

# Expanding Participation in Alzheimer's Association Safe Return® by Improving Enrollment

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Every adult with a diagnosis of progressive dementia is at risk for wandering away or becoming lost. Those with dementia may not have the capacity to remember crucial contact information or recognize an unsafe situation, so enrollment in a program like Alzheimer's Association Safe Return is crucial. One facility-level enrollment plan at the James A. Haley Veterans Hospital in Florida has had a relatively high participation rate. A mailed survey was used to help evaluate that enrollment process and the results are described here. Of 262 respondents to the survey, 193

(74%) indicated the person with dementia enrolled in Safe Return. Potential enrollees need the following facilitators: perception of an unsafe situation, financial support and easy processing. Safe Return is not just focused on those who wander but is essential for all persons with dementia as these individuals can become lost in the course of normal daily activities.

**Keywords:** Alzheimer's; dementia; Safe Return; veterans; wandering

## Introduction

Every adult with a diagnosis of progressive dementia is at risk for wandering away from his or her caregiver and becoming lost, regardless of stage of disease, past behavior, age, or any other characteristic.<sup>1,2</sup> Common circumstances include exiting the home when the caregiver is distracted by other tasks, being out on a normal activity but not successfully returning, leaving the home when angry, becoming separated from the

caregiver while out in the community, and leaving a professional care setting alone.<sup>1</sup> While most individuals are safely returned, some who become lost are seriously injured or die before they are found.<sup>2</sup> Because incidents of wandering away are unpredictable, prevention is challenging. It is important to ensure that anyone who identifies a lost person with dementia can rapidly get assistance to return the individual to his or her care setting.

In 1993, the Alzheimer's Association established Safe Return,<sup>1</sup> a national identification and support program helping adults with Alzheimer's or related dementias who may wander away and become lost. Because a person with dementia may not have the capacity to remember his or her name and address or to recognize an unsafe situation, participation in a program like Safe Return is crucial. Enrollment is typically done on an individual basis, and historically there has been minimal response, even when a large

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<sup>1</sup> In fall 2007 the Alzheimer's Association renamed this program 'MedicAlert® + Safe Return®' as the result of a merger. For general information on the new program see [http://www.alz.org/we\\_can\\_help\\_medicalert\\_safereturn.asp](http://www.alz.org/we_can_help_medicalert_safereturn.asp).

organization covers the enrollment fee as part of its community service.<sup>3,4</sup> One facility-level enrollment program in progress at the James A. Haley Veterans Administration Medical Center in Tampa, Florida (Tampa VA) has had a notable 25% participation rate. We discuss the Tampa VA's efforts here so that other organizations can devise strategies to increase enrollment into Safe Return.

## Overview of Safe Return

Safe Return is a nationwide program that provides 24-h assistance when a person is lost. When an enrollee is reported missing the support network is immediately activated. Safe Return faxes the person's information and photograph to local law enforcement. When the person is found, the official or citizen calls a toll-free number and Safe Return alerts the contacts. More often, Safe Return is notified that an enrollee has been found who was never reported missing, in which case Safe Return contacts the caregivers on file. A comprehensive list of included benefits is described elsewhere<sup>5</sup> or by visiting <http://www.alz.org>. By 2007 the program had registered more than 145 000 individuals and facilitated the recovery of over 11 000 individuals to their caregivers.

## Overview of the VA enrollment program

In spring of 2005, the Patient Safety Center at the Tampa VA partnered with the Alzheimer's Association to implement large-scale enrollment into Safe Return to enhance patient safety for a vulnerable group of veterans, the majority of whom are community-dwelling. Each year a clinical database extraction is done. Any veteran seen at the Tampa VA and diagnosed with Alzheimer's disease or dementia is contacted by letter, sent out in batches annually, introducing the Safe Return program. Included is a special enrollment brochure that verifies for the Alzheimer's Association the veteran's eligibility for a fee waiver. Letters are also available in outpatient clinics and from social workers for distribution to newly diagnosed patients. These veterans or their caregivers then mail the completed form. The veteran is not subject to the enrollment fee: rather, the Tampa VA pays after receiving an invoice from the Alzheimer's Association. The main drawback to this method is that the responsibility of enrollment for community-dwelling patients lies with veterans'

families. A more comprehensive option would be to assist the patient and family with form completion, although that would require a longer time in clinic and greater personnel resources. This may, however, be considered for those having a difficult time completing the enrollment form. For veterans who received letters but did not enroll, at least two follow-up phone calls are initiated by the Alzheimer's Association and assistance with enrollment is given at that time. Frontline providers at the Tampa VA are also provided with notification and education about the program.

## Enrollment Questionnaire

To evaluate enrollment into Safe Return, brief (one page) questionnaires were sent to every veteran ( $n = 1910$ ) who had previously received an invitation by mail to join the program (see Tables 1 and 2 for complete questions). The questionnaire contained items about choosing to participate in the program, other times they had heard about Safe Return, and items on facilitators and barriers to enrollment. These items were generated from the authors' knowledge and experience regarding Safe Return enrollment. They were listed in an easy-to-complete check-off format but additional information could be handwritten. To facilitate broad participation, the questionnaire was purposely short and focused specifically on the enrollment process.

Because of privacy issues and the mailed format, we were unable to identify if the forms were completed by the person with dementia or by the caregiver. Although it is probable that responses differed by respondent type, in general the caregiver decides about enrollment into Safe Return. In addition, eligible veterans have varying degrees of dementia which may have affected the completeness and accuracy of responses. Privacy restrictions did not allow us to positively confirm participation in Safe Return for those who stated that they enrolled. These limitations mean that our analysis is descriptive in nature, and we report only variable frequencies and comments.

Within 4 months we received 320 (17%) responses to the mailed survey. Many replies were simply notices that the veteran had died, and others were grossly incomplete. Those indicating this was the first time they had heard of the Safe Return program though the VA were taken out of analysis ( $n = 19$ ). These respondents maintained that they had never received a mailed invitation to enroll. Because there was no way to verify receipt this may have

**Table 1.** Enrollment Status by Method of Contact

How did you Hear About the Safe Return <sup>®</sup> Program? <sup>a</sup>	Safe Return <sup>®</sup> Status	
	Enrolled, n = 193 (%)	Did Not Enroll, n = 69 (%)
Received letter in the mail	151 (78)	48 (70)
VA health care provider	60 (31)	10 (14)
Other	28 (15)	5 (7)

a. Multiple answers acceptable.

**Table 2.** Factors Affecting Enrollment

Which of the Following Influenced Your Decision (to Enroll in Safe Return <sup>®</sup> )? <sup>a,b</sup>	Safe Return <sup>®</sup> Status	
	Enrolled, n = 193 (%)	Did Not Enroll, n = 69 (%)
Made caregiver feel safer	154 (80)	5 (7)
Enrollment fee paid by VA	141 (73)	4 (6)
Made me feel safer	131 (68)	4 (6)
Not applicable: I do not get lost	20 (10)	31 (45)
Monitored continuously so not needed	14 (7)	16 (23)
No current photo	29 (15)	1 (1)
Misplaced pamphlet	8 (4)	10 (14)
Could not find law enforcement number	7 (4)	1 (1)
Recipient would not wear jewelry	10 (5)	3 (4)
Could not measure wrist	5 (3)	0
Other	16 (8)	5 (7)

a. Multiple answers acceptable.

b. Respondents reported experiences as well as influences.

been true, but a more plausible explanation is that the individual with dementia opened the letter without assistance from a caregiver. The final sample size was 262 veterans.

## Questionnaire Results

Gender was the only demographic variable available: individuals eligible for Safe Return registration were overwhelmingly male (95%), which is reflective of the older VA population. From the respondents, 193 (74%) indicated the person with dementia had enrolled in Safe Return and 69 (26%) had not enrolled (Table 1). Almost 3 out of 4 respondents reported learning of Safe Return from the original mailed invitation to participate in the program. One in three veterans who enrolled reported that a VA health care provider told them of the program; the rate was half that (ie, one in six) for those who did not enroll. The most common entry for the "other"

category signifying where the veteran had learned about the program was the Alzheimer's Association, particularly local support groups, although the frequency was low (7%-15%).

There was wide variation in answering the question "Which of the following influenced your decision [to enroll in Safe Return]?" and multiple answers were acceptable. The sole requirements for enrollment are completion of contact information on the enrollment form; additionally, a current photo, local law enforcement contact information, and wrist measurement for jewelry are recommended. Respondents plainly included experiences as well as decision factors, because some answers appeared contradictory (eg, enrolled in program but also marked "no photo" or "monitored continuously so not needed"). The top reason (80%) for enrollment was making the caregiver feel safer, followed closely by the fee waiver (73%) and making the person with dementia feel safer (68%). The most frequent reasons cited by those who did not enroll were

“Not applicable: I don’t get lost” (45%) and the belief that the caregiver could provide continuous monitoring (23%).

## Discussion

Results of the survey suggest that current strategies for the Tampa VA’s Safe Return enrollment program are modestly effective and that barriers to increasing enrollment are often centered in veterans’ perceptions that the program is unnecessary, even with evidence to the contrary. Comments on questionnaires indicated that some of the recipients had never wandered. This was given as a reason for many not to enroll; conversely, others in the same situation considered Safe Return a type of insurance policy for future adverse events. It is clear that potential enrollees need the following facilitators: perception of an unsafe situation, financial support, and easy processing. Although very few respondents indicated they had received a follow-up call from the Alzheimer’s Association, we know from the clumping of enrollment (a large group within 4 weeks of mail out, and then another group after the phone calls) that it was useful to have follow-up calls within 6 to 8 weeks of mailing the letters.

Nonenrollees had little or no perception of a safety issue or they could not find the original pamphlet. Several wrote they did not have Alzheimer’s or a similar dementia, typified with this comment, “Thank the Lord I don’t have dementia.” Such assertions are in direct contrast with their medical records. As stated earlier, many who did not enroll reported they did not get lost. Some caregivers felt strongly that Safe Return was not necessary since they successfully monitor the veteran, even when the veteran lived alone. Comments indicating other reasons for not enrolling included veterans not being ambulatory, taking of medications or placement in a nursing home.

## Recommendations for Practice

Research has begun to differentiate the problem of wandering (defined as aimless or repetitive walking around the environment) from that of becoming lost in the community.<sup>1,2</sup> When working with the patient and family, it is critical to differentiate these two issues as all individuals with dementia are at risk for

becoming lost in the community regardless of whether the individual wanders. When presenting the Safe Return program, it is important to emphasize that the program is not just for those who wander and is essential for all persons with dementia as these individuals can become lost in the course of normal daily activities.<sup>1</sup> One effective approach has been to illustrate that, even in the best care giving situations, the patient and caregiver may get separated and it is unlikely that the person with dementia will be able to remember essential information that would facilitate a rapid reunion. Safe Return can provide that voice. Building on the lessons from the current Safe Return enrollment program, the Tampa VA plans to expand enrollment, collaborating with the VA National Center for Patient Safety to export this program nationally.

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