ALZHEIMER’S DISEASE IN 2026

The Human Side of Alzheimer’s Care

Supporting patients, families, and caregivers across the journey

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CARE • CULTURE • ACCESS • COMMUNITY

A diagnosis affects more than memory

The person

Identity, routines, relationships, dignity, independence, and the right to be involved in decisions.

The family

Changing roles, grief, uncertainty, time demands, financial pressure, and difficult decisions.

The community

Language access, trusted information, culturally responsive services, and support beyond the clinic.

Our goal: protect quality of life while adapting support as needs change.

Culture is the framework—not a footnote

Ask before assuming.

- What language does the person prefer for care conversations?
- Who does the person want involved in decisions?
- How do faith, food, family roles, and traditions shape care?
- What does the family believe is happening—and what worries them most?

Culturally responsive care means...

- Qualified interpreters and translated materials
- Respectful, plain-language explanations
- Shared decisions without judgment
- Asking about stigma, trust, cost, transport, and time off work

Avoid treating any community as one story. Let each person define what matters.

Care goals change across the journey

EARLY / MILD

- Clarify diagnosis and options
- Include the person in decisions
- Plan finances, legal matters, and future care
- Protect meaningful routines and independence

MIDDLE / MODERATE

- Simplify tasks and communication
- Build predictable routines
- Review home safety and supervision
- Share caregiving and plan respite

LATER / ADVANCED

- Prioritize comfort, dignity, and connection
- Support eating, mobility, skin, and personal care
- Discuss goals of care and palliative support
- Prepare for changing care needs

At every stage: ask what matters most to the person and revisit the plan.

Behavior is communication

When distress appears, ask: “What might this person be communicating?”

CHECK THE CAUSE

Pain • hunger • thirst • constipation
Poor sleep • infection • medication effects
Noise • fear • loneliness

CHANGE THE APPROACH

Speak calmly and simply
Offer reassurance, not an argument
Reduce noise; give time and space
Redirect to a familiar activity

KEEP THE PERSON CONNECTED

Music, photos, folding towels, prayer, gardening, walking, familiar foods, or conversation.

Sudden or rapidly worsening confusion or behavior change needs prompt medical assessment.

Who is the caregiver—and what are they carrying?

Adult child

May be balancing work, parenting, finances, and care for a parent while navigating role reversal.

Spouse or partner

May be grieving changes in companionship while managing nearly constant responsibility.

Grandchild, sibling, or friend

May have fewer formal supports, feel invisible, or be coordinating care across distance.

Caregiving is not one role. Ask who helps, who decides, who pays, and who gets a break.

Caregiver burnout is a care issue

Signs support may be overdue

- Exhaustion, sleep disruption, or frequent illness
- Feeling isolated, resentful, anxious, or hopeless
- Missing appointments or neglecting personal needs
- Feeling there is no safe person to call for help

Make support specific

- Schedule respite—not just “call if you need me”
- Assign concrete tasks to family and friends
- Offer caregiver groups, counseling, and education
- Build a backup plan for emergencies
- Revisit support as care needs change

The goal is not to ask one person to be stronger. It is to make care more sustainable.

New therapies matter—but access is not automatic

WHO MAY BENEFIT?

Some anti-amyloid treatments are for people in early symptomatic stages, after specialist evaluation and confirmation of amyloid pathology.

WHAT DOES CARE REQUIRE?

Potentially repeated infusions, MRI monitoring, appointments, a care partner, transportation, and discussion of risks and benefits.

WHAT CAN BLOCK ACCESS?

Out-of-pocket costs, insurance rules, specialist shortages, travel, language barriers, time off work, and digital access.

Ask the care team: eligibility • expected benefit • risks • monitoring • total cost • coverage • alternatives

Digital tools can support care—when they fit the family

COORDINATION

Shared calendars, medication lists, appointment reminders, and family messaging—using tools everyone can access.

SAFETY & CONNECTION

Video visits, emergency contacts, door alerts, location devices, or home sensors when appropriate and agreed upon.

EQUITY & PRIVACY

Check cost, internet access, language, digital confidence, consent, privacy, and whether alerts create more stress.

Technology should support human connection—not replace a trusted person or professional care.

No family should have to navigate alone

CLINICAL TEAM

Primary care • memory specialist
Social worker • pharmacist
Ask for plain-language explanations, interpreters, written next steps, and a named contact.

COMMUNITY SUPPORT

Alzheimer's Association
Adult day programs • respite care
Area Agency on Aging
Faith and cultural organizations
Caregiver groups and local aging services

PLAN TOGETHER

Document preferences and goals
Review legal/financial planning with qualified help
Name backup caregivers
Revisit decisions as the disease changes

A warm handoff is better than a list of phone numbers.

Five questions that can change the care experience

1. **What matters most to you right now?**
2. What changes or worries you most at home?
3. Who is helping—and who needs support?
4. What makes care difficult to access or afford?
5. What is one next step we can take together?

Care is more than treatment.
It is how we show up.

Listen to the person.
Support the caregiver.
Remove barriers to care.

Thank you.

Adolis Estevez Ramos, MPH • Questions / discussion

Trusted resources & references

National Institute on Aging — Alzheimer's caregiving	https://www.nia.nih.gov/health/topics/alzheimers-caregiving
NIA — Behavior and communication changes	https://www.nia.nih.gov/health/communication-and-behavior-problems-resources-alzheimers-caregivers
NIA — Caring for yourself as a caregiver	https://www.nia.nih.gov/health/alzheimers-caregiving-caring-yourself
Alzheimer's Association — Hispanic Americans and Alzheimer's	https://www.alz.org/alzheimers-dementia/how-alzheimers-impacts-different-groups/hispanic-americans
FDA — Leqembi MRI safety monitoring update (Aug. 28, 2025)	https://www.fda.gov/drugs/drug-safety-and-availability/fda-recommend-additional-earlier-mri-monitoring-patients-alzheimers-disease-taking-leqembi-lecanemab
CMS — Medicare coverage for Leqembi	https://www.cms.gov/newsroom/press-releases/statement-broader-medicare-coverage-leqembi-available-following-fda-traditional-approval
NIA — Telehealth and dementia care	https://www.nia.nih.gov/news/telehealth-improving-dementia-care
Alzheimer's Association 24/7 Helpline: 800-272-3900	https://www.alz.org/help-support/resources/helpline

Educational presentation; treatment decisions should be made with the person's qualified care team.