

Towards autonomy and safety for people with dementia

Margaret MacAndrew, Elizabeth Beattie, Linda Schnitker, Deborah

Brooks and Nicole Shepherd summarise their research on people with dementia getting lost and interventions to improve the safety of people with dementia while maintaining their autonomy and dignity. The research is a contribution to the ongoing debate about risk and freedom of movement for people with dementia as exemplified by the *AJDC* article 'Taking the risk: strategies to support getting out and about' (April/May 2017 issue) and the *AJDC* editorial 'Unlocking the barriers' by Professor Joseph Ibrahim (August/September 2018)

Our recent review of online news reports has revealed that between 2011 and 2015, 132 Australians with dementia were reported missing (MacAndrew, Schnitker, Shepherd, Beattie 2018). Ninety-two of these reports included details on outcomes related to those who became lost. Alarming, 20% of these people were found seriously injured and 20% were found dead. These unacceptable findings have prompted our research team to explore how to improve the safety of people with dementia while maintaining their autonomy and dignity.

Getting lost is defined as being "away from their expected location and unable to return independently, no matter how long or where they were lost" (Tsoi *et al* 2018 p3355). When dementia impacts the areas of the brain responsible for navigation – the hippocampus, the parietal cortex, and the anterior basal forebrain – there is a greater risk that the person with dementia will not be able to independently navigate to a desired destination.

Internationally it has been estimated that between 30% and 70% of people with dementia will experience at least one getting lost event during their disease trajectory (Pai & Lee 2016). While this risk increases as the disease progresses, people in the very early stages of dementia can experience navigation problems and subsequently are at risk to become lost. Recent evidence suggests that increasing difficulties building cognitive maps of new surroundings may be an early preclinical sign of Alzheimer's disease, with people at risk of, and becoming lost very early on (Allison *et al* 2016). The most reliable predictors that a person with dementia will experience a getting lost event are: 1) a previous



getting lost event, and 2) failure to implement safety measures after the first getting lost event has occurred (Pai & Lee 2016).

Common features

Using the findings of the reported outcomes of getting lost events in Australia involving a person with dementia, common features of these events have been highlighted:

- The average age of the person was 75 years old.
- More men than women were reported missing. More women experienced serious injury, while more men were found dead.
- For most, the last known location of the missing person was their home or residential aged care facility and most people left that location on foot.
- Most people were found just 1km from their last known location and those who were found deceased were frequently

under thick vegetation.

- Missing for more than 6-12 hours increases the risk of finding the person dead (MacAndrew *et al* 2018).

Recommendations

These findings were almost identical to those from a comparable study conducted nearly 20 years ago in the US (Rowe & Bennett 2003). As a result of these and other international findings related to the characteristics of a getting lost event involving a person with dementia (Tsoi *et al* 2018) the following recommendations were made:

- Carers need a current photo of the person with dementia.
- Family, neighbours and the broader community should be aware of the risk.
- In the event that a person with dementia becomes lost, this should be reported immediately to the police.
- When police receive a missing person report involving a person with dementia a coordinated search protocol that includes an intense search of the immediate area where the person was last seen to a radius of 5km is initiated.
- The search includes looking under vegetation and inside outdoor structures (eg garden shed).
- The general public are informed and provided with identifying details and a photo so they can assist with the search effort (Tsoi *et al* 2018).

While in Australia the recommendations related to the police search protocol have been implemented by the Search and Rescue Unit throughout Australia, the similarity in findings 20 years later suggests that not all these recommendations have been adopted in the Australian context. In addition, Australian carers have reported that they

Getting home safely

Safely Home is a program available in NSW with a similar program, Safe Return, offered in South Australia and the Northern Territory. The programs are joint initiatives between Dementia Australia and the respective state police services and offer some peace of mind to anyone who cares for a person living with dementia.

A carer is able to confidentially register the person in their care with the programs. The person who is registered then wears a stainless steel bracelet that has an engraved personal identification number and toll free police phone number. If someone finds the person confused or seemingly lost they can call the phone number to initiate the safe return process with police. Police will access the program's database, accurately identify the person and support them safely back to their home.

Carers may also find the service useful if they need to report someone missing, as police will already have key information to be able to start their search.

Information about the programs can be found on the Dementia Australia website at www.dementia.org.au.

There are other options that may support a person living with dementia to maintain their independence. Dementia Australia's National Dementia Helpline staff can provide information about assistive technology programs and products for safe walking. Dementia Australia staff do not endorse any individual products or services, instead they aim to provide a broad picture of the options available so carers can explore what might work best for their situation. More information is also available at: <https://www.dementia.org.au/files/resources/GPS-tracking-and-monitoring-devices.pdf>.

Resources

Safer walking for people with dementia

Four-page help sheet with practical information from Dementia Australia on safer walking for people with dementia. Available at: <https://bit.ly/2RNaOel>

Alzheimer's Society's view on safer walking technology

This detailed position statement sets out the issues facing people with dementia and their supporters when it comes to considering GPS systems to support safe walking in the community. Available at: <https://bit.ly/2RMARrH>

Systematic literature review

Neubauer NA, Azad-Khaneghah P, Miguel-Cruz A, Liu L (2018) What do we know about strategies to manage dementia-related wandering? A scoping review. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. Available at: <http://bit.ly/2ENacrc>

find balancing safety and autonomy for the person with dementia challenging and some reported using extreme measures, such as locking the person within their home or using chemical or physical restraint, to provide the level of security they perceived as necessary (Beattie & MacAndrew, in review).

Considering the known risk of becoming lost for people with dementia, we recommend three key approaches that aim to maintain safety while promoting autonomy and dignity: 1) Be aware of the risk and prepare for a getting lost event; 2) Implement evidence-based strategies to prevent a getting lost event; 3) Initiate a rapid response to a getting lost event.

Prevent a getting lost event

While the available evidence for interventions to prevent a person with

dementia from leaving a safe environment is of low quality, some guidelines related to non-pharmacological interventions are available. A review of the literature related to interventions to support safer walking revealed two approaches: environmental modifications and Smart Home Technology (MacAndrew, Brooks & Beattie 2018).

Environmental modifications

Environmental modifications that were found to be effective in reducing the number of attempts to leave a safe environment included camouflaging the door using material of the same colour as the wall (Feliciano *et al* 2004), and discouraging entry through a door using a rubber mat (Moore 2014) or black strips (Padilla *et al* 2013).

Smart Home Technology

Smart Home Technology, such as the use of motion detector alarm systems to alert carers that the person is out of bed or approaching the exit (Evans *et al* 2011; Orpwood *et al* 2008), were also found to be effective in reducing unsupervised exits and falls. However, this evidence needs to be taken with caution as the testing has relied mainly on single case studies. There is also strong evidence that alarm systems can be disarmed by the person being monitored and false alarms can result in carers becoming desensitised and therefore failing to respond (Aud 2004; Aud 2013). Consequently, preparing for the possibility that a person with dementia could become lost is important.

Prepare for a getting lost event

Maintaining autonomy and dignity are fundamental to achieving optimal quality of life for all humans. However, due to the potential for a person with dementia to become lost, putting mechanisms in place to help the person to navigate successfully, or to be found if they do not make their intended destination when expected, could reduce the risk while enabling the person to remain independent for as long as possible.

Strategies such as raising awareness in the broader community that the risk exists for an individual, carrying an ID card in the wallet or wearing an ID bracelet/necklace (Dementia Australia 2019) and using tracking technology (eg wearable GPS devices) can promote autonomy and safety when applied appropriately (White *et al* 2010).

However, tracking technology is only effective if used correctly, if it has adequate battery life and is continuously worn by the person with dementia (MacAndrew *et al* 2018). In addition, there is still conflicting opinion from people with dementia regarding the benefits of such devices versus the right to privacy as these devices identify where the person is at all times (MacAndrew *et al* 2018).

Rapid response to a getting lost event

As there is currently no fail-safe means to ensure that a person with dementia does not leave a safe environment alone and that they will return home safely, evidence from previous getting lost events involving a person with dementia can be used to develop strategies for reporting a missing person with dementia and directing the search that then follows.

In Australia there is currently no standardised approach to reporting a missing person with dementia. According to the Queensland Search and Rescue Unit, the coordinated search that is known



■ From left: Dr Margaret MacAndrew is Lecturer at the Queensland University of Technology (QUT) and Knowledge Translation Research Fellow at the Dementia Centre for Research Collaboration (DCRC); Professor Elizabeth Beattie is the Director of the Queensland hub of the DCRC; Dr Linda Schnitker is a Lecturer at QUT; Deborah Brooks is a PhD Candidate at QUT; and Nicole Shepherd is a Lecturer at the University of Queensland. To follow-up on this article contact Dr MacAndrew at margaret.macandrew@qut.edu.au.

to be effective is often delayed because the police call centre is not informed of the diagnosis of dementia or carers delay informing the police. Delaying the initiation of a coordinated search for the missing person with dementia reduces the likelihood of finding the person alive.

Internationally, programs have been implemented to address this issue and include the Silver Alert System in the US and two new systems in Scotland and Canada which use a phone app to disseminate vital information about the missing person to the general public. These systems also raise awareness of the potential risk of people with dementia getting lost.

Getting Home Safe Project

While it is not clear if systems such as these would be effective in Australia, we aim to explore this further through the Getting Home Safe Project. The Getting Home Safe Project aims to improve the safety of people with dementia through the development, trial and implementation of a national approach to rapidly reporting a missing person with dementia to police so that a search can begin, thus improving the likelihood of finding the person alive and well. Phase 1 of this project, which has received funding through the Dementia Australia Research Foundation, began in Brisbane in March 2019 and runs until March 2021.

In Phase 1 we will work with our Project Ambassador, John Quinn, and co-investigators Dubhglas Taylor and Senior Sergeant Jim Whitehead to identify national and international approaches to reporting a missing person with dementia. We will then consult with the experts (carers of people with dementia, people with dementia, emergency services and health professionals) to propose recommendations for a standardised approach to reporting in Australia.

With informed collaboration we can

prevent injury and tragedy and help people with dementia to continue to enjoy their community. ■

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