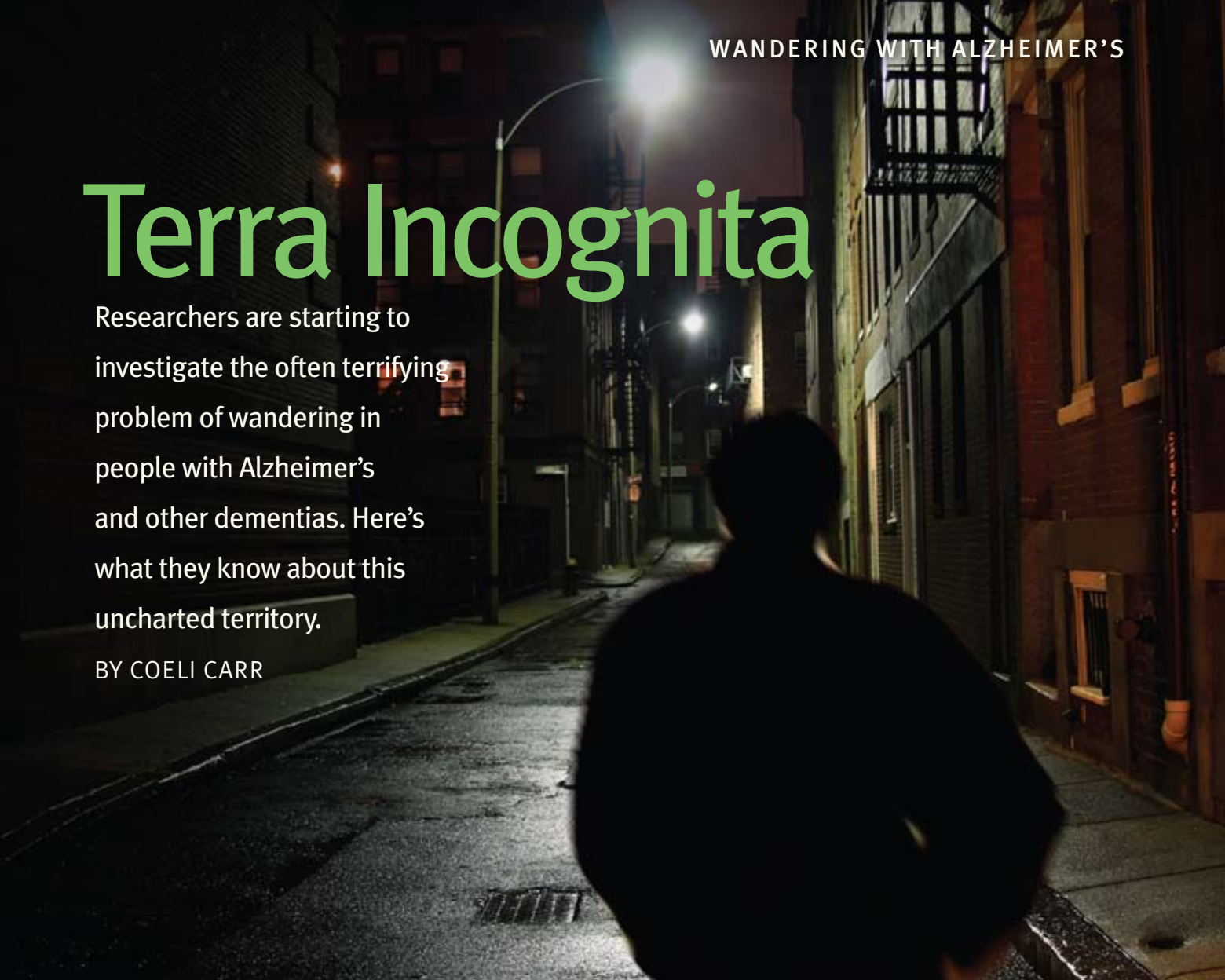


Terra Incognita

Researchers are starting to investigate the often terrifying problem of wandering in people with Alzheimer's and other dementias. Here's what they know about this uncharted territory.

BY COELI CARR



Meg and Skip Curtis were living their dream when Skip was diagnosed with Alzheimer's disease (AD) in 2006. Married 42 years, they were year-round innkeepers of Stonewall Farm Bed & Breakfast, a 224-year-old edifice set on 12 acres in Hillsborough, NH.

One year later, while visiting friends in Nantucket, Skip left the guest room to use the bathroom. "The next thing I remember is hearing a woman say, 'Here you go, Skip, here's where your room is,'" says Curtis, 61. He had mistakenly wandered into the nanny's bedroom.

It was a prelude of things to come.

One day this fall, Curtis found Skip sitting at their kitchen table at four o'clock in the morning, as if it were four in the afternoon.

"Every new episode is frightening," says Curtis, who refers to Skip, 62, as a "gentle wanderer." Although she knew wandering was a possible problem, she never believed it would happen to Skip. "I was in total denial," Curtis admits.

WANDERING

The Alzheimer's Association reports that of the estimated 5.3 million Americans living with the AD, six out of 10 will wander from their homes or caregiving facilities at some point during their illness.

Experts define AD as a degenerative brain disease related, at least in part, to the accumulation of proteins called amyloids in the brain. AD results in progressive cognitive decline, including memory impairment. Paranoia and anxiety are often part of the Alzheimer's package as well. So is wandering, a behavior that typically shows up in the middle stages of AD. Wandering is also common in people with frontotemporal dementia (FTD), a condition marked by communication difficulties and personality changes that generally hits individuals in their 50s or 60s.

Changes in the neurochemicals serotonin and dopamine seem to be associated with behavioral changes such as wandering. However, research hasn't definitively established this connection, says Marwan Sabbagh, M.D., a geriatric neurologist, dementia specialist, and director of clinical research at Banner Sun Health Research Institute in Sun City, AZ. Although

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wandering is a major issue for caregivers, it remains a woefully under-investigated aspect of the illness, Dr. Sabbagh says.

Because of the limited research that's been conducted, there aren't many options. Doctors generally use drugs that are intended to treat other medical conditions to treat the behavioral changes of AD, says Dr. Sabbagh. For example, he says, physicians might prescribe an antidepressant to address a wandering patient's perceived anxiety which they believe might provoke the wandering. Without a drug to control this activity, caregivers whose loved ones begin to wander often find themselves in uncharted territory.

WANDERING VS. GETTING LOST

People who wander don't usually have a destination or endpoint. Whether the Alzheimer's patient paces back and forth, shadows the caregiver from room to room, or shuffles items from one spot to another, most experts agree that wandering is a purposeless activity.

In contrast, says Dr. Sabbagh, getting lost, which tends to occur in earlier stages of Alzheimer's, is usually associated with purposeful activity. Someone can lose their way while heading to the supermarket—they may become confused about how to get there or suddenly forget what it was they had planned to do—but their initial goal was to buy groceries.

Sometimes the two activities seem intertwined, such as when a person with AD loses his directional bearings and then starts to wander. Although scientists don't know for sure why these individuals wander, certain factors do seem to fuel it, says Brian Ott, M.D., a neurologist and director of the Alzheimer's Disease and Memory Disorders Center at Rhode Island Hospital in Providence, and professor of neurology at the Warren Alpert Medical School of Brown University.

One stimulus is the delusion of wanting to go home—not to their current domicile but often to the place where they were raised, says Dr. Ott. He adds that the wanderer's confused state, memory impairment, and perceptual problems will often contribute to their getting lost while trying to find that place. Usually a person in this predicament relies on good judgment to get

help. But a person with Alzheimer's, whose judgment is already impaired, may not seek assistance, Dr. Ott says.

Another provocation is restlessness. Like lions in a cage, some individuals pace compulsively, especially at night.

THE NIGHT WANDERER

Wandering often occurs at night because of the disruption of the patient's sleep-wake cycle, which is part of the disease, says Dr. Sabbagh, author of *The Alzheimer's Answer: Reduce Your Risk and Keep Your Brain Healthy* (Wiley, 2008).

Kim Farris installed gates in the upstairs hallway blocking the stairs so her mother, Ethel Smith, would be deterred when she wandered. Ethel is 85 and was diagnosed with dementia four years ago. Unfortunately, Ethel—affectionately known by her maiden name, "Hobbie"—doesn't respond well to restrictions.

"She wakes up in the middle of the night, gets fully dressed, puts on all her gold jewelry, wanders down the hall, and rattles that gate, trying to figure out how to open it, which she cannot do," says Farris, 54, a medical transcriptionist who works from the home in Roswell, GA, that she shares with her husband and teenage son. "Hobbie's most dangerous time is between four and seven o'clock in the morning, when she's the most agitated and disruptive to the family." And, says Farris, when she puts her mother back to bed, "Hobbie fights like a tiger."

Marion Somers, Ph.D., a geriatrics consultant based in Gardena, CA, who has more than 40 years of experience in the field, believes there's another reason people with dementia confuse their days and nights.

"Caregivers and institutional administrators—concerned about harm

that might come to their charges outdoors—often keep wanderers indoors where they don't get enough Vitamin D, and this deficiency affects their internal clocks set by the sun," she says. "If you're unable to take the wanderer outdoors, sit them daily by the window for about fifteen minutes on each side." Your first priority, underscores Dr. Somers, is to keep your loved ones safe from harm.

TIPS ON CONTAINING WANDERING

Most experts agree that giving loved ones who wander as much freedom as possible, while keeping them safe, is the best strategy. Some points to keep in mind:

- ▶ **BE INFORMED.** Avail yourself of local support groups and online information.
- ▶ **PROVIDE COMPANIONSHIP.** Your loved one may be less inclined to wander if they're stimulated and engaged, especially in activities they enjoyed before behavioral changes set in.
- ▶ **SECURE YOUR ENVIRONMENT TO SECURE THE WANDERER.** Investing in locks, gates, and even alarm systems will keep nimble loved ones contained when your back is turned, or when you're trying to sleep through the night.



THE SAFETY FACTOR

Up to half the people with AD who wander will suffer serious injury or death if not found within 24 hours, says the National Alzheimer's Association. Because wandering can occur at any time, says Dr. Ott, caregivers must not only be vigilant but also put safety nets in place in case the person breaks free. Even if the person is not lost, the potential consequences of wandering—falls or the potential to go outside with inappropriate clothing—can be serious.

So what should families faced with this challenge do?

A good place to start is MedicAlert + Alzheimer's Association Safe Return®, a nationwide identification program designed to assist in the return of those who wander and become lost. You might consider having your loved ones wear a device that allows them to be tracked. Farris also encourages caregivers to enlist the help of their neighbors who can keep an eye out for elderly wanderers.

But harm can come to a wanderer indoors too.

The leading reason people with Alzheimer's are placed in institutional care is because of behavior, which includes the type of agitated wandering that eventually exhausts the caregiver, Dr. Sabbagh says.

"It's helpful for caregivers to understand that a lot of behavior associated with Alzheimer's is a reversal of development," says Dr. Ott, noting wanderers' return to exploratory activities

and checking things out. "All of a sudden, it's like living with a very young child."

Not surprisingly, many caretakers in a position to do so have wander-proofed their homes by installing child-proof safety locks on interior doors (often out of reach of the wanderer) and outside gates in the backyard.

This fall Meg Curtis renovated the B&B to provide a self-contained living and sleeping area for her and Skip. Their previous bedroom was upstairs and far from the bathroom. Their room is now on the main floor and includes a bathroom and kitchenette, eliminating the risk of descending the stairs. Curtis also installed keyed deadbolt locks, which lock from within, on all four doors of their new room.

Farris, who had long used an assortment of locks and gates, rearranged the furniture in Hobbie's room and in other parts of the house so that she has items to grab for physical support. "In the bedroom, the chair is aligned right next to the bed that's right next to the dresser," says Farris. "It's not pretty, but it's functional."

Farris also programmed her home's alarm system so that a chime sounds whenever a person exits to the outside and installed hand rails in certain areas of the home as a safety precaution. Perhaps most importantly, she hired a night sitter so that Hobbie could stay in her room through the night and installed a hook-and-eye latch on the door that her mother can't reach.

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THE PERSON INSIDE THE WANDERER

Many families who care for people whose brain degeneration provokes them to wander find the experience heartbreaking. The important thing for caregivers to keep in mind is that their loved ones probably don't know how to keep the window open to their true nature, says Dr. Somers, author of *Elder Care Made Easier: Doctor Marion's 10 Steps to Help You Care for an Aging Loved One* (Addicus Books, 2006).

"Keep in mind who the person is," advises Dr. Somers. If, in younger days, wanderers were outgoing, athletic, and had a high energy level, it's almost certain that those aspects of the personality and physicality still remain, she says. Those individuals may wander excessively to use up their innate energy. On the other hand, she says, someone with dementia who was accustomed to a more sedentary lifestyle might not wander as extensively or explosively.

It's also important to remember that these individuals had lifestyles, talents, and interests which can provide cues to keep them from restless nomadic behavior, says Dr. Somers. For example, someone who painted or photographed might welcome looking through art books or family snapshots. A person who was a gourmet cook might be calmed by doing simple tasks—or merely sitting—in the kitchen.

For a wandering former librarian whose family enlisted her expertise, Dr. Somers found comforting wallpaper: the design replicated bookshelves with the spines of the volumes facing the viewer. "The family papered all the home's exit doors with this wallpaper, and my client would stare at the papered books, no longer tempted to leave," she says.

For another client, who had a gardening hobby, Dr. Somers painted large sunflowers and a white picket fence on the family's home exit doors, resulting in the wanderer's never again setting foot, alone, beyond the painted barricades.

"With creative effort, most caregivers can come up with highly personalized solutions to excessive wandering and restlessness," says Dr. Somers. "The key is to tap into the person they were before Alzheimer's and wandering set in."

Because every person who wanders brings a unique set of past experiences to the table, every strategy to address wandering will similarly require a personal approach. But in the end, kindness and understanding may be all that matters.

"It's better if you say 'yes' to your loved ones who wander more than you say 'no,'" says Farris, who has maintained her compassion for her errant mother. "They're fixated and can't focus on anything other than what they want, which for my mom is to 'go home.' It's not a real place, but it's where she was in control." NN

RESOURCES

PRODUCTS

- ▶ **EmSeeQ:** Worn on the wrist of a person with Alzheimer's or other forms of dementia, the device, created by EmFinders, uses cell phone-location technology to determine the precise location of the wearer. If the wearer gets lost, the caregiver contacts local police or 911, and then calls EmFinders, who activates the system. EmFinders can locate a lost person in all 50 states, no matter how far the distance the wanderer has covered. Available online for \$185, plus a \$25 monthly service fee. Go to emfinders.com
- ▶ **The Alzheimer's Store:** An online retailer that sells items caregivers to wanderers can use, such as locks and alarm systems. Go to alzstore.com

PROGRAMS

- ▶ **MedicAlert + Alzheimer's Association Safe Return®** is a nationwide identification program designed to assist in the return of those who wander and become lost. Go to alz.org/safetycenter/we_can_help_safety_medicalert_safereturn.asp

BOOKS

- ▶ **The Complete Guide to Alzheimer's Proofing Your Home**, revised ed., by Mark L. Warner (Purdue University Press, 2000).

DVDS

- ▶ **Understanding Alzheimer's and Alzheimer's and Safety** (50 minutes, \$24.95). This two-program DVD, developed under the guidance of Alzheimer's Association experts, contains practical advice for caregivers and people with dementia.
- ▶ **Plain Talk About Alzheimer's Disease: Alzheimer's Related Dementia and Wandering** (62 minutes, \$24.95). Created by Kimberly R. Kelly, a former sheriff, this instructional DVD is primarily designed for law-enforcement agencies. It describes the general behavior of people diagnosed with Alzheimer's and other forms of dementia and addresses why they wander.

WEB SITES

- ▶ nia.nih.gov/Alzheimers/Publications/homesafety.htm: A good source of room-by-room safety tips.