

Behavioral Issues in Dementia

and

Caregiver Burden

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Disclosures

- I have no relevant financial relationships with ineligible companies.
- Any commercial products named today in this presentation are not specifically endorsed by myself, Maine Dartmouth Geriatric Medicine, or MaineGeneral Health.
- I will be discussing the use of medications that are not approved by the FDA for management of behavioral disturbances in dementia; however they do fall within the described bounds of content validity under Standard 1 of ACCME Standards for Integrity and Independence in Accredited Continuing Education (<https://www.accme.org/accreditation-rules/standards-for-integrity-independence-accredited-ce>).

Objectives

Dementia
with
behavioral
disturbances
(DBD)

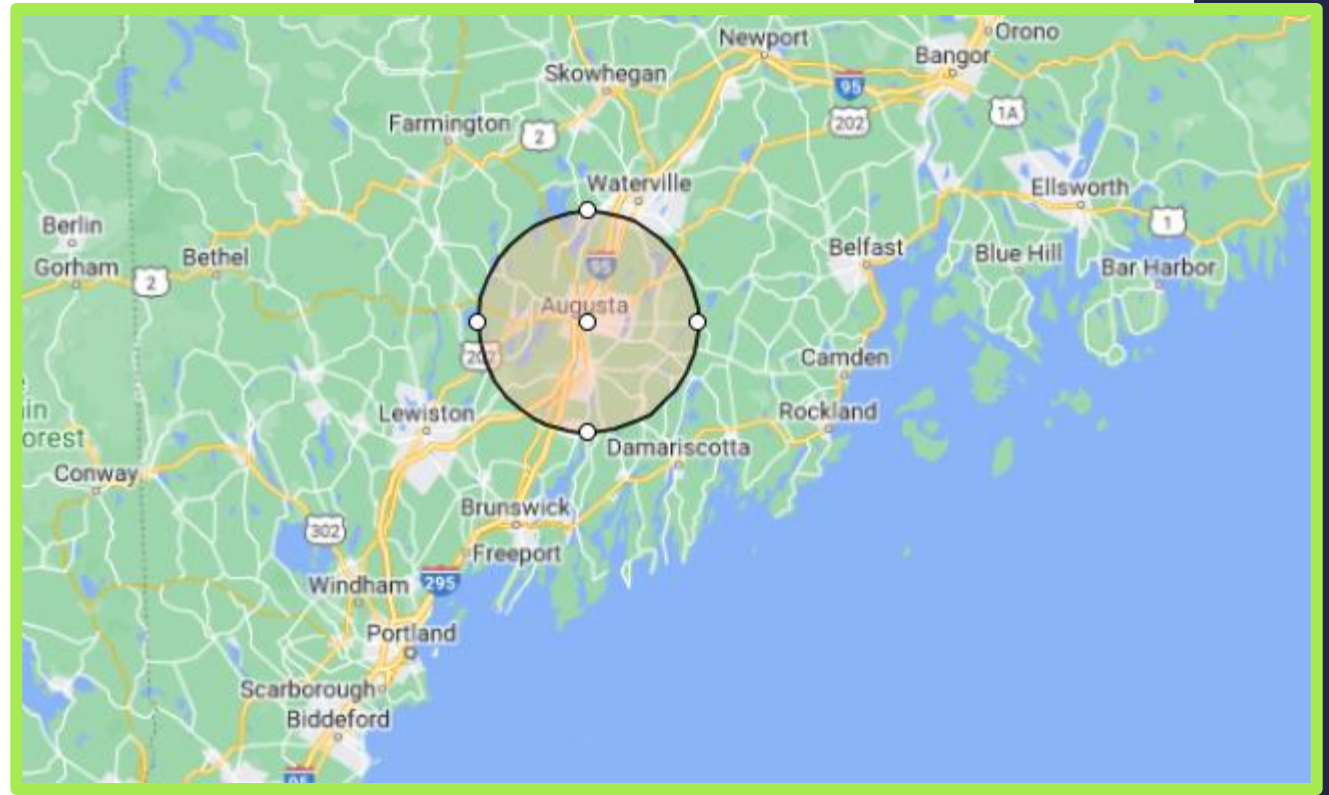
1. Define and assess
most burdensome
behaviors in dementia

2. Consider options for
treating mood
disorders, behavioral
issues, and psychosis
in DBD

Caregiver
burden

1. Consider ways to
assess and engage
caregivers for patients
with dementia

2. Develop resources
to support caregivers
along the disease
trajectory

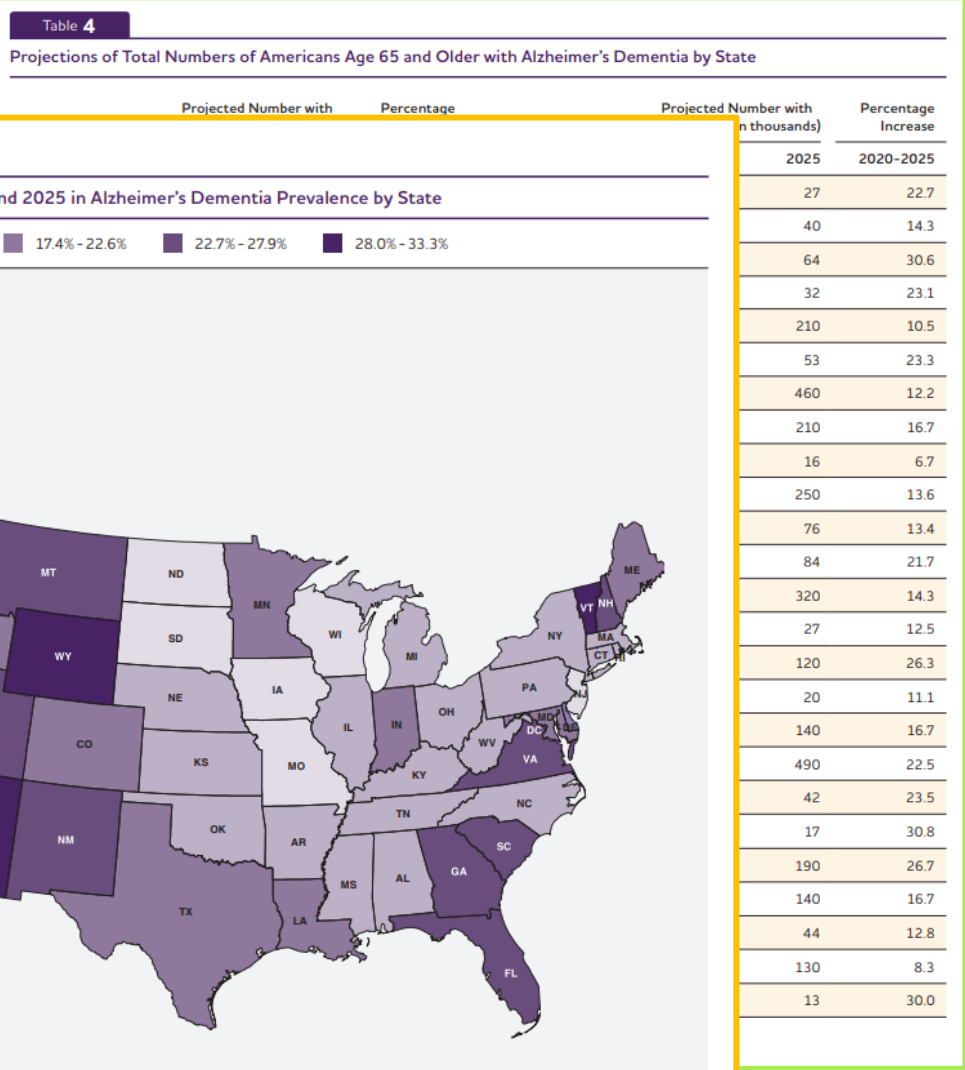


Maine Dartmouth Geriatric Medicine

- Serving Maine's Mid-Coast, Kennebec River valley region
- Geriatric outpatient primary and specialty care, and home based primary care (HBPC); also provide inpatient consultation and nursing home care
- Geriatric fellowship program site through MDFMR

Reminder

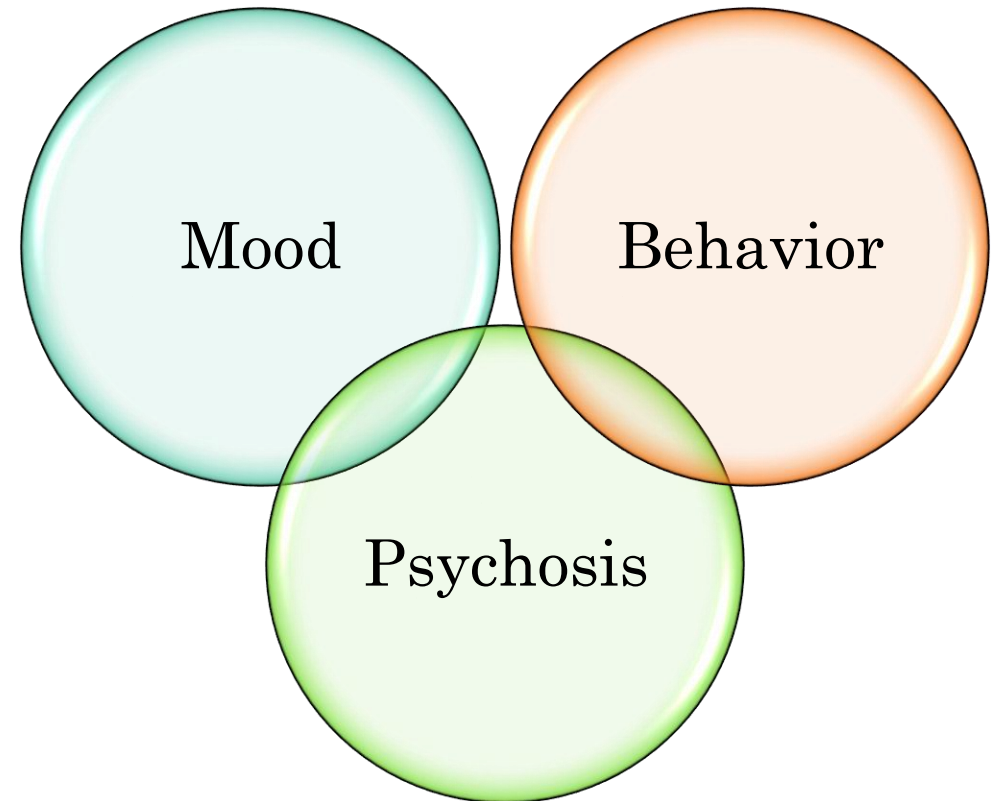
- Projected that every state will experience at least 5% increase in Alzheimer's prevalence by 2025
- Increasing strain on Medicaid funding and coverage for long term care¹



Behavioral Disturbances

What are behavioral disturbances in dementia?²

- Anxiety or fear
- Apathy
- Depressed mood
- Hallucinations
- Delusions
- Agitation
- Wandering
- Disinhibition – sexual, verbal, culturally inappropriate behavior
- Hoarding
- Aggression
- Screaming and crying



- Cause the most caregiver distress
- Treatment can reduce stress and improve quality of life for the patient and caregiver

Set Expectations

- Most common in the middle stages and more likely as the disease progresses
- Once behavioral disturbances are present, they tend to remain
- These can be the most challenging aspect to manage
- Often patients may have simultaneous psychological and behavioral symptoms²

Stages of Dementia: Helping Patients and Caregivers Understand What to Expect

After receiving the diagnosis, people living with dementia, and their caregivers, often want to know how their current memory and function problems may progress. Initiating these discussions early in the illness, before further cognitive decline, lays a foundation for ongoing conversations, and gives patients and caregivers the opportunity to plan for the future.






For some, it is helpful to provide guideposts, which indicate where the person currently fits into the disease progression. Breaking dementia progression into three stages—early, middle, and late—is one way to help patients and caregivers understand what to expect.*

Early Stage	Middle Stage	Late Stage
→ Trouble managing finances	→ Needing help with complex chores or hobbies	→ Swallowing and eating problems
→ Forgetting recent events and/or names	→ Getting lost in familiar places	→ Inability to walk, bathe, dress, and toilet independently
→ Difficulty remembering to take medications	→ Periods of irritability and/or agitation	→ Minimal verbal communication
→ Difficulty recognizing acquaintances	→ Difficulty recognizing family members	→ Recurrent infections

*Guideposts are meant to provide a framework—the specific stages and symptoms occur at different times and intensities, depending on the individual and the type of dementia.

This handout accompanies CAPC's course, *Communicating About What to Expect as Dementia Progresses*. Visit CAPC's online curriculum, "Best Practices in Dementia Care and Caregiver Support" for more.

Common Assessment Tools

- Acute change and/or concern for delirium  Confusion Assessment Method (CAM)
- Pain  Pain Assessment in Advanced Dementia Scale (PAINAD)
- Sleep changes  Sleep Diary
- Mood disorder  Geriatric Depression Scale (GDS)
- Multidimensional assessment  BEHAVE-AD

Common Assessment Tools

Confusion Assessment Method (CAM)*

Acute onset/fluctuating course and inattention, and EITHER altered level of consciousness or disorganized thinking³

PAINAD Scale[^]

Works well for nonverbal patients, advanced dementia⁴

Sleep diary

Caregiver may be able to complete

Confusion assessment method (CAM) for the diagnosis of delirium*

Feature	Assessment
1. Acute onset and fluctuating course	Usually obtained from a family member or nurse and shown by positive responses to the following questions: <ul style="list-style-type: none"> • "Is there evidence of an acute change in mental status from the patient's baseline?" • "Did the abnormal behavior fluctuate during the day, that is, tend to come and go, or increase and decrease in severity?"
2. Inattention	Shown by a positive response to the following: <ul style="list-style-type: none"> • "Did the patient have difficulty focusing attention, for example, being easily distractible or having difficulty keeping track of what was being said?"
3. Disorganized thinking	Shown by a positive response to the following: <ul style="list-style-type: none"> • "Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?"
4. Altered level of consciousness	Shown by any answer other than "alert" to the following: <ul style="list-style-type: none"> • "Overall, how would you rate this patient's level of consciousness?" • Normal = alert • Hyperalert = vigilant • Drowsy, easily aroused = lethargic • Difficult to arouse = stupor • Unarousable = coma

* The diagnosis of delirium requires the presence of features 1 AND 2 plus either 3 OR 4.

Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
			Total**	

*Five-item observational tool (see the description of each item below).

**Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

5. Delusion of infidelity (social and/or sexual unfaithfulness).

- (0) Not present.
- (1) Conviction that spouse, children, and/or other caregivers are unfaithful.
- (2) Anger towards spouse, relative, or other caregiver for their infidelity.
- (3) Violence toward spouse, relative, or other caregiver for their infidelity.

6. Suspiciousness/Paranoia other than above.

- (0) Not present.
- (1) Suspiciousness (e.g., hiding objects which they may later be unable to locate or a statement such as "I don't trust you").
- (2) Paranoid (i.e., fixed conviction with respect to suspicions and/or anger as a result of suspicions).
- (3) Violence as a result of suspicions.

GDS^{±5}

Geriatric Depression Scale: Short Form

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life? **YES / NO**
2. Have you dropped many of your activities and interests? **YES / NO**
3. Do you feel that your life is empty? **YES / NO**
4. Do you often get bored? **YES / NO**
5. Are you in good spirits most of the time? **YES / NO**
6. Are you afraid that something bad is going to happen to you? **YES / NO**
7. Do you feel happy most of the time? **YES / NO**
8. Do you often feel helpless? **YES / NO**
9. Do you prefer to stay at home, rather than going out and doing new things? **YES / NO**
10. Do you feel you have more problems with memory than most? **YES / NO**
11. Do you think it is wonderful to be alive now? **YES / NO**
12. Do you feel pretty worthless the way you are now? **YES / NO**
13. Do you feel full of energy? **YES / NO**
14. Do you feel that your situation is hopeless? **YES / NO**
15. Do you think that most people are better off than you are? **YES / NO**

Answers in **bold** indicate depression. Score 1 point for each bolded answer.

A score > 5 points is suggestive of depression.

A score ≥ 10 points is almost always indicative of depression.

A score > 5 points should warrant a follow-up comprehensive assessment.

BEHAVE-AD^{6§}

- Delusions
- Hallucinations
- Disturbing activities (wandering, disinhibition)
- Agitation
- Depression and anxiety/fear
- Sleep changes

*Graphic from UpToDate, 2023.


^Graphic from <https://geriatrictoolkit.missouri.edu/cog/painad.pdf>

±Graphic from The Hartford Institute for Geriatric Nursing, Rory Meyers College of Nursing, New York University

§ Graphic from <https://dementiaresearch.org.au/wp-content/uploads/2016/01/BEHAVE-AD-1.pdf>

Non-pharmacologic²

- **ALWAYS** begin with non-pharmacologic options and continue them throughout
- Redirection is key
- Food – snacks, coffee
- Pet therapy, creative activities, gardening
- Music – appropriate for generation⁷
- Movement – stretching, chair exercises, walking inside and outside, [senior center classes](#)
- Reminiscing – photo albums, movies, personal past events⁸
- Chores/tasks – folding laundry, setting table, clearing up, place settings, mail delivery, plant care

 **What Caregivers Should Know About Persons with Dementia**
Living Better with Dementia
Record information about this person that allows caregivers to personalize his/her care. Do not answer questions that would violate privacy.

Name: _____ Preferred name: _____

Birthplace (city and state): _____

Parents' names: _____

Parents' occupation(s): _____

Names of brothers: _____

Names of sisters: _____

Important information about brothers/sisters: _____

Name of spouse/partner: _____

Special memories of wedding day/honeymoon: _____

Children's names: _____

Grand-/great grandchildren's names: _____

Places lived: _____

Educational accomplishments: _____

Occupation(s): _____

Favorite job(s): _____

Leisure activities: _____

Spiritual affiliation/practices: _____

Favorite spiritual songs: _____

Favorite holiday: _____

Favorite vacation activity/location: _____

Favorite music: _____

Non-pharmacologic

- Maintain routine – daily schedule, holiday celebrations, large calendar
- Environment management – furniture layout the same, label items with words and pictures, day and night orientation
- Safety concerns – exits with locks, appliances changed to auto shut off, disabled stoves, water heater temperature lowered, guns removed
- Support groups, counseling, educational activities

caringkind The Heart of Alzheimer's Caregiving

CaringKind Early-Stage Services

Join Us!

Small group program for people with early-stage Alzheimer's or dementia.



Cognitive Stimulation Therapy Program (CST)

Improve thinking abilities, communicate, and interact with others in a relaxed, fun, and social setting.

CST Sessions include:

- Discussions around current events.
- A main activity with a theme.
- Validation of thoughts and opinions.
- Stimulating conversation.
- Enjoyable connections.

CST, an evidence-based program, creates a positive, accepting atmosphere where opinions rather than facts are shared and new ideas, thoughts, and associations are generated. CST activates various aspects of peoples' minds and its research shows improvements in cognitive function, mood, and quality of life.

Program Details

- 16 sessions, 45-60 minutes, twice a week for 8 weeks
- Small groups 5-8 people
- Virtual (Zoom) or In-person
- Available in Spanish



CaringKind's CST services are currently provided free of charge to clients living with Alzheimer's or another form of dementia. The CST program (valued at \$800 per person) is funded through grants, donations, CaringKind Walks, Forget-Me-Not Gala, fundraising events, and other philanthropic efforts. Contributions toward the program's sustainability are welcome.

For more information, call our Helpline: 646-744-2900 or email: helpline@cknyc.org

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,333,945 with 75% funded by ACL/HHS and \$333,977 and 25% funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

CaringKind
360 Lexington Avenue, 3rd Floor New York, New York 10017
Helpline: 646-744-2900 caringkindnyc.org
[/caringkindnyc](https://www.facebook.com/caringkindnyc) [@caringkindnyc](https://www.instagram.com/caringkindnyc) [@caringkindnyc](https://www.tiktok.com/@caringkindnyc)
Formerly known as the Alzheimer's Association, NYC Chapter

Case Break

A resident at memory care ALF is continuously stealing other residents' personal items during the day. He is often found napping with these items stacked on his rollator. He is taking Risperidone 0.25mg BID for behavioral disturbances which include physical aggression. Staff reports he's taken an urn containing a loved one's ashes and insists it belongs to him. Staff is wanting a PRN dose of Risperidone for situations like this in the future.

- Will a dopamine antagonist treat this specific behavior?
- Could there be a reason why he is doing this?

Baseline Management

In addition to incorporating non-pharmacologic tools:

- **Senses** – address teeth, eyes, ears*
- **Pain** – Acetaminophen 1000mg TID scheduled
- **Constipation** – Senna/sennosides 8.6mg 1 tab QHS, Polyethylene glycol 1 capful in AM, or Sorbitol 70% oral solution
- **Sleep** – Melatonin 5mg tab QHS scheduled, Mirtazapine 7.5mg po QHS, or Trazodone 25mg po QHS

*For ALFs, write an order for these items to be placed every morning and removed every night

Mood Disorder²

- **Incredibly common**
- **Anxiety and depression occur in >50% of patients with Alzheimer's⁹**

Non-pharmacologic:

- Counseling, talk therapy – can be beneficial *early* in the disease
- Encourage social interactions with small groups of people

Pharmacologic:

- SSRI – Escitalopram, Sertraline, Citalopram
- **Increase** the dose

*Watch Na periodically, QTc prolongation

Behavior: Wandering

Non-pharmacologic: Identification

- Notify local police station
- Alzheimer Association – MedicAlert, Safe and Found
- Identification bracelet
- QR Code stickers

Non-pharmacologic: Deterrents

- Door and window alarms
- Complicated locks
- STOP signs
- Flexible bright fencing, orange construction fencing



No pharmacologic option
will directly prevent
wandering

Classic Medical ID Bracelet Black

\$27.98



Color: Black
Size: 6.5"

Personalization (Edit)

- (LINE EMPTY)
- (LINE EMPTY)
- CALL
- MEDICALERT
- (LINE EMPTY)

Protection Plan: Advantage 1 Year

\$49.99

For your convenience and to avoid interruption of service, your membership will automatically renew on your anniversary date. See auto-renew terms here. You can opt out of auto-renewal or cancel your membership at any time

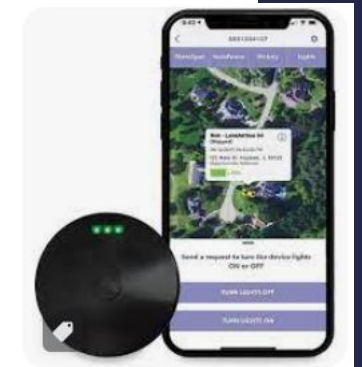


Behavior: Wandering

No pharmacologic option
will directly prevent
wandering

Non-pharmacologic – Tracking/monitoring

- Apps – Life360 (free), need a smartphone
- Apple AirTag or Tile – cheapest up front investment, requires Bluetooth, distance around 30 feet
- Apple Watch – \$250 minimum plus monthly cellular plan for location services
- Cameras (Ring, Nest, baby monitors, etc) – \$60 minimum, motion detection capability, fee for video storage
- AngelSense – \$200 device for tracking plus \$40-60 monthly, audio and video of surroundings
- Guardline Long Range – \$100, no wifi, ¼ mile of receiver, 40 ft from sensor
- Smart Sole – \$350 plus \$30 monthly, rechargeable, lasts 24-48 hours
- Itraq Nano – \$129 plus \$150 for 1 year of reporting, similar to Tile, rechargeable and works globally, can create geofencing
- LandAirSea - \$30 for tracker, monthly plans depend on frequency of updates (seconds to minutes)



Case Break

A patient with vascular dementia spends most of his day sitting in his shed. In the afternoon he has a tendency to drive around on his riding scooter and often falls asleep near the road which has been a major traffic concern. His family wants to preserve his quality of life, but they refuse to disable the scooter.

- More than 1 intervention is typically needed
- Driveway alarm
- Motion detection camera on scooter
- Pressure mat with alarm

Psychosis: Delusions, Hallucinations²

Delusions: home is not home, items are being stolen, infidelity, family member is not their family member (Capgras)

Hallucinations: more likely to be *visual*, consider Lewy Body Dementia if visual hallucinations are early in the disease process

Non-pharmacologic:

- Avoid denying or validating; remain calm and reassuring
- Not sure what to say to the patient? Just listen, show support, and move on
- Restate what the patient described to you

“If that happened to me I would be upset too.”

“I don’t see the child, but let me see if I can find out what’s going on.”

Psychosis: Delusions, Hallucinations²

Pharmacologic:

- Cholinesterase inhibitor – **may** help depending on etiology of memory loss (**LBD** vs **FTD**) – donepezil, rivastigmine patch, galantamine ER
- SSRIs – can help with general fear, anxiety, depression; remember to titrate up

Escitalopram – starting dose 5mg

Sertraline – starting dose 12.5 or 25mg

- Dopamine antagonist – initiate when person is unable to be redirected, shows or vocalizes distress about what they are experiencing and it's disrupting their daily function

Risperidone – starting dose 0.25mg QD or BID (tablets, ODT, solution) – less sedating

Olanzapine – starting dose 2.5mg QD – more sedating

Quetiapine – starting dose 12.5mg QHS – quite sedating at low dose, less likely to help psychosis

Aripiprazole – starting dose 2 or 2.5mg QD

Consider: Prazosin – starting dose 1mg po QHS

A Brief Discussion: Dopamine Antagonists

- Consider “*dopamine antagonist*” rather than “*antipsychotic*”

To discuss with caregiver, POA, family, etc.:

- Acknowledge the **black box warning** including risk of sudden cardiac death and cerebrovascular events, as well as risk of parkinsonism, falls, tardive dyskinesia, seizures, hyperglycemia²
- Be **specific** about what symptom(s) this medication is going to treat
- Enlist help from the care team to monitor for efficacy (behavior log, notes, etc)
- There has to be someone present to observe response to medication
- This is NOT a medication that is initiated and not reassessed for months on end

“We will attempt to use this medication for the shortest amount of time, and in smallest dose possible. However, it may become a longer term medication depending on the response. We will periodically reassess and attempt dose reduction if possible.”

Behavior: Agitation

- Agitation can be verbal and/or physical
- Often used as a vague, catch-all term
- It is extremely important to identify specifically what happened prior to, during, and after an outburst, as well as who was present
- Physical agitation while toileting, showering/bathing or pericare is common
- Determining a potential source for the agitation can direct the management
Examples: pain, insomnia or sleep dysregulation, anxiety or depression, constipation, hearing loss, environmental factors
- **Dopamine antagonists** should be introduced when a patient is causing danger to themselves, other residents/patients, or to the staff, or when a pattern of agitation is developing without a clear cause

Case Break

A patient with Alzheimer's is living at home with 24/7 hired private caregivers. Previously she was often upset about the neighbors, insisting they are laying in the street outside her home. She is becoming frightened of the television, often believing it is speaking directly to her. Recently she was visibly shaken by seeing her own appearance in a mirror, and demanded "that person" leave her home. It now takes hours for the caregivers to reassure and calm her down.

- **Maximize** SSRI potential
- Check on sleep regulation
- Time for a dopamine antagonist

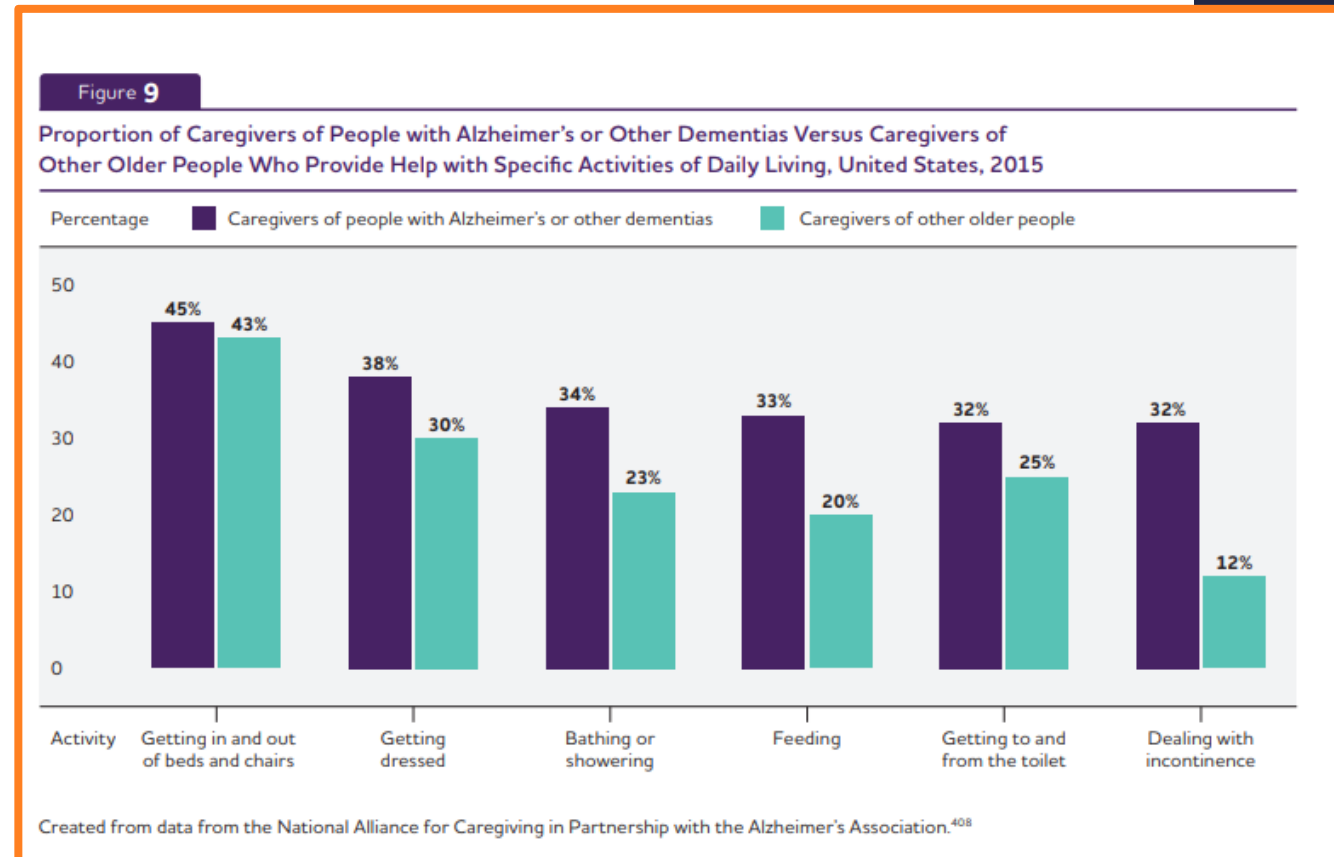
Try one medication change at a time

Caregiver* Burden

*a more inclusive term is “care partner”

Who are they, and what are they doing?¹

- Women comprise the majority of caregivers for dementia
- About 50% care for a parent or parent-in-law with dementia
- Approximately 25% care for an aging parent and also at least one child
- Spouses make up about 10% of caregivers
- Disproportionately more help with personal self care – showering, feeding, toileting and incontinence



Graphic from 2023 Alzheimer's Disease Facts and Figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

The Cost of Caregiving

- Recognize that caregiver health has implications on health of the patient^{10,11}
- Assessing caregiver stress is a first step
- Ask at every visit

Table 11

Percentage of Dementia Caregivers Who Report Having a Chronic Health Condition Compared with Caregivers of People without Dementia or Non-Caregivers

Condition	Dementia Caregivers	Non-Dementia Caregivers	Non-Caregivers
Stroke	5.2	3.4	3.2
Coronary heart disease	8.3	7.2	6.6
Cardiovascular disease*	11.8	9.5	8.6
Diabetes	12.8	11.1	11.3
Cancer	14.3	13.3	11.5
Obesity	32.7	34.6	29.5

*Combination of coronary heart disease and stroke.

Table includes caregivers age 18 and older.

Created from data from the Behavioral Risk Factor Surveillance System survey.⁴⁰⁹

Graphic from 2023 Alzheimer's Disease Facts and Figures.
<https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

Caregiver Assessment Tools

Zarit Burden Interview (ZBI)	Assesses distress, perceptions of social and physical health, and financial and emotional burden; providers can also use the short-form version
Geriatric Depression Scale (GDS)	Short-form version (15 questions) screens for depression in the elderly population
Benjamin Rose Institute Caregiver Strain Instrument	Assesses caregiver feelings about caregiving, relationship strain, health, and social isolation
Caregiver Self-Assessment Questionnaire	Developed by the American Medical Association, caregivers indicate specific episodes of physical and emotional strain
"What Do I Need as a Family Caregiver?"	Developed by Next Step in Care , asks caregivers about their living situation, caregiving responsibilities, worries, and sources of support
REACH II Risk Appraisal (RAM)	Developed and validated by REACH II data, identifies risk for depression, social support, and safety



Caregiver strain leads to increased health care costs of more than

\$1,300

PER CARE RECIPIENT⁵

AND

\$4,766 more

per year per person

FOR CAREGIVERS THEMSELVES⁶

Piecing Information Together

- Small, discrete “doses” of information are usually best
- Utilize your multidisciplinary team members!

IDEAL:

- **Early** – Dementia roadmap, communication resource, advance directive completion, financial planning
- **Middle** – Tailored to specific concerns: behavioral issues, adult day program, safety including driving, what to expect next
- **Late** – Reducing pill burden, reducing medical appointment burden/transportation, supporting in home, discuss hospice criteria, quality of life

REALITY:

- Meeting a family in middle or late stages and playing catch-up on many aspects

Dementia Care Resources for Caregivers

Taking care of a family member or friend living with dementia can be overwhelming. *You are not alone.* Along with your medical team, there are many resources available to you for support throughout the course of the disease. See the resources below for online education about dementia, and information about support groups, respite care, and more.

Online Caregiver Education

- Visit **Alzheimer's Association** for caregiver support groups, online community message boards to connect with other caregivers, and access to local resources.
alz.org/help-support/caregiving
- **Alzheimer's Association** also offers information for caregivers about the stages of dementia and how to respond to behavioral symptoms of dementia, such as aggression or repetition.
alz.org/help-support/caregiving/stages-behaviors
- The **National Institute of Aging** offers support, including how to respond to behavioral symptoms of dementia, legal and financial planning information, tips for home safety, and resources for caregiver stress relief and self-care.
nia.nih.gov/health/alzheimers/caregiving
- The **UCLA Alzheimer's and Dementia Care Program** offers videos to help understand how to care for people living with dementia. Topics include home safety, responding to aggressive language, depression and apathy, repetitive behaviors, sleep disturbances, and wandering.
uclahealth.org/dementia/caregiver-education
- Find resources specific to different types of dementia from the **Family Caregiver Alliance**.
caregiver.org/resources-health-issue-or-condition
- No matter your location, **Alzheimer's of Greater Los Angeles** offers a series of tip sheets for caregivers in both English and Spanish on a variety of topics, including medications, toileting, and behavioral symptoms of dementia.
alzga.org/professionals/caregiver-tip-sheets
- The **AARP's Home Alone Alliance** offers educational videos and tip sheets in English and Spanish on wound care, mobility, and managing medications.
aarp.org/ppi/initiatives/home-alone-alliance.html

You are not alone. Call Alzheimer's Association 24/7 Helpline for around-the-clock support for all types of dementia. 800-272-3900

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GetPalliativeCare.org/dementia

Graphic from capc.org: <https://www.capc.org/toolkits/implementing-best-practices-in-dementia-care/>

Our Roles

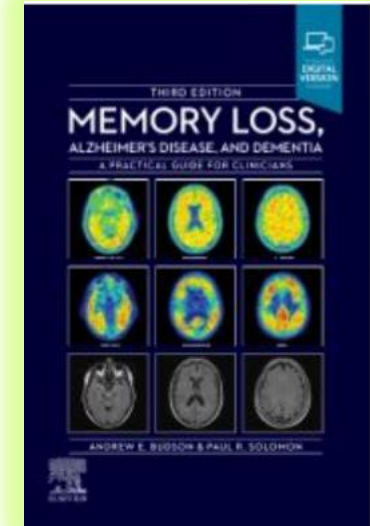
- Inform – present diagnosis and disease trajectory, as well as expected or unexpected complications
- Advise – recommend treatment and management for medical and non-medical aspects

Specific for caregivers:¹²

- **Reassure** they are doing what is best for the patient in a situation they did not create
- **Acknowledge** the difficult task they are undertaking, perhaps unwillingly
- **Identify** personal limitations
- **Encourage** self-care including forgiveness, and modify expectations
- **Avoid judgement** – Complicated family dynamics, socioeconomic status, permit caregivers to have “bad” feelings

Develop Your Toolkit

- Free CME for professionals, handouts for caregivers, toolkit:
<https://www.capc.org/toolkits/implementing-best-practices-in-dementia-care/>
- Geriatric Depression Scale – Stanford website, numerous translations:
<https://web.stanford.edu/~yesavage/GDS.html>
- National Sleep Foundation – sleep diary, can be completed by caregiver:
<https://www.thensf.org/nsf-sleep-diary/>
- PAINAD tool:
<https://geriatrictoolkit.missouri.edu/cog/painad.pdf>



Develop Your Toolkit

- Alzheimer's Association – VT chapter – virtual/in-person support groups for care partners and patients:
https://www.alz.org/vermont/helping_you/support-groups#In-Person%20Support%20Groups%20for%20People%20living%20with%20Dementia
- Vermont Association of Area Agencies on Aging:
<https://www.vermont4a.org/>
- CaringKind – NYC based, caregiver resources:
<https://www.caringkindnyc.org/publications/>
<https://www.caringkindnyc.org/caregivertips/>
- Online support groups for women caring for aging parents, focus on dementia:
<https://www.daughterhood.org/>
- Tip Sheets in various languages on how to handle behaviors and stages of dementia:
<https://www.alzheimersla.org/for-professionals/caregiver-tip-sheets/>
- Teepa Snow – Instagram: teepasnows_pac

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Thank You

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