



EDWIN'S STORY

Reconnecting a missing adult living with dementia.

Edwin had been living with dementia for some years, and his dementia was advanced. Edwin lived with his wife in a sheltered housing complex in a large town. Edwin still appreciated being independent, and regularly used his free bus pass to travel on public transport locally. Edwin had been very resistant to going to live in a care home.

Edwin had been missing before and, on the last occasion, had been found a long distance away from home, having travelled by bus. In the past, he had been found in potentially dangerous situations, where he was at risk of being hurt.

On this occasion, Missing People were contacted by Edwin's family, who were extremely worried about his welfare. Edwin's wife had left him at home alone while she went to the local shops, and when she returned she realised that he was missing, along with his coat and walking stick.

Missing People immediately contacted the investigating police officer to confirm the details of the incident and to get permission to circulate publicity, in addition to the family's own efforts. Having been granted permission, Missing People were immediately able to circulate an urgent appeal for Edwin on the charity website.

The appeal was circulated to the charity's 35,000 Facebook followers and 58,000 Twitter followers, who were able to share the appeal with their friends and followers too. Edwin's appeal was also shown on digital billboards in the town where Edwin lives. Case publicity volunteers arranged for posters to be displayed immediately in relevant local locations such as shops that Edwin might visit.

Edwin was found nine hours after he went missing, walking along a dual carriageway, after concerned members of the public contacted the police. Edwin was taken to hospital for assessment, where he was found not to have sustained any injuries, although he was slightly dehydrated. Local social services were contacted by the hospital so that they could assess Edwin's living arrangements.

DEMENTIA AND GOING MISSING

This case study explores the experiences of missing people with dementia who go missing and then return, and the effect on their families. It is estimated that there are around 800,000 people living with dementia in the UK, and that there will be over a million by 2021. Two-thirds of people with dementia live in the community, one-third in care homes (Alzheimer's Society, 2014a). Dementia is a condition that usually occurs in older people, but can be present in younger people too. It can lead to "problems with: memory loss; thinking speed; mental agility; language; understanding; and judgement [...] increasing difficulties with tasks and activities that require concentration and planning; depression; changes in personality and mood; periods of mental confusion; difficulty finding the right words" (NHS Choices, 2014).

Dementia can contribute to people becoming missing in a number of ways. A person with dementia might leave their home to travel to somewhere particular, such as a former home or familiar place, and if no one is aware of the journey, they may be reported missing. A person with dementia might become lost whilst taking a regular walk or journey, thus becoming missing. A person with dementia might leave their home with no particular intention

and become lost in the local area⁴ (Rowe et al, 2004; Rowe et al, 2011). Research studies have estimated that between 60 and 80 per cent of people diagnosed with Alzheimer's disease (a form of dementia) will have one or more missing incidents (Rowe and Glover, 2001; Hope et al, 2001).

It is difficult to estimate how many missing incidents are influenced by the missing person's dementia. UK police forces do not routinely report how many missing person incidents include dementia as a contributory factor. Research, including analysis for this study, has found that between 5 per cent and 10 per cent of missing people referred to the charity have dementia; in 2003 Biehal et al found that problems 'way-finding'⁵ were "the most common reason for going missing ascribed to those aged 60 or over, was present in one third of the case files for this age group and appeared equally likely to affect all ethnic groups" (Biehal et al, 2003: 19).

This is likely to be a lower proportion than all police incidents, because the majority of cases referred to the charity have been ongoing for more than 3 days whilst 70 per cent of police missing person cases are resolved within 16 hours (UK Missing Persons Bureau, 2013: 26), and most missing people with dementia are usually found "within a few days" (Biehal et al, 2003; 43).

MISSING PEOPLE, APPEAL DURATION

18% of the 690 police cases the charity worked on in 2011 were referred to Missing People within two days of the disappearance, 23% between 3 and 7 days after the disappearance, and 28% between a week and a month (the remainder were either unknown (7%) or more than one month (24%)).

38% of these cases were closed within a week of being referred to the charity, a further 19% were closed between a week and a month after being referred. 20% of these cases were closed between a month and a year after being referred. (The remainder had been open for more than one year, at the time of analysis).

98% of people who were found were found within a year of being reported to Missing People.

For people with dementia, going missing can present significant risks. Although most people are found alive within a short period, for a small minority becoming lost can result in serious injury, illness or death. A previous Missing People research report indicates that 15 of 186 fatal incidents worked on

by the charity in 2006-2007 involved a person with dementia, and that they were most commonly found outdoors (Newiss, 2011: 33).

For some families caring for someone with dementia, missing incidents can become a regular part of life.

⁴ There is some relationship between the specific behaviour of 'wandering' and going missing, but the two terms are not interchangeable. Rather, becoming lost may be a result of wandering behaviour, but may also be unrelated.

⁵ Way-finding is the process by which people orient themselves in their environment and choose routes by which to travel to their destination.

“Once he had an idea, it was almost like he had to see it through in order to, erm, get it out of his system or something. And just occasionally he would just head off to the day centre. [...] I think probably eleven o’clock at night was the latest he was found. [...] Maybe he would knock on someone’s door looking for a drink, or he’d got muddled and thought he lived there. He tends to seek out people, and they would then contact the police and he’d be brought back safe. Completely oblivious that he’d done anything odd at all. Coming home in a police car or whatever.”

(Daughter of a missing adult, interviewed for Living in Limbo (Holmes, 2008))

DEMENTIA AND RECONNECTION

Challenges with search and reconnection

In cases where the missing person has dementia, their help-seeking behaviour may not centre on being missing. Adults who encounter people with dementia asking for help may not realise they are missing, and so may not endeavour to alert anyone to where they are, meaning that publicity will be of paramount importance. In 2011 Missing People circulated appeals for 12 people with dementia – a sample that is too small to draw meaningful conclusions. However, in at least one of these

instances the person was found as a direct result of Missing People’s publicity appeal.

It is also particularly important, in cases when a missing person is known or suspected to have dementia, that search strategies are well informed by intelligence and knowledge about likelihood of travel in given directions. Research examining police missing person cases resulted in a guidance booklet being produced that provides some such advice (Gibb and Woolnough, 2007). Further research should be conducted to understand way-finding in people living with dementia, and to explore how they can be supported to continue to live independently whilst also being safe. Research should also explore the experience, response and needs of carers in order to inform future policy and practice responses in line with national strategy.

A new project to address some of these concerns has been developed in recent years and has been piloted across three county areas. The Neighbourhood Return project involved a network of volunteers who could be mobilised to search their local area for a missing person with dementia. Adults with dementia could be pre-registered, to allow for a near-instant response to a disappearance. The pilot project has now been concluded, and evaluation findings are due to be published in autumn 2014 (Neighbourhood and Home Watch Network, 2014a and 2014b).

PRACTICE EXAMPLE: MISSING PEOPLE/OUTDOOR MEDIA CENTRE PARTNERSHIP

In order to bring high risk missing person appeals to the greatest possible number of people, Missing People and industry body Outdoor Media Centre have created a pioneering partnership.

Outdoor Media Centre’s members, using technology provided by Grand Visual, provide pro bono advertising space on digital billboards nationwide to be used for missing person appeals. These appeals can be created and circulated within minutes, meaning that a missing person’s details will be seen by the largest possible number of people in a regionally targeted area.

More details about this prize-winning partnership can be found here: http://www.outdoormediacentre.org.uk/outdoor_media/news/Missing_People_brochure/

Attempts to prevent future incidents

“It’s so scary thinking it might happen again.”

(Sister of a formerly missing adult, Family Feedback Survey 2014 participant)

Like the families of many missing people without dementia, family members of returned adults with dementia may be concerned that they are at risk of going missing again. After reconnection, people caring for the missing adult may seek to curtail their freedoms to prevent further missing incidents.

“[The] experience really shook me. I kept thinking that she could have got on another bus to somewhere else. How on earth could I ever have found her? My solution after that was never to let her out of my sight. If she wanted to go out, I went with her. Sometimes she’d be hostile but I would still go along.”

(Quote from the husband of a formerly missing woman with dementia, Member of the Neighbourhood Return advisory group Alzheimer’s Society 2013a)

The use of ‘safer walking technologies’ can help people with dementia to stay independent, and to reduce the worry for carers. Safer walking technologies are devices based on Global Positioning Systems (GPS) or similar, that a person with dementia can carry with them, and that allow their family or police to locate them should they go missing.

For people with dementia, going missing or becoming lost may be a trigger for being moved into supported living or a care home. Research by McShane et al (1998) found that, in their sample of 104 people with dementia, those who got lost during the study period were more likely to be rehomed permanently in institutions (McShane et al, 1998). While current government strategic plans on dementia do not specifically mention missing incidents, they acknowledge that crises can lead to carers or adults with dementia choosing residential care over independent living. Such crises might include incidents where the person with dementia was lost or missing. The National Dementia Strategy recognises that people admitted to hospital after such a crisis might well be moved straight from hospital into residential care “partly because a lack of knowledge and understanding about dementia [that] leads some professionals to the erroneous assumption that residential care is the only option. It is also due to home care staff and family carers not receiving training and advice in dementia, and so not having the skills and competences to provide appropriate care” (Department of Health, 2009: 50).

Researchers fear that imposing restrictive boundaries, in order to keep a person with dementia physically safe, can cause ‘silent harms’ and lead to a decline in their skills and wellbeing: “Rather than simply stopping something which is perceived as risky, such as going for a walk, we need to think about finding ways to make it possible. This could include involving other people – such as alerting neighbours, using volunteer help, informing the police of the person’s address, employing new

GPS or mobile phone technology or engaging peer support” (Professor C. Clarke; ESRC, 2013).

Response to incidents

When people with dementia are found or return after a missing incident, they may require a different approach to returned people who do not have dementia. The Alzheimer’s Society’s guidance suggests: “When the person returns, try not to scold them or show them that you are worried. If they have got lost, they may be feeling anxious themselves. Reassure them, and quickly get them back into a familiar routine” (Alzheimer’s Society, 2013b: 9).

In order to ensure the most effective response to vulnerable adults who have been missing, police forces should consider all appropriate referral routes. Where dementia is flagged (either diagnosed or potential), this referral should include both health and social care services. It is still relevant to offer a return interview, but this should include a dementia-specific component to take account of the different needs of the returned adult and their family.

“We’ve actually got him a social worker so we’ve been able to get help there.”

(Niece of a formerly missing adult, Family Feedback Survey 2014 participant)

RECOMMENDATIONS

10. It is likely that it will be harder to reach out directly to missing people who have dementia; they may not carry a mobile phone, they may not realise that they will have been reported missing, and they may not be able to reach out for help if lost. This makes the role of publicity appeals especially important. In order to make local people aware that someone with dementia is missing in their community, Missing People and the charity’s current and potential partners should continue to pursue opportunities to access publicity channels to publicise missing incidents quickly.
11. Return interviews with people with dementia, like those for all missing adults, would be best conducted by independent organisations. Organisations with expertise in dementia, and sufficient training in issues around missing people, might undertake this work, in order to share their knowledge about living with dementia, the experiences of carers, strategies to keep people with dementia safe, and sources of additional support.