

# Return Discussions

## Pilot Evaluation

University of Edinburgh

Alzheimer Scotland

Police Scotland

## Final Report

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THE UNIVERSITY  
*of* EDINBURGH



**POLICE**  
**SCOTLAND**  
Keeping people safe  
**POILEAS ALBA**



**Alzheimer**  
**Scotland**  
Action on Dementia

University of Edinburgh  
Professor Heather Wilkinson, Director of ECRED  
Debbie Gray, PhD Intern

Alzheimer Scotland  
Tommy Petillo, Purple Alert Coordinator  
Caroline O'Hara, Dementia Advisor

Police Scotland  
Yocksan Bell, Missing Persons Operational Coordinator

# Contents

<b>BACKGROUND TO THE PILOT</b> .....	4
<b>METHODOLOGY</b> .....	6
<i>Baseline data</i> .....	6
<i>Monitoring data</i> .....	6
<i>Analysis of data</i> .....	6
<b>FINDINGS</b> .....	8
<i>Baseline data</i> .....	8
<i>Demographic information from Police Concern Reports</i> .....	9
<i>Timing of the incidents</i> .....	9
<i>Repeated missing cases</i> .....	10
<i>Return Discussion details</i> .....	10
<i>Purple Alert and Herbert Protocol</i> .....	12
<i>Qualitative information related to the Return Discussions</i> .....	13
<i>What happened to make people go missing?</i> .....	13
<i>What happened whilst people were missing?</i> .....	13
<i>Interactions with the police</i> .....	14
<i>Views of the family/carers</i> .....	14
<i>What can be done to prevent future missing occurrences?</i> .....	14
<b>CONCLUDING POINTS</b> .....	16
<b>REFERENCES</b> .....	17

## **BACKGROUND TO THE PILOT**

There are an estimated 90,000 people living with dementia in Scotland and 40% will be reported missing at some point, with 30% of these reported missing on more than one occasion. For some people living with dementia, going missing is a very real event and the upset and worry caused can be traumatic for those involved.

Alzheimer Scotland have been so concerned about the number of people with dementia going missing and the serious consequences of these missing incidences, that in response, they have developed a digital app, Purple Alert (<https://www.alzscot.org/purplealert>). The app is used by the families of those living with dementia to call for assistance in finding the person should that help be required. This process follows the Herbert Protocol – a national scheme introduced by Police in partnership with other agencies which encourages carers to gather useful information that could be used in the event of a vulnerable person going missing (Police Scotland, 2021). This paper-based approach is complementary to the Purple Alert app. When a Purple Alert is raised, it notifies users of the app nearby that a person living with dementia has gone missing. The notification informs users of the missing person's last known location and key information such as their name, photos, places of interest, clothes they were wearing, habits, routines, and relevant medical information. It is a community focussed app which encourages local people to be mindful of the vulnerable people within their community.

Within Edinburgh alone, 120 people living with dementia were reported missing in the year 2021. However, only 3 Purple Alerts were activated. This tells us that we are not reaching enough vulnerable families in their communities with resources that could help make them safer and give their families valuable resources and support. Police Scotland identified that they could be working in closer partnership with Alzheimer Scotland to ensure families get access to expert support. Police Scotland have a similar partnership with Barnardo's who support young people who go missing in Edinburgh.

Previously, Police Scotland have carried out a 'safe and wellbeing check' within 24 hours of the person returning home and to gather information about the missing occurrence. They would log this in the Police Scotland National Missing Person Database as a reference for the future. However, we know that Dementia Advisors and Purple Alert Coordinators have a holistic knowledge of dementia as a condition, Alzheimer Scotland services, and an overview of the available local services and technologies which could make a positive difference to families going forward and reduce the risk of a missing occurrence happening again in the future. Police Scotland have identified Alzheimer Scotland as an experienced provider of

support for people with dementia and recognise the value their support can have on families going forward.

As such, Alzheimer Scotland have been working in partnership with Police Scotland and the University of Edinburgh to pilot a project within Edinburgh – a unique service for people living with dementia and their families called Return Discussions.

Return Discussions are a ‘free flowing’ conversation facilitated by a Dementia Advisor that takes place after a missing person with dementia returns home. The aim is to understand and gather as many details as possible in relation to the missing occurrence. It is also an opportunity to comfort and reassure the carer, provide a debrief of the missing occurrence, advise how to prevent future missing incidences, and provide information and access to resources and support.

A Dementia Advisor can offer the carer and person living with dementia access to a range of support within Alzheimer Scotland and digital activities. As well as assessing the circumstances that led to the event, they can offer support to look at digital supports such as the Purple Alert app, or GPS and phone technologies that might help. They can link families to telehealth services within Edinburgh for an assessment for door sensors and other equipment that may be available. They can also provide emotional support and access to therapeutic activities. We expect that a Return Discussion will allow for the family to make decisions based on their own circumstances.

**The main aim of the evaluation is to examine the information collected in the Return Discussions regarding: the profile of people with dementia who are reported missing, the circumstances surrounding the missing incidences, and the processes and services that could best support them.**

## **METHODOLOGY**

A mixed methods approach was undertaken in order to analyse the quantitative baseline and demographic data provided by Police Scotland and the qualitative monitoring data gathering by Alzheimer Scotland Dementia Advisors as part of the Return Discussions.

### *Baseline data*

Edinburgh Police data on the number of people with dementia who are reported missing and the number of incidences of people with dementia who are reported missing during the years from 2016 were collated to establish a baseline against which corresponding pilot data could be compared.

### *Monitoring data*

Monitoring data was collected for all missing people with dementia reports received between 25<sup>th</sup> of April 2022 and 25<sup>th</sup> of September 2022. A total of 40 Return Discussions took place during this time period. Data collected included:

**Demographic information from Police Concern reports:** gender, age, ethnicity and living arrangements

**Quantitative information related to each Return Discussion undertaken:** time and date of the missing person report, length of time missing, interview date and time, interview location, interview duration, how they travelled, if they accessed money, if they stayed overnight anywhere, any alcohol/substance use, how they returned home, any indications of exploitation/harm. Additional information regarding the number of Purple Alert downloads and Herbert Protocol completions were also provided by the Return Discussion team.

**Qualitative information related to each Return Discussion undertaken:** what happened to make the person go missing, what happened whilst they were missing, what can be done to prevent future missing occurrences, what the police interaction was like, any concerns/issues raised including views of the family/carers.

All information was anonymised and transferred to the evaluation team for analysis.

Ethical approval was gained from School of Health in Social Science Research Ethics Committee at the University of Edinburgh to use secondary data that is routinely collected or is an existing anonymised dataset.

### *Analysis of data*

An Excel spreadsheet was constructed for the purposes of inputting and analysing the files received from the Return Discussion team. This file consisted of all missing persons with dementia incidents that were reported to the police across Edinburgh during the data

collection period (so for example, people with dementia who were reported missing twice during this period were inputted twice in this file).

Descriptive statistics of demographic information and quantitative Return Discussion information were carried out using SPSS.

A Framework Analysis Method (Ritchie & Spencer, 1994) was used to thematically analyse the qualitative information related to each Return Discussion in NVivo. A 5-step process was followed which included familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. The first step, familiarisation, involved becoming immersed in the data by reading over the information gathered in order to develop an overview of the main ideas that were emerging from within the data. The second step involved developing a theoretical framework, whereby reoccurring ideas and concepts were identified and grouped together into potential themes. The third step, indexing, refers to identifying parts of the data that are related to specific themes. The Framework Matrices function was used to link parts of the qualitative data to the appropriate codes. As part of the fourth step, charting, the data was arranged and summarised into columns (each representing a theme) and rows (each representing a participant). This method means that the data can remain electronically linked to the original source so that the context of the data remains. The final step of mapping and interpretation resulting in analysing the main characteristics described in the previous step.

## **FINDINGS**

In this section we present the findings from the Return Discussion Pilot evaluation project. This includes baseline and demographic data provided from Police Scotland, and both quantitative and qualitative information related to the Return Discussions, provided by Alzheimer Scotland.

### ***Baseline data***

Table 1 shows the incidences relating to someone missing with dementia from 2016 – 2022. In 2016 there were 147 incidents and by the end of 2022 it is predicted that there will be a total of 90 incidences (see Figure 1). When compared to the previous year (2021), a reduction can be seen in the number of incidences, number of individuals, total number of repeat cases and most prolific cases.

	2016	2017	2018	2019	2020	2021	2022 (to 31/10/2022)
<b>Number of incidences</b>	147	110	127	119	121	106	75 (projected end of year total 90)
<b>Number of individuals</b>	129	92	105	101	67	79	61
<b>Repeat individuals</b>	15	12	17	13	11	17	15
<b>Total number of repeat cases</b>	36	30	39	32	64	45	33
<b>Most prolific individuals by cases</b>	5	5	5	5	3	6	3

Table 1: Incidences relating to someone reported missing with dementia from 2016 – 2022

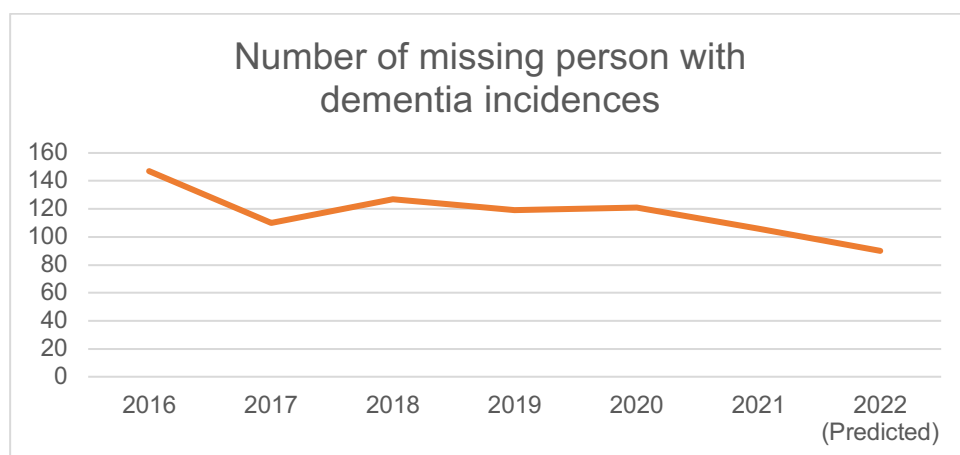


Figure 1: Number of missing person with dementia incidences from 2016-2022



### **Demographic information from Police Concern Reports**

A total of 40 Return Discussions took place during the pilot evaluation period, involving 31 people with dementia. Demographic information can be found in Table 2. Within the sample, 55.0% were male and the average age was 80.7. The most common type of residences people stayed in was at home with their family/spouse (38.7%). However people also stayed at home alone, in a care home, at hospital, in a retirement complex and within sheltered accommodation. White Scottish was the most commonly reported ethnicity (61.3%).

<b>Gender (N, %)</b>	
Male	17 (54.8)
Female	14 (45.2)
<b>Age (Mean, SD)</b>	80.7 (8.0)
<b>Current Residence (N, %)</b>	
Alone	5 (16.1)
Care home	5 (16.1)
Home with family/spouse	12 (38.7)
Hospital	1 (3.2)
Retirement complex	2 (6.5)
Sheltered accommodation	1 (3.2)
Unknown	5 (16.1)
<b>Ethnicity (N, %)</b>	
White British	9 (29.0)
White English	1 (3.2)
White Irish	1 (3.2)
White Scottish	19 (61.3)
Unknown	1 (3.2)

Note: N=31

Table 2: Descriptive statistics of demographic information obtained from Police Concern reports

### **Quantitative information related to the Return Discussions**

#### *Timing of the incidents*

The average amount of time that people were missing for was 86.4 minutes (SD = 108.1), with times ranging from 5 minutes to 8 hours. In 62.5% of cases, the person was missing for less than 1 hour. The time of day that incidents were most likely to take place was in the afternoon (35.0%; 12pm – 5pm). See Figure 2 for more detail.

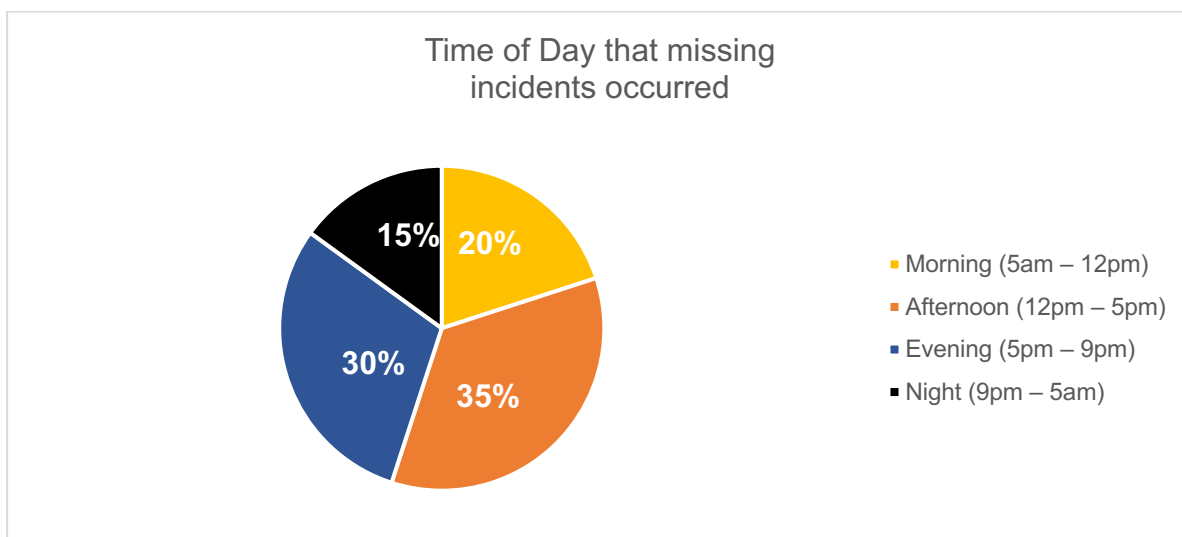


Figure 2: Time of day that missing incidents occurred

### *Repeated missing cases*

The majority of people 33 (82.5%) were only reported missing once during the pilot period, 5 (12.5%) were reported missing twice, and 2 (5.0%) were reported missing three times (see Figure 3).

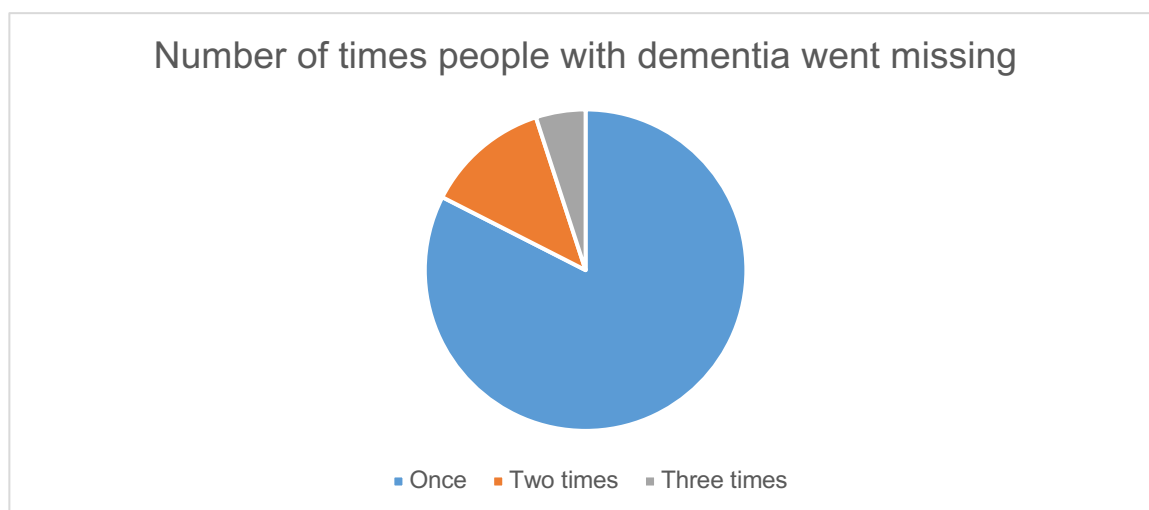


Figure 3: Number of times people with dementia went missing during the trial period

### *Return Discussion details*

Descriptive statistics of the length and location of the Return Discussions can be found in Table 3. The length of the Return Discussions ranged from 5 to 110 minutes, and took an average of 35.5 minutes to complete. The Return Discussions typically took place over the phone (65.0%) or at the home address of the missing person/carer (22.5%). Return Discussions had also taken place within Alzheimer Scotland (2.5%) and care homes (7.5%).

<b>Length of the Return Discussion (mean, SD)</b>	35.5 (25.4)
<b>Location of the Return Discussion (N, %)</b>	
Alzheimer Scotland	1 (2.5)
Care home	3 (7.5)
Home address	9 (22.5)
Over the telephone	26 (65.0)
Unknown	1 (2.5)

Table 3: Descriptive statistics of Return Discussion details

Miscellaneous details about the missing incidents obtained from the Return Discussions can be found in Table 4. During the missing incident, people were most likely to travel on foot (70.0%). Over half did not have access to money (52.5%) whilst over one third did (37.5%). No one stayed overnight anywhere. In 85% of cases, there was no alcohol or substance use, whilst 12.5% had consumed some alcohol during the incident. Those reported as missing were often assisted home by the police (70.0%). However people were also reported to be returned by care home staff, family/carers, members of the public, paramedics or on their own accord. In nearly every incident (87.5%), there were no signs of exploitation or harm. However in two cases, the missing persons experienced a fall, and in another case they had a sore and swollen ankle. There was also one case of potential exploitation by neighbours which was still being investigated.

	<b>N (%)</b>
<b>How did they travel?</b>	
Bus	5 (12.5)
Foot	28 (70.0)
Foot and bus	4 (10.0)
Taxi	1 (2.5)
Unknown	2 (5.0)
<b>Did they have access to money?</b>	
Yes	15 (37.5)
No	21 (52.5)
Unknown	4 (10.0)
<b>Did they stay anywhere overnight?</b>	
Yes	0 (0.0)
No	40 (100.0)
<b>Any alcohol/substance use?</b>	
Yes	5 (12.5)
No	34 (85.0)
Unknown	1 (2.5)
<b>How did they get home?</b>	
Care home staff	2 (5.0)
Family/carer	4 (10.0)
Member of the public	1 (2.5)
On their own accord	3 (7.5)
Paramedics	1 (2.5)
Police	28 (70.0)
Unknown	1 (2.5)

Any indication of exploitation/harm?	
No	35 (87.5)
Yes	3 (7.5)
Maybe	1 (2.5)
Unknown	1 (2.5)

Table 4: Miscellaneous details about the missing incidences from the Return Discussions

*Purple Alert and Herbert Protocol*

Before the Return Discussion, 7.5% had already downloaded the Purple Alert app. After the Return Discussion had taken place, this increased by 10% to 17.5% (see Figure 4).

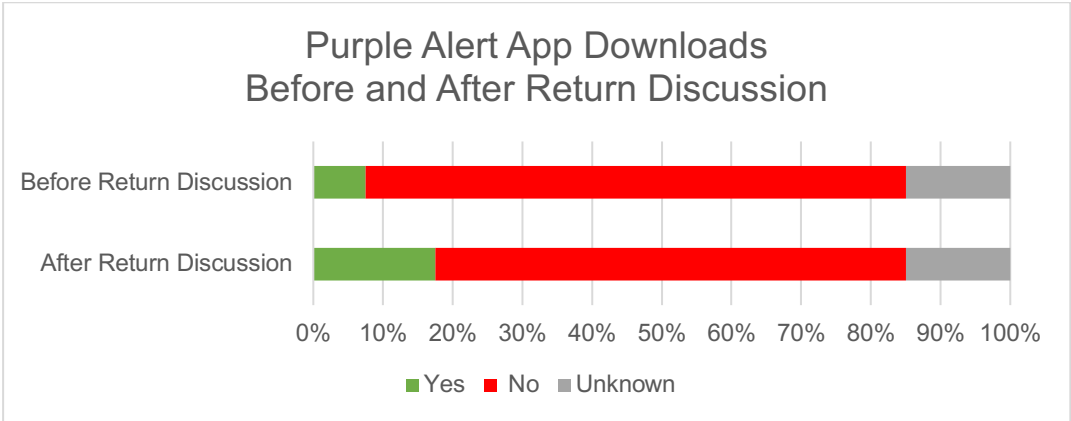


Figure 4: Purple Alert app downloads before and after the Return Discussions

Before the Return Discussion, 30.0% had already completed the Herbert Protocol. After the Return Discussion, this increased by 25% to 55.0% (see Figure 5).

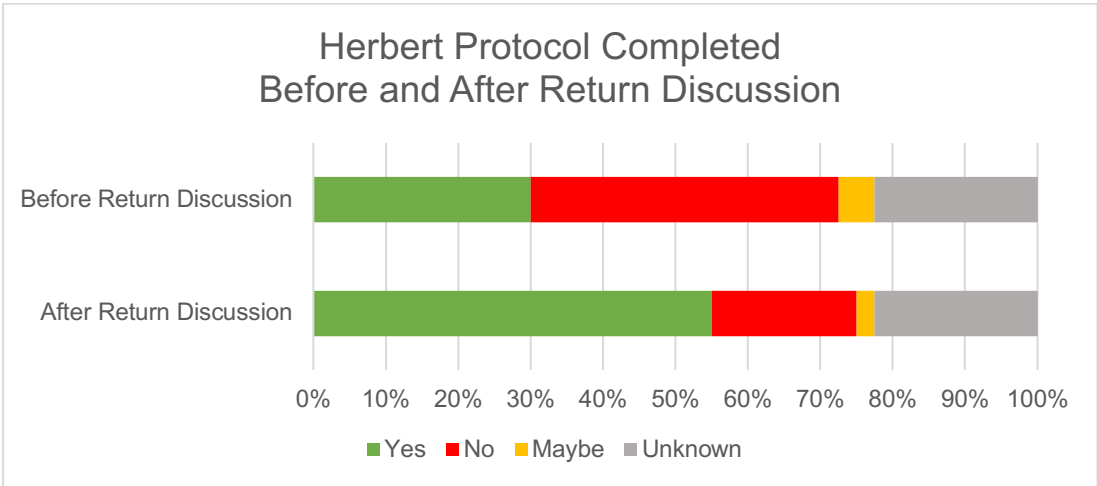


Figure 5: Number of Herbert Protocols completed before and after the Return Discussions

### ***Qualitative information related to the Return Discussions***

#### *What happened to make people go missing?*

The Return Discussions provided an opportunity to gain a better understanding about what people were doing prior to going missing. Given that the Return Discussions were completed by a family member/carer, as the person with dementia would be unlikely to remember the incident, there was often not a lot of information given regarding the circumstances before the missing incident. It was sometimes reported that beforehand, people were settled at home, had carers visit, or were busy doing activities. In other cases, some people appeared unsettled, agitated, confused or had a lot on their mind. Whilst others had simply stated that they wanted to go out e.g. out for a walk, to go home or to see family. However there was no clear pattern and circumstances were often very individual.

#### *What happened whilst people were missing?*

The Return Discussions were also an opportunity to find out more information about what happened during the missing incident, such as where they went. It was often a family member or carer who first noticed that the person with dementia was not within their residence. There were also a few instances where the person's door alarm had been activated and the police were subsequently called. Typically the family, carer and/or care home staff would conduct a thorough search of the residence and surrounding areas. When their attempts of finding the person were unsuccessful, the police would then be called for further assistance.

There were a few instances where local people and services had assisted in finding the person who had been reported missing. For example, members of the public approached the missing person and offered their assistance, another member of the public told the searching family that they had seen the individual at a nearby bus stop, one individual flagged down a passing motorist who then gave them a lift home, and Lothian bus drivers were sometimes contacted and were able to confirm that a missing person was on their service.

It was often reported that people were 'walking with purpose' e.g. out for a leisurely walk, going to see a family member, were on their way to an old address or childhood home, or were going to use the local amenities such as shops, the bank or the pub.

The majority of people who were reported missing were not aware that they had been reported as such, and did not consider themselves to be lost or missing. However there was a small number of people who did appear lost and confused. A common opinion of families and carers was that their loved one had no recollection of the incident.

### *Interactions with the police*

Of those who were returned home by the police, it was often reported that people had positive interactions with the police officers, had a good rapport with them, and were happy to be returned home and arrived back home safely in good spirit. There was only a couple of occasions where the person was either annoyed by the police presence, or were initially resistant to the intervention.

### *Views of the family/carers*

The most common word that families used to describe how they felt was that of 'relief' that their loved one had returned home safely. However there were a small number who were angry or unhappy that the incident was able to occur in the first place, particularly those who went missing from a care home or hospital. Carer stress was also reported by several people. Many expressed that they were worried about the future in case the person goes missing again, with concern that the person may have to move to a care home as a result. Concerns were also expressed for people's safety, wellbeing and vulnerability when they go out. For example, would they be able to safely cross a road, could they judge the speed of approaching vehicles, and not being aware of potential danger they could be in (especially in the evening or when streets are not well lit).

### *What can be done to prevent future missing occurrences?*

Since the missing incidents, a couple of people were subsequently detained under the Mental Health Act in order to keep them safe. And for a few other people, there have been thoughts or discussions about moving the person into sheltered accommodation or a care home.

For those who were reported missing from care homes, a number of changes have since been implemented, such as:

- Accurate sharing of information e.g. pre-admission forms and visitor lists to be shared with non-clinical staff such as receptionists
- Reception to be made aware of residents who are deemed to be at risk of leaving the care home and the front page of the Herbert Protocol to be shown to them, along with a picture to help identify them
- Visitors will no longer have key codes to enter and exit the building - they will have to buzz to get in and out instead
- Polite notices put on doors to remind visitors not to let anyone exit with them
- Operational managers number to be passed onto families in emergencies, rather than going through the switchboard

- Welfare checks put in place for certain residents to ensure staff have regular visual contact throughout the day
- 15 minutes observations or 1:1 support being provided by staff members
- Repairs being made e.g. to a door a resident was able to leave from
- Upgrades made to security e.g. from all outside doors having an alarm to now being fitted with an electronic keypad instead
- Staff members briefed to ensure door alarms are always reset

An important feature of the Return Discussion is that the Dementia Advisor can provide reassurance, information, support and advice – all of which could prevent the person from going missing again in the future and help keep them safe. The Dementia Advisor would tailor their recommendations to the person's individual circumstances.

People were often advised of the Herbert Protocol. Some already had this in place, but for others a copy would be provided for the family to complete.

The use of technology was often discussed, such as the Purple Alert App, GPS trackers, Apple air tags, Ring doorbells, cameras and door alarms/sensors. Some people were advised of and referred to the Alzheimer Scotland Digital Dementia Advisor and the service they offer so that they could discuss these options in more detail.

A range of other support, services and information provided by Alzheimer Scotland were also discussed. This included About Digital and Me (ADAM), the counselling service, Dementia Friends Sessions, Edinburgh monthly 160 cafes, monthly oasis café, Edinburgh newsletter, under 65 service, carers afternoon tea, Time For You carers fund and dementia wallet cards. The Dementia Advisor would also leave their contact details should people need further information or advice again in the future.

Other types of support and services out with Alzheimer Scotland were also discussed. This included assisted walking services, buddy and befriending services, Capital Theatre newsletter, day centres, dementia friendly activities, Edinburgh Leisure Movement for Memories, Libertus, post diagnostic support via NHS Dementia Link Workers, Sight Scotland Veterans, and Social Care Direct.

Other types of healthcare professionals who are involved in supporting the person with dementia were also mentioned such as carers, community psychiatric nurses, dementia nurse, general practitioners and social workers.

## **CONCLUDING POINTS**

The main conclusion is that Return Discussions are an appropriate intervention, particularly with regards to gaining a better understanding of the missing incident and helping to identify people who could benefit from further support. Dementia Advisors are well informed on the range of support and services that are available to people, both within and outside of Alzheimer Scotland. The support provided during the Return Discussions could improve outcomes for people with dementia, reduce carer stress, and could help prevent future missing occurrences.

In order to build upon these findings, it would be beneficial to explore people's experiences of doing the Return Discussions, either through questionnaires or interviews, to gain a better sense of the impact they have on people with dementia and their families. This could provide further evidence of the benefits that Return Discussions have, providing justification for the potential roll out to other areas within Scotland.



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