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Staying safe 'going out' –The experience of people with dementia and their carers

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"This study will fill some important gaps in our understanding of missing persons"

- College of Policing, UK

Background

- **Out of doors mobility** is an important part of living well with dementia¹.
- However, poor topographical memory leads to **poor navigation** and increased risk of getting lost².
- Therefore, people living with dementia are **at risk of becoming lost** even in familiar environments³.
- Despite their elevated risk, the majority of people with dementia who go missing are found **safe and well**.
- However the 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.
- Concern about missing leads to **preventative measures** such as locking people with dementia indoors.
- Over **40,000 people** are reported missing in Scotland annually. People with dementia make up **2%-3%** of the reported missing population⁴.



(Source: screenshot from Jack & Jill [vimeo.com/149265279](https://www.youtube.com/watch?v=149265279))



The Story So Far

- People with dementia go missing during routine daily activities^{4,5}.
- Difficult to identify antecedents to missing incidents⁶.
- Missing incidents often occur in a brief lapse of supervision⁵.
- Harm is associated with older age and length of time missing¹.
- Usually found alive in populated areas and found dead in natural, isolated areas³.
- Higher chance of survival if found within 24 hours³.
- Usually found close to home or place last seen⁷.

Research Design

Phase 1- Focus Groups

- Focus group interviews with 6 groups of people with dementia and their families (approx. 60 participants).
- Focus group participants will watch Jack and Jill (a film which portrays someone going out and going 'missing') based on a research study⁹.
- Facilitated discussion around issues of identity, place, agency and control, purpose, the right to independence, safety and 'going out'.

Phase 2- Walking Interviews

- A sample of 15 people with dementia plus family members and/or care staff will be recruited in Scotland with the support of Alzheimer Scotland.
- Mobility levels and capacity to consent.
- Interviews will investigate how people with dementia and family members engage with 'going out' and prevent being missing and/or recover situations when they have transitory experience of feeling lost.

Wandering vs Missing

Wandering can be defined as "a syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally-disordered and/or spatially-disoriented 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"⁸.

People with dementia can wander without getting lost and they can go missing without wandering

Whereas a missing incident can be defined as "unpredictable, non-repetitive, temporally appropriate but spatially-disordered, and while using multiple means of movement (walking, car, public transportation). Missing incidents occurred without the discernible pattern present in wandering such as lapping or pacing, repetitive and temporally-disordered"⁶.

The individual may know exactly where they are, so are they really missing?

Project Aims

- To find out more about the experience of being missing from people with dementia and their families.
 - How do people with dementia re-locate themselves if they feel 'lost'?
 - How does someone with dementia interact with their environment and what influences their decision making?
- To explore how they negotiate this experience and how it affects their:
 - Sense of identity;
 - Independence;
 - Control over their lives;
 - Sense of purpose.
- To facilitate people with dementia to be able to 'go out' more safely.

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