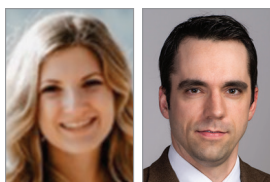# Wandering & Sundowning in Dementia

Preventive and acute management of some of the most challenging aspects of dementia is possible.

By Taylor Thomas, BA and Aaron Ritter, MD

Alzheimer disease (AD) and related dementias are complex disorders that affect multiple brain systems, resulting in a wide range of cognitive and behavioral manifestations. The behavioral symptoms often have clinical analogs in idiopathic psychiatric disorders and are frequently referred to as neuropsychiatric symptoms (NPS) of dementia. Many therapeutic strategies for NPS are borrowed from treatment of idiopathic psychiatric disorders. For example, selective serotonin reuptake inhibitors (SSRIs) commonly used to treat major depressive disorder may also be prescribed for depressive symptoms in AD. This strategy has been deemed the "therapeutic metaphor" and has shown varying degrees of success in clinical trials.[1]

Clinicians face significant challenges, however, when there is no suitable metaphor to guide treatment for behaviors that emerge solely in dementia. This is particularly problematic for 2 of the most burdensome behavioral manifestations of dementia—sundowning (the worsening of symptoms in the late afternoon and early evening) and wandering. Despite being among the most impactful behaviors in dementia, there is very little research evidence to guide therapeutic approaches. This review provides a brief update of the current literature regarding wandering and sundowning in dementia. Using evidence-based approaches from the research literature, where available, and best practices adopted from our own clinical practice when little evidence exists, we outline a practical treatment algorithm that can be used in the clinic when facing either of these common and problematic behaviors.

Wandering Frequency, Consequences & Causes

Wandering is a complex behavioral phenomenon that is frequent in dementia. Approximately 20% of community-dwelling individuals with dementia and 60% of those living in institutionalized settings are reported to wander[2] Most definitions of wandering incorporate a variety of dementia-related locomotion activities, including elopement (ie, attempts to escape), repetitive pacing, and becoming lost.[3] More recently, the term "critical wandering" or "missing incidents" have been used to draw distinctions between elopement and pacing vs wandering and becoming lost.[4] Critical wandering episodes have a high mortality rate of 20%, placing this symptom among the most dangerous behavioral manifestations of dementia.[5]

The risk of wandering increases with severity of cognitive impairment, with the highest rate in those with Mini-Mental State Exam (MMSE) scores of 13 or less.[6] Individuals who frequently wander (ie, multiple times per week) almost always have at least moderate dementia. Few studies have compared wandering rates among people with different types of dementia.[7] Experience from our clinical practice suggests that wandering is most common in AD—where spatial disorientation and amnesia are common clinical features—but can also occur in moderate to advanced stages of behavioral variant frontotemporal dementia (FTD) and Lewy body dementia (LBD). The presence of comorbid NPS (eg, severe depression, sleep disorders, and psychosis) may increase the likelihood of wandering.[8]

Causes of wandering are not well understood. Some hypothesize wandering emerges from disconnection among brain regions responsible for visuospatial, motor, and memory functions. A positron-emission tomography (PET) study of 342 individuals with AD, 80 of whom were considered wanderers, found a distinct pattern of hypometabolism in the cingulum and supplementary motor areas among wanderers. Correlations between specific brain regions and the type of wandering (eg, pacing, lapping, or random) were also seen.[9]

A relatively larger body of research informs psychosocial perspectives on wandering with 3 scenarios identified in which wandering behaviors commonly emerge, including 1) escape from an unfamiliar setting; 2) desire for social interaction; and 3) exercise behavior triggered by restlessness or lack of activity. Other factors that increase wandering behavior include lifelong low ability to tolerate stress, an individual's belief that they are still employed at a job, and a repeated desire to search for people (eg, dead family members) or places (eg, a home where they no longer reside).[10]

Managing Wandering

There is little empiric evidence to inform treatment approaches to wandering in dementia. Nonpharmaceutical interventions that promote "safe walking" instead of aimless wandering are preferred initial approaches. Several "low tech" options with low associated costs and negligible side effects have some evidence for use, including exercise programs, aromatherapy, placing murals and other paintings in front of exit doors, or hiding door handles.[11] More recently, the explosion of discrete and affordable wearable devices that have global positioning system (GPS) tracking ability have significantly expanded the number of "high-tech" options available to address elopement. These include GPS tagging, bed and door alarms, and surveillance systems. Few have been tested in prospective, placebo-controlled studies, however, making it hard to make firm conclusions regarding efficacy.[12] The ethical implications of using these technologies—including potential infringements on privacy, dignity, and autonomy of individuals—are seldom considered in clinical trials or clinical practice.[13]

Considering the high prevalence and often deadly consequences associated with wandering, we offer a practical, algorithmic approach to wandering in dementia (Figure 1).

Screening for Wandering

To screen for wandering behavior, we ask the following 2 questions of or about all persons with dementia:

1. Have they ever wandered away from their home?
2. Have they ever gotten lost while in public?

If either of these are responded to affirmatively, we make recommendations and stratify risk as described below. If both questions are responded to with "no," we ask if they:

1. ever seem disoriented at home or in familiar places?
2. ever report a desire to go home even while at home?
3. become excessively nervous while in public?
4. talk about needing to fulfill prior work obligations?
5. ask about the whereabouts of past family or friends?

An affirmative answer to any of these 5 questions may indicate an increased risk for wandering. For those who wander or are at high risk for wandering we provide basic education, recommend increased diligence, and maximize behavioral strategies to improve orientation (eg, display a written calendar and/or a large digital clock with time and date and optimize use of cognitive-enhancing agents when appropriate).

Creating a Wandering Safety Plan

Once a wandering event has occurred, we recommend families develop a neighborhood awareness and safety plan. The Alzheimer's Association's website has excellent resources devoted toward developing this plan (https://www.alz.org/help-support/caregiving/stages-behaviors/wandering). At a minimum, the safety plan should include notifying neighbors that the person has dementia, keeping a list of places they are
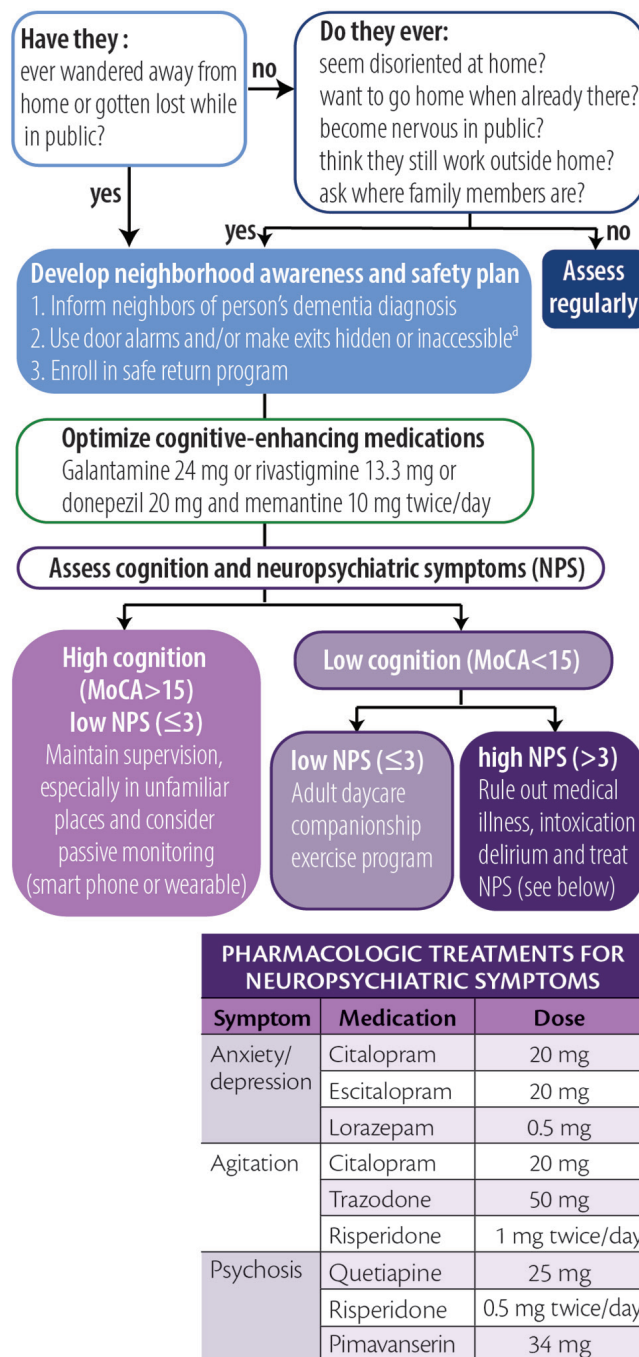
Figure 1. Algorithmic approach to wandering.
Abbreviation: MoCA, Montreal Cognitive Assessment. [a]Persons with dementia should never be left alone behind locked doors.

likely to wander to, and having a recent photo readily available for emergency medical and other services. We also educate families about the initial steps to take if wandering occurs, including immediately searching areas favoring the direction of the dominant hand, focusing the search within 1.5 miles of the home, and calling 9-1-1 no more than 15 minutes after

a person with dementia has been determined to be missing. Additional recommendations include obtaining medical identification jewelry, installing door alarms, and making locks inaccessible (ie, hiding them or placing them out of reach). Families should be encouraged to enroll in a safe return program (eg, MedicAlert, Project Lifesaver, or Silver Alert) if one is available in their area. It is important to note that people with dementia should never be locked by themselves inside a home.

Managing Risk by Stratified Wandering Type

Cluster analyses show people who wander can largely be grouped into 1 of 3 different types based on cognitive and behavioral characteristics.[14] These groupings are useful for tailoring interventions and can be identified for an individual with combined cognitive test scores and behavioral symptom profiles. We use the Montreal Cognitive Assessment (MoCA)[15] and the Neuropsychiatric Inventory–Questionnaire (NPI-Q)[16] because they are relatively quick to administer while providing important information and can be simultaneously administered to caregivers (NPI-Q) and patients (MoCA). These assessments can be used to stratify patients as follows.

Group 1: High Cognitive Function, Low Behavioral Disturbances. Individuals who score greater than 15 on the MoCA and have 3 or fewer behavioral symptoms wander infrequently (<1 time/month) and often only in unfamiliar settings. Because wandering is usually triggered by unexpected stressors, the main goal for these individuals is to provide adequate supervision in unfamiliar settings. Those in this group may also still carry a mobile phone with several high-tech options (eg, GPS systems or "find my phone" apps) that may be beneficial.

Group 2: Low Cognitive Function, Low Behavioral Disturbances. Persons with lower cognitive test scores (eg, ≤10 on the MoCA) and fewer than 3 NPS may wander because of boredom or a lack of physical or cognitive stimulation. For this group, we recommend a companion caregiver or adult daycare program to engage the patient in enjoyable activities and incorporate supervised walks or exercise programs during the day. Individuals in this group may benefit from the creation of an outdoor area that may be explored safely.

Group 3: Low Cognitive Function, High Behavioral Disturbances. People in this group require the most proactive approaches because they are likely to be the most frequent wanderers and may be at highest risk for dangerous outcomes. Wandering in this group may be driven by delusions, particularly the persecutory type.[8] We recommend, as a first step, determining whether other factors such as pain, delirium, or intoxication may be contributing to the person's NPS. If no additional etiologies can be clearly identified, comorbid NPS should be addressed with best clinical practices, borrowing heavily from psychiatry with the "therapeutic metaphor" (See *Neuropsychiatric Symptoms in Dementia* in this issue). Many in this group may require institutionalization or constant supervi-

sion from hired caregivers to prevent harm. Nonpharmacologic strategies recommended for this group include taping a 2-foot black threshold in front of each door to serve as a visual barrier, installing cameras and warning alarms for outward facing doors, and installing safety gates around the house.

Sundowning Frequency, Consequences & Causes

Sundowning is the term used to describe the emergence or intensification of NPS occurring in the early evening. This phenomenon, thought to be unique to people with dementia, has long been recognized by researchers and caregivers as being among the most challenging elements of dementia care.[17] Although most frequently seen in AD, sundowning has also frequently been observed in other forms of dementia. Sundowning is among the most common behavioral manifestations of dementia, with rates in institutionalized settings exceeding 80%.[18] The risk of sundowning increases in moderate and severe dementia and because of its close association with sunlight, is more common in the autumn and winter seasons.[19]

The impact of sundowning on persons with dementia is immense. Sundowning is among the most common reasons for institutionalization and is associated with faster rates of cognitive decline and increased risk for wandering.[17] Sundowning also increases care partner stress, which, in turn, may increase risk for agitation in patients.[18]

The causes of sundowning are likely multifactorial. Sundowning is commonly linked to alterations in circadian rhythms.[19] Autopsy studies of people who had AD show a disproportionate loss of neurons in the suprachiasmatic nucleus (SCN), which regulates the release of melatonin in response to light.[20] Other research links sundowning to reductions in cholinergic neurotransmission,[21] and at least 1 study showed increased levels of cortisol, which may suggest alterations of the entire hypothalamic-pituitary axis.[21] Sleep disruption, inadequate sunlight exposure, and disrupted routines increase the likelihood of sundowning.[17] Medications with anticholinergic properties and sedatives may also exacerbate sundowning.

Management of Sundowning

The Progressively Lowered Stress Threshold (PLST) model provides a framework for understanding and managing sundowning.[22] In this model, sundowning occurs because diurnal alterations in circadian rhythms temporally correlate with increases in pain, hunger, or fatigue that occur later in the day. Disruptions in emotional regulation emerge when a person's ability to tolerate such stressors is exceeded.

As with wandering, there is little empiric evidence to guide pharmacologic management of sundowning. Melatonin has been studied in several open-label studies and case series with varying levels of success.[23] Cholinesterase inhibitors and memantine reduce agitated behaviors, but have not been studied for management of sundowning.[24] Nonpharmacologic

interventions (eg, eliminating daytime naps, increasing sunlight exposure, aerobic exercise, and playing music) can reduce sundowning,[17] but it is difficult to make firm conclusions about the efficacy of these measures because most have not been evaluated in prospective, placebo-controlled studies.

Analogous to headache management, approaches to sundowning can be broadly categorized as acute or preventive (Figure 2). Although preventive approaches may be more effective, caregivers may be able to reduce NPS associated with sundowning when it occurs.
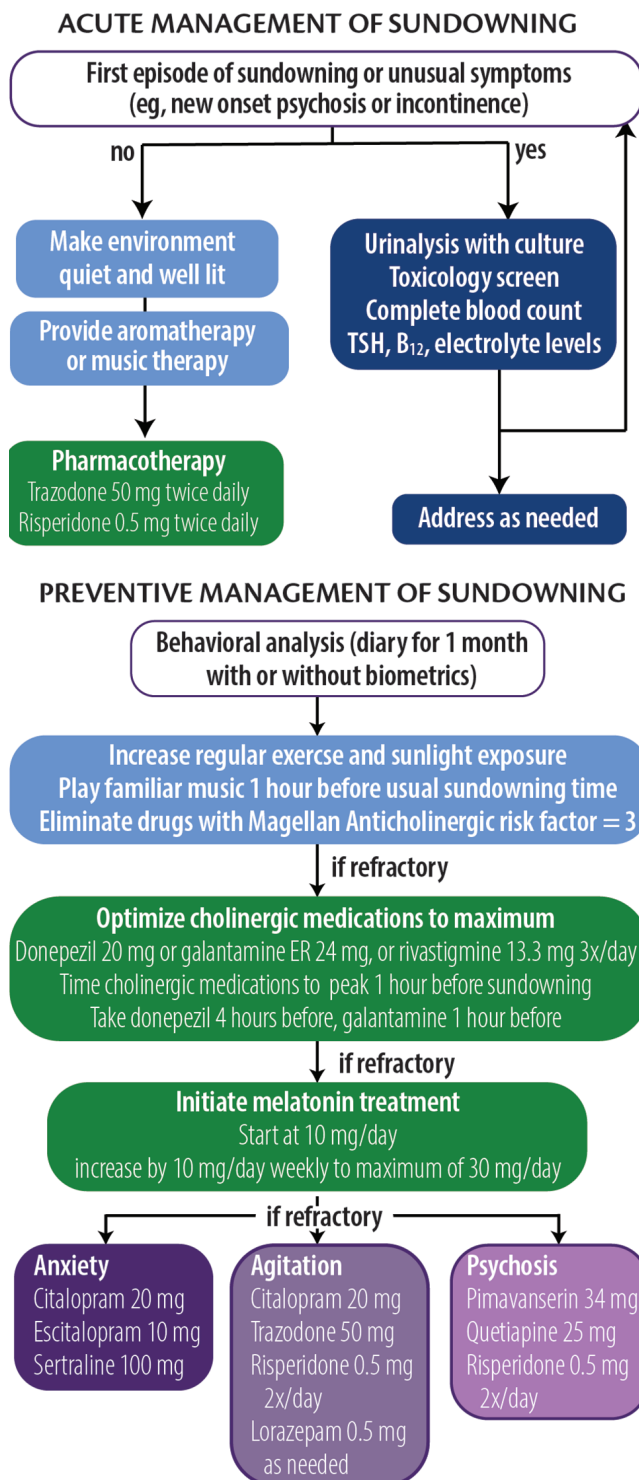
Acute Management

The PLST model can be used to identify any and all triggers that may contribute to sundowning episodes. For a first or unusual episode, it is recommended that a targeted medical and laboratory evaluation including urine culture, complete blood count, drug toxicology, and levels of electrolytes, thyroid-stimulating hormone (TSH), and vitamin B_{12} be obtained. During an episode, whenever possible, a quiet, well-lit environment should be provided. Aromatherapy and familiar music at a medium volume may also help reduce anxiety and agitation. For persons at risk of hurting themselves or others, a low-dose psychotropic medication (eg, trazodone 50 mg repeated 1 hour later followed by risperidone 0.5 mg) may be necessary.

Preventative Management

In our clinical experience, prevention strategies may reduce the severity and frequency of sundowning. The first step is to conduct a behavioral analysis of the sundowning behavior. We recommend a daily journal be maintained for at least 1 month to document the types of behavior (eg, agitation, anxiety, psychosis, and disorientation) that occur, time of onset, and any extenuating circumstances that may have contributed to episodes of sundowning. Care partners can also provide information regarding medication administration and sleeping behavior to inform the analysis. The health care professional should analyze the journal, looking for patterns and correlations with other factors (eg, shift changes at care homes or changes to daily routines). The journal can be supported by biometric data from wearable technologies that provide objective measures of physical activity and sleep, which can be helpful in tailoring both pharmacologic and nonpharmacologic approaches.

We also recommend increasing the amount of regular exercise and sunlight exposure, preferably in the early afternoon. Caregivers are advised to start playing soothing or familiar music approximately 1 hour before sundowning behavior typically starts. Any medication with Magellan Anticholinergic Risk Scale scores of 3 should be eliminated, which requires scrutiny of medication lists.[25] Optimization of cognitive-enhancing medication doses and timing administration such that mean peak plasma concentrations are reached 1 hour before a person's typical time of sundowning behavior may be beneficial.

ACUTE MANAGEMENT OF SUNDOWNING

First episode of sundowning or unusual symptoms (eg, new onset psychosis or incontinence)

no → **Make environment quiet and well lit** → **Provide aromatherapy or music therapy** → **Pharmacotherapy** Trazodone 50 mg twice daily Risperidone 0.5 mg twice daily

yes → **Urinalysis with culture Toxicology screen Complete blood count TSH, B_{12}, electrolyte levels** → **Address as needed**

PREVENTIVE MANAGEMENT OF SUNDOWNING

Behavioral analysis (diary for 1 month with or without biometrics)

↓

Increase regular exercse and sunlight exposure Play familiar music 1 hour before usual sundowning time Eliminate drugs with Magellan Anticholinergic risk factor = 3

if refractory ↓

Optimize cholinergic medications to maximum Donepezil 20 mg or galantamine ER 24 mg, or rivastigmine 13.3 mg 3x/day Time cholinergic medications to peak 1 hour before sundowning Take donepezil 4 hours before, galantamine 1 hour before

if refractory ↓

Initiate melatonin treatment Start at 10 mg/day increase by 10 mg/day weekly to maximum of 30 mg/day

if refractory

Anxiety Citalopram 20 mg Escitalopram 10 mg Sertraline 100 mg

Agitation Citalopram 20 mg Trazodone 50 mg Risperidone 0.5 mg 2x/day Lorazepam 0.5 mg as needed

Psychosis Pimavanserin 34 mg Quetiapine 25 mg Risperidone 0.5 mg 2x/day

Figure 2. Acute and preventative approaches to sundowning. Abbreviation: TSH, thyroid-stimulating hormone.

If problematic sundowning behavior still persists, we recommend melatonin supplementation at an initial dose of 10 mg

taken at nighttime, followed by a weekly increase by 10 mg to a maximum dose of 30 mg. This regimen is instituted regardless of reported sleep quality. If symptoms persist, the next step is to target NPS based on the individual's most recent NPI-Q profile. The mantra of "start low and go slow" should guide therapeutic interventions, waiting at least 2 weeks before altering doses. In general, antidepressants are preferred first steps unless safety concerns necessitate more proactive approaches. ■

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