

## Dementia and Wandering Behaviour in Long-term Care Facilities

*Nina M. Silverstein, PhD, Associate Professor, Gerontology, University of Massachusetts Boston, College of Public & Community Service, Boston, MA.*

*Gerald Flaherty, Director of Special Projects & Safe Return Alzheimer's Association, Massachusetts Chapter, Boston, MA.*

*Nearly half of all residents in long-term care settings suffer from some type of dementing illness, with Alzheimer disease by far the most common type. People with dementia should be presumed at high risk for wandering due to their cognitive deficits and unpredictable behaviour. Recommendations are shared to minimize attempts to wander and actual wandering episodes by promoting a more therapeutic environment both through the physical structure and through staff training. In addition, effective strategies to follow in situations when a resident is, in fact, missing are presented.*

**Key words:** dementia, wandering, long-term care, environment.

### Introduction

The Canadian Study of Health and Aging Working Group estimates that of the 364,000 Canadians 65 years and older who have Alzheimer disease or a related dementia, half live in institutional care settings.<sup>1</sup> The working group further estimates that by 2031, over 750,000 Canadians will have Alzheimer disease or a related dementia.<sup>2</sup>

Nearly half of all residents in long-term care settings have some type of dementing illness,<sup>3</sup> with Alzheimer disease by far the most common type. Reports on the prevalence of wandering from long-term care institutions range from 11–24%,<sup>3,4</sup> yet many experts agree that all people with dementia should be presumed at high risk for wandering due to their cognitive deficits and unpredictable behaviour.<sup>5,6</sup>

Increasingly frequent wandering episodes, in part, account for why caregivers of community-residing persons with dementing illnesses make the decision to institutionalize. Often, there is the assumption that an institutional environment will be safer, but safety cannot be assumed. Decades ago, Burnside reported that approximately 20% of the staff in long-term care facilities were aware of at least one incident resulting in the serious

injury or death of a wanderer.<sup>7</sup> In the 1990's, Kennedy estimated that each week one resident of a nursing home facility in the U.S. wandered off the premises and died.<sup>8</sup>

Attempts at wandering are also a problem in institutions. Research conducted by Gaffney in an institutional setting found that over a 15-hour period, "a population of 28 wanderers attempted to leave the unit 457 times and attempted to use an exit 274 times."<sup>9</sup>

Interventions and management strategies must take into account this critical information. There are many safeguards that can minimize both attempts to wander and wandering episodes, and there are effective practices to follow in situations when a resident is, in fact, missing.

### Costs and Consequences Associated with Unsafe Wandering Behaviour

When considering a common problematic behaviour, it is important to understand its economic impact as well as its stressful and dangerous nature. There is often a large cost associated with the recovery of those who have wandered and become lost. Such costs are accrued "in terms of lost time for nursing home

staff and often the public safety costs of police, fire and rescue units searching for these individuals."<sup>10</sup>

A study of insurance claims against nursing homes reveals that 70% of elopement claims involve deaths of residents, 45% of elopements occurred within the first 48 hours of admission, and 80% of elopements involved chronic, or repeat, wanderers.<sup>11</sup>

Regarding injury, Mayer and Darby cite the potential for encountering hazards, falls and fractures that is associated with this problem behaviour.<sup>12</sup> Additionally, individuals with dementing illnesses who wander and become lost are at high risk of dehydration and hypothermia, and may experience a catastrophic reaction (i.e., a severe and disorienting anxiety attack) at any time when lost.<sup>13</sup>

### Physical Environment and Level of Staff Training

Two critical factors to consider in measuring how well a facility is likely to manage wandering behaviour are the physical environment and the level of staff training. Considering the relationship between environment and staff training, the goal of the long-term care industry should be to place well-trained staff in a therapeutically dementia-friendly environment. Cohen-Mansfield *et al.* note that while "nursing home residents who pace or wander present significant management problems for caregivers", staff should consider pacing a reflection of good physical health and a behaviour—under optimal environmental conditions—to be encouraged rather than restricted.<sup>14</sup> This positive orientation to a high-risk behaviour is not likely to come naturally to staff, and suggests a need for specialized training.

A negative orientation to a high-risk behaviour such as wandering is likely to involve dependence on physical and chemical restraints. Yet physical restraints often result in serious injuries and

increased agitation.<sup>14,15</sup> Souren and colleagues further argue that “physical restraint does not relieve the existing anxiety and agitation and often leads to more disruptive behaviours, such as screaming and aggression. Physical restraint also promotes a premature loss of ambulation.”<sup>16</sup> Chemical restraint bodes no better for residents with dementia, and may cause serious side effects such as paranoia and hallucinations.<sup>15</sup> In light of this evidence, an increasing number of nursing homes are utilizing alternatives to restraints.<sup>17</sup> Facilities must continue to focus on effective interventions that safely accommodate wandering behaviour, since measures to eliminate it have proven counterproductive.

The optimal situation is to have staff specially trained in dementia care and working in a therapeutically supportive environment. Where the optimal situation does not exist, facilities’ short-term goals should be to have well-trained staff compensate for a less than optimally therapeutic environment, and vice versa—that is, a strong environment that compensates for staff with minimal training. Trained staff who are aware of the specialized needs of dementia residents on their units and who can provide appropriate activities under close supervision, including daily outdoor walks, may be able to minimize the effect of an

environment with poor exit control. Similarly, a staff unfamiliar with the specialized needs of dementia residents that does not provide close supervision may avoid potentially catastrophic situations when working in an environment with strong exit control.

Staff training, particularly in the areas described in Table 1, is important for the successful management of wandering residents. Levels of staffing and specialized training are observable and measurable. Ideal staffing ratios, for example, have been suggested at one staff person for every five residents, with a ratio of 1:8 or more considered “insufficient”.<sup>9</sup>

The environment, however, requires assessment by a trained eye to know what, exactly, makes it therapeutic and supportive. Zeisel and colleagues defined eight environmental factors in institutional settings that can have a therapeutic influence on the behaviour of residents with Alzheimer disease (Table 2). With Zeisel’s Environmental-Behaviour (E-B) checklist, it is possible to walk through a facility and objectively assess the degree to which its environment therapeutically responds to behaviours associated with dementia.<sup>18</sup>

Three of the environmental influences specifically relate to managing wandering behaviour: exit control, wandering paths and outdoor freedom. *Exit*

*control* refers to the boundary conditions of each facility—the surrounding walls, fences and doors, and how these are locked or otherwise limit or allow people to come and go. *Wandering path* refers to both indoor and outdoor spaces that residents use to move around. *Outdoor freedom* refers to residents’ access to common outdoor areas and the way in which these areas support residents’ needs. It should be noted, however, that regulations vary by locality and may impact a facility’s ability to implement dementia-friendly design criteria.

### Recommended Management Strategies

Strategies to protect individuals and long-term care facilities from the risks associated with wandering behaviour can be grouped as follows:

- **Environmental management strategies** for both the interior and exterior, including design and layout features as well as the use of assistive devices and techniques such as alarms, camouflage and other exit control techniques. These visual cues and barriers capitalize on the cognitive deficits and visual agnosia common in residents with Alzheimer disease or a related disorder.
- **Formal strategies** such as conducting facility and individual level assessments, developing a Lost Person Plan, conducting appropriate staff training and other organizational policies, such as registering residents in the Alzheimer Wandering Registry in Canada.
- **Stimulation strategies** such as providing increased activity, chores and other stimulation during the day, eliminating negative stimulation (e.g., avoiding high noise and traffic areas; removing clutter, food trays and medical or cleaning equipment; playing soothing music), and generally creating a calm environment.
- **Visual cues** such as posting traffic stop signs at exit doors, and removing coats, hats and umbrellas from exit areas to avoid “cueing” the dementia resident to exit.

Table 1

#### Staff Training for Successful Management of Wandering Patients

Approaching residents in ways that avoid catastrophic reactions:

- never confront or argue
- foster trust through eye contact and non-threatening interaction
- communicate reassurance in voice and manner

Responding with creativity and acceptance, not in punitive and controlling ways. Try to gently redirect to an alternative activity, for example.

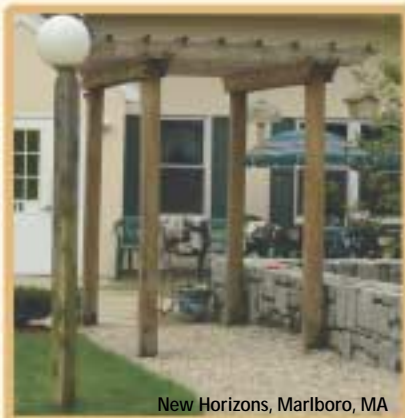
Recognizing the importance of residents’ need to move, and what constitutes an environment designed for safe movement.

Accounting for each resident’s whereabouts on the shift change report before the end of each shift.

Communicating with families.

**Back Home Visual Cue**

Residential exit clearly announces to residents in the garden—this is the way back home.



New Horizons, Marlboro, MA



Esplanade, Manhattan, N.Y.

**Residential Back Patio**

Cookouts and garden parties with the families make everyone feel at home.

**Outdoor Privacy**

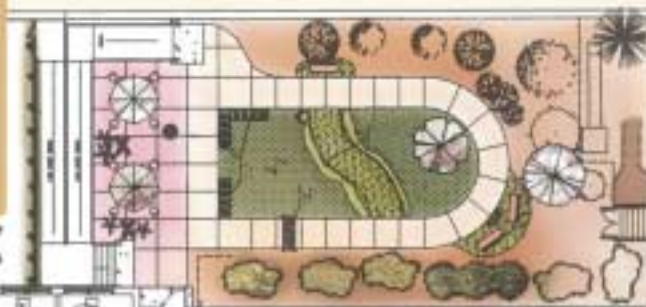
A solitary bench provides a private place outdoors.

**Obvious Walking Path**

Clearly delineated garden path with plants and grass on both sides is self evident to residents.

**Outdoor Security**

A high decorative fence and building walls create full security in the garden and thereby offer independence.



**The Park: A Chance to Get Away**

Several benches surrounded by bushes and trees look back over the gently sloped garden—a peaceful retreat.



Choate, Woburn, MA

**Actively Decorated Walking Path**

Direct pathway to dining room and beyond is decorated with resident-selected photographs to provide a recognizable sense of place.



Esplanade, Manhattan, N.Y.

**Hearthstone Alzheimer Treatment Residences:**

**A Model Therapeutic Environment**

- **Monitoring strategies**, including walking with, following or shadowing the resident.

## Develop and Implement a Formal Plan

Karcher notes that: “Written policies and procedures must exist that comply with legislative and statutory regulations for their use. These guidelines should include education and training requirements for staff, residents and families; procedures to obtain informed consent; consistent monitoring; documentation of the rationale for and continued use of restraints; regular observation and reporting to ensure that guidelines are followed; and periodic reviews of policies and procedures.”<sup>19</sup> In attempting to mitigate wandering risk, facilities should develop and implement a Lost Person Plan, which should include both a written plan for risk management as well as a plan of action in the event of a resident wandering and becoming lost. To assist in accurate identification, a photograph of each resident (with consent to use as necessary) should be taken at the time of move-in, and these photos should be kept in an easily accessible place. (For more information on creating a Lost Person Plan, see *Dementia and Wandering Behavior: Concern for the Lost Elder*, pp. 152–5).

Additionally, facilities should enroll residents in the Alzheimer Wandering Registry.<sup>20</sup> Similar to the Safe Return Program in the U.S.,<sup>21</sup> the Alzheimer Wandering Registry is a database registry designed to safely return people with Alzheimer disease who have wandered and become lost. Established in 1995 in partnership with Alzheimer Canada, Health Canada, Solicitor General Canada, the Royal Canadian Mounted Police, Block Parent Program of Canada and the Canadian Association of Chiefs of Police, the program has registered about 12,000 Canadians with dementia.

For a one-time fee of \$25, the person is registered in the national database and receives an identification bracelet, a Caregiver Handbook and identification cards. If the registrant is reported as miss-

ing, the registry can alert law enforcement agencies nationwide. If the registrant is found wandering, the identification bracelet advises the person who finds him to call the local police. The police then enter the identification number on the bracelet into their national computer database for information on where the person lives and who to contact in the case of an emergency. For more information on the registry, call 1-800-616-8816, or visit the Alzheimer Society of Canada’s website at [www.alzheimer.ca](http://www.alzheimer.ca).

A facility’s Lost Person Plan should direct staff to search the immediate vicinity as soon as a resident is determined to be missing, but staff should not spend more than 15 minutes on this task before calling police. It is imperative that staff do not wait until the end of meals or shifts to search or to call police. Let police know the resident is missing, and whether they are registered in the Alzheimer Wandering Registry. Then call the resident’s primary family caregiver.

## Conclusion

In summary, wandering and becoming lost is one of the most common and life-threatening behaviours associated with Alzheimer disease and related disorders. A well-trained staff, in combination with a therapeutically supportive environment, can minimize the risks associated with this behaviour. Registering residents in the Alzheimer Wandering Registry can assist search and rescue efforts in the event of a wandering episode. The real goal of long-term dementia care is to maintain safety in the least restrictive environment, and to use interventions that help maintain residents’ sense of independence and self-determination while also keeping them safe. Not every intervention will work for every resident. Facilities are encouraged to conduct ongoing assessments or “audits” to discover the strategies and safeguards that are most effective. Interventions should be multifaceted and geared as much as possible to the specific needs of individual residents. If one technique fails, there should be other safeguards in place. ◆

Table 2

### Zeisel’s Environmental-Behaviour (E-B) Checklist

Exit control
Wandering paths
Individual away spaces
Common space structure
Outdoor freedom
Residential scale
Autonomy support
Sensory comprehension

Material in this column is adapted from Silverstein NM, Flaherty G, Tobin TS. *Dementia and Wandering Behavior—Concern for the Lost Elder*. Chapters 6 and 9. New York: Springer Publishing Company, 2002.

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