity rate**, place a high burden on police and search teams, and results in immense stress for families and individuals themselves.



In Scotland, 2% (538) of investigations involved someone with dementia (Police Scotland, Missing Persons Annual Report 2017/2018).



What we know about missing incidents

- People with dementia tend to go missing during **routine daily activities** (Bowen *et al.*, 2011; Rowe *et al.*, 2011).
- **Difficult to identify antecedents** to missing incidents (Rowe & Glover, 2001).
- Missing incidents often occur in a **brief lapse of supervision** (Bowen *et al.*, 2011).
- **Harm** is associated with **older age** and **length of time missing** (Bantry White & Montgomery, 2015).
- Usually found **alive in populated areas** and found **dead in natural, isolated areas** (Rowe & Bennett, 2003).
- **Higher chance of survival if found within 24 hours** (Rowe & Bennett, 2003).
- Usually found **close to home** or place last seen (Rowe and Glover, 2001).

Research Aims

- To understand the experience of 'going out' and potentially being 'missing' for people with dementia and their families
- How people with dementia negotiate this experience and how it affects their independence, sense of identity, control and purpose
- How can we facilitate people with dementia to 'go out' safely?



Research Design

Focus Groups

- Five in total
- One with carers
- Two with people with dementia
- Two with carers and people with dementia

Walking Interviews

- A series of interviews with ten people with dementia
- Meeting each participant up to three times

Family/ Care Partner Interviews

- Ten total participants

Resilience and coping strategies

“I try not to drive at night anymore”

“I walk along the same route”

“I time him”

“This wee book rules my life”

“The next time you see me, I’ll probably have one of those tracker things around my neck”

“I don’t go to unfamiliar places”

Changes in environment

“Things like scaffolding can really throw me”

“Cut down trees can be disorientating”

“uneven surfaces affect my balance”

Signage and landmarks

“The signs for men’s and women’s toilets start to look so similar”

“Simple things like black writing on a yellow sign make such a difference”

“Aha! There’s the church. I know where I am now”

Other people’s reactions

“There’s still a stigma”

“I find people very intimidating now... I’ve lost trust in people”

“I’m not confident using the bus because drivers pull away before you can sit down”

“I’m careful about who I ask for help... Someone in uniform or wee old ladies are best”

Ability can fluctuate

“I have good days and bad days”

Sensory impairments

“That lift can look like a black hole”

“When I’m in the car it feels like everything is coming towards me... I have to close my eyes”

“it all started when he was having problems with his vision”

Case Study: Jim

Context

- 65 year old retired male with dementia
- Lives at home with his wife who works part-time
- Had a career in the army and emergency service planning
- Is still driving
- Loves walking and goes out on his own every day
- Very socially active

Challenges Encountered

- Driving- forgetting where he parked and disorientation when driving
- Getting lost and being missing- was reported missing by his wife once
- Concerns around his memory
- Sensory impairments- didn't see a car coming because it was a dark colour, the same as the road

Case Study: Jim

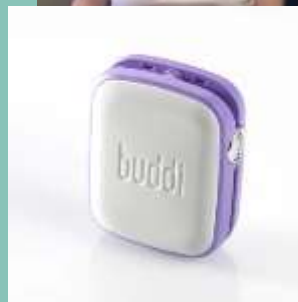
Strategies Described

- Driving- changed to a simpler car, no longer drives at night or in bad weather
- Getting lost- sticks to walking paths, is getting a tracking device
- Memory problems- keeps to a strict routine

Lessons Learned

- Although Jim was never lost, the 'missing' episode was still traumatic and has lasting impact on him and his family
- We cannot assume that every dementia case involves someone who is lost or had gone 'wandering'

Working Towards Impact



References

- Bantry White, E., & Montgomery, P. (2015). Dementia, walking outdoors and getting lost: Incidence, risk factors and consequences from dementia-related police missing-person reports. *Aging and Mental Health*, 19(3), 224–230. <https://doi.org/10.1080/13607863.2014.924091>
- Bowen, M. E. *et al.* (2011) 'Prevalence of and antecedents to dementia-related missing incidents in the community', *Dementia and Geriatric Cognitive Disorders*, 31(6), pp. 406–412. doi: 10.1159/000329792.
- Brooks, J., Savitch, N., & Gridley, K. (2016). Removing the “gag”: involving people with dementia in research as advisers and participants. *Social Research Practice*, Winter(3), 3–14.
- Mcshane, R., Gedling, K., Keene, J., Fairburn, C., Jacoby, R., & Hope, T. (1998). Getting Lost in Dementia: A Longitudinal Study of a Behavioral Symptom. *International Psychogeriatrics*, 10(3), 253–260. <https://doi.org/10.1017/S1041610298005365>
- Nygård, L. (2006). How can we get access to the experiences of people with dementia? *Scandinavian Journal of Occupational Therapy*, 13(2), 101–112. <https://doi.org/10.1080/11038120600723190>
- Police Scotland. (2018). *Missing Persons Annual Report 2017 / 18*.
- Rowe, M., & Bennett, V. (2003). A look at deaths occurring in persons with dementia lost in the community. *American Journal of Alzheimer's Disease and Other Dementias*, 18(6), 343–348. <https://doi.org/10.1177/153331750301800612>
- Rowe, M. A. *et al.* (2011) 'Persons with dementia missing in the community: Is it wandering or something unique?', *BMC Geriatrics*. BioMed Central, 11(1), p. 28. doi: 10.1186/1471-2318-11-28.
- Rowe, M. A. and Glover, J. C. (2001) 'Antecedents, descriptions and consequences of wandering in cognitively-impaired adults and the Safe Return (SR) program', *American Journal of Alzheimer's Disease & Other Dementias*, 16(6), pp. 344–352. doi: 10.1177/153331750101600610.

Thank you for listening!

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