Dementia Care at Home: A National Practice Module

Caring for a person living with dementia at home.

Why this module matters. About 7.4 million Americans 65 and older live with Alzheimer's dementia, cared for by nearly 13 million unpaid caregivers, and 59% of those caregivers report high emotional stress.

About this module

This module gives teams a shared, evidence-based approach to caring for a person living with dementia at home. It draws on current federal rules and national guidance, and it ends with a checklist that agencies, clinicians, and families anywhere in the United States can adopt.

Item	Details
Who it is for	Family caregivers, home care aides, supervisors, and clinicians
Format	7 units, case scenarios, a knowledge check, and a national checklist
Time	About 2 hours
How to use it	Families and aides use Units 2 and 4 to 7. Clinicians and agencies use all units.

Learning objectives

After completing this module, learners will be able to:

1. Describe the national impact of dementia.
2. Recognize stages and delirium.
3. Use national programs and services.
4. Communicate effectively.
5. Respond to distress without medicines first.
6. Keep the home safe.
7. Plan ahead.

Scope. Aides and family caregivers observe, support, and report. Clinical assessments, medication changes, and treatment decisions belong to licensed clinicians. Follow your state scope-of-practice rules and agency policies.

Unit 1. The national picture

Measure	Figure	Source
Americans 65 and older with Alzheimer's dementia	About 7.4 million (2026)	Alzheimer's Association
Projected by 2050	About 13 million	Alzheimer's Association
Unpaid dementia caregivers	Nearly 13 million	Alzheimer's Association
Unpaid care provided in 2025	More than 19 billion hours, valued at more than $446 billion	Alzheimer's Association
Health and long-term care costs (2026)	$409 billion; 64% paid by Medicare and Medicaid; $103 billion out of pocket	Alzheimer's Association
Rank as cause of death, age 65+ (2024)	Fifth	Alzheimer's Association
Dementia caregivers with high or very high emotional stress	59%	Alzheimer's Association

Unit 2. Understanding dementia

Dementia is a general term for a decline in memory, thinking, and daily function severe enough to interfere with life. Alzheimer's disease is the most common cause. Others include vascular dementia, Lewy body dementia, and frontotemporal dementia.

Stage	What it may look like	Care focus
Early	Forgetting recent events, trouble planning, misplacing items	Diagnosis, planning, independence with support
Middle	Confusion, needing help with daily tasks, behavior changes, wandering	Routine, supervision, safety, caregiver support
Late	Needs help with all care, limited speech, trouble swallowing and walking	Comfort, dignity, skin and nutrition, hospice when appropriate

> **Sudden change.** Sudden confusion is not normal dementia progression. It may be delirium from infection, medicines, or dehydration. Report it the same day.

Unit 3. National programs and treatment

Program or development	What it means
Medicare GUIDE Model	A CMS model that pays participating programs for dementia care coordination, caregiver training and support, a 24/7 support line, and respite services
Medicare cognitive assessment and care planning	Medicare covers a visit to assess cognition and create a care plan
Medicare caregiver training services	Clinicians can bill for training family caregivers (since 2024)
New treatments	FDA-approved anti-amyloid medicines may slow decline in early Alzheimer's for some people; they require specialist evaluation and monitoring
National Family Caregiver Support Program	Respite, training, and support through Area Agencies on Aging

Unit 4. Communicating with a person with dementia

Do	Avoid
Approach from the front and say your name	Startling the person from behind
Speak slowly, use short sentences, one question at a time	Long explanations or many choices
Use the person's name and gentle touch if welcome	Talking about them as if they are not there
Join their reality; respond to feelings	Arguing or correcting ("Your mother died years ago")
Show, do not just tell; use gestures	Rushing
Give simple choices: "Blue shirt or red?"	Open questions: "What do you want to wear?"

Unit 5. Responding to distress and behavior

Behaviors are often a way of communicating an unmet need: pain, hunger, a full bladder, boredom, fear, or too much noise. A simple approach is to describe, investigate, create a plan, and evaluate.

Behavior	Possible causes	Try
Agitation in late afternoon	Fatigue, low light, hunger	Rest earlier, more light, snack, calm activity
Refusing a bath	Fear, cold, loss of privacy, pain	Warm room, towels for privacy, choice of time, sponge bath
Repeated questions	Anxiety, memory loss	Reassure, answer calmly, a note or calendar
Wandering	Restlessness, looking for something, routine	Walks, door alarms, ID bracelet, a plan if lost
Striking out	Pain, fear, feeling rushed	Step back, stay calm, check for pain, report to the nurse

Medicines. Medicines for behavior, especially antipsychotics, carry serious risks in older adults with dementia. They should be used only after non-drug approaches, and reviewed by a clinician.

Unit 6. Safety at home

Risk	Steps
Falls	Clear paths, night lights, grab bars, supervised walking
Wandering and getting lost	Door chimes, ID bracelet, recent photo ready, alert neighbors
Stove and appliances	Knob covers, automatic shut-off devices
Medicines	Locked storage; caregiver gives medicines
Driving	Clinician driving assessment; plan for stopping
Firearms	Remove or lock up and store ammunition separately
Scams	Limit access to accounts; watch mail and phone calls

Unit 7. Planning ahead

- Complete a durable power of attorney for finances and a health care proxy while the person can take part.
- Record wishes about care, hospital use, and end of life.
- Review finances and benefits, including Medicaid eligibility.
- Plan for future care needs and the caregiver’s own support.
- Consider hospice when the disease is advanced; it can be provided at home.

Case scenarios

Case 1. Sundown agitation

Every evening around 5 p.m., Mr. P becomes restless and tries to leave the house.

- What might be causing it?
- What could help?

Discussion: Fatigue, low light, hunger, or a past routine of going home from work. Try an earlier rest, brighter lights, a snack, a calm activity, and door chimes for safety.

Case 2. Sudden worse confusion

Mrs. R's confusion is much worse over two days, and she is sleeping more.

- Is this dementia getting worse?
- What should happen?

Discussion: Possibly delirium. Report to the clinician the same day to check for infection, dehydration, or medicine effects.

Knowledge check

1. About how many Americans 65+ have Alzheimer's dementia in 2026? *(About 7.4 million)*
2. What share of dementia care costs do Medicare and Medicaid pay? *(About 64%)*
3. What does sudden worse confusion suggest? *(Possible delirium; report the same day)*
4. Name two communication tips. *(Approach from the front, short sentences, simple choices, respond to feelings)*
5. What is the Medicare GUIDE Model? *(A CMS model for dementia care coordination and caregiver support, including respite)*
6. Why avoid antipsychotics where possible? *(Serious risks in older adults with dementia)*

National Dementia Care at Home Checklist

This checklist turns national dementia care practice and programs into one tool for families, agencies, and clinicians. The “National basis” column shows where each item comes from. Adapt it to your state rules and policies.

Name or ID	Date	Completed by and role
Agency or organization	Reviewed by	Next review date

A. Diagnosis and planning

Action	National basis	Done	Notes
Cognitive assessment and care plan with a clinician	Medicare cognitive assessment benefit	☐	
Legal and financial documents completed	Best practice	☐	
Wishes for care and end of life recorded	Age-Friendly 4Ms	☐	
GUIDE Model or local dementia program explored	CMS GUIDE Model	☐	

B. Daily care

Action	National basis	Done	Notes
Consistent routine and caregivers	Best practice	☐	
Caregivers trained in dementia communication	Best practice; state rules	☐	
Non-drug approaches tried first for behaviors	National guidelines	☐	
Sudden changes reported the same day	Best practice	☐	

C. Safety

Action	National basis	Done	Notes
Fall, wandering, stove, medicine, and firearm risks addressed	CDC STEADI; best practice	☐	
ID bracelet and recent photo ready	Best practice	☐	
Driving assessed	Best practice	☐	

D. Caregiver support

Action	National basis	Done	Notes
Respite plan in place	NFCSP; GUIDE Model	☐	
Caregiver training offered	Medicare caregiver training services	☐	
Support group or counseling offered	Older Americans Act	☐	

Completed by: signature	Printed name and title	Date
Reviewed by: signature	Printed name and title	Date

Sources and further reading

Alzheimer's Association: 2026 Alzheimer's Disease Facts and Figures (alz.org)

Rural Health Information Hub: Caregiver Training Services (ruralhealthinfo.org)

CDC STEADI Pocket Guide (cdc.gov)

McCarter & English: CMS Age Friendly Hospital measure (4Ms) (mccarter.com)

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