

End-of-Life Scenarios and Cost Pathways for Alzheimer's Disease and Other Dementias

USA vs Hawai'i (with island-level nursing facility rate benchmarks)
plus international context and low-cost U.S. state comparisons

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Executive Summary

What this report covers. This report maps common end-of-life trajectories in Alzheimer's disease and other dementias, the care settings families typically use, and the planning choices that drive both outcomes and cost. It provides (1) USA baseline costs, (2) Hawai'i-specific costs and nursing-facility rate benchmarks by county (island group), and (3) a practical comparison to other U.S. states and broad international models.

- Clinical reality: dementia is a progressive terminal condition. Late-stage dementia commonly involves loss of mobility, swallowing difficulties, infections, weight loss and increasing dependence; hospice eligibility is often considered around FAST stage 7 with serious complications.
- Costs vary more by care setting than by diagnosis. The biggest cost inflection points are (a) the jump from family care to paid in-home care, and (b) the transition into residential memory care or a nursing facility.
- Hawai'i is among the most expensive places in the U.S. for long-term care. Using 2024 medians, Hawai'i's annual costs exceed U.S. medians by ~25% (home health aide) to ~76% (nursing home semi-private).
- Island-level nursing-facility rates vary materially: based on Hawai'i DOH/SHPDA facility-reported daily room rates, average SNF semi-private rates are highest on Kaua'i and lowest on O'ahu (see Hawai'i section).
- Published lifetime cost: the Alzheimer's Association estimates the total lifetime cost of care for someone with dementia at \$405,262 (2024 dollars), with ~70% borne by families as unpaid caregiving and out-of-pocket costs.
- Modeled direct paid-care pathways (illustrative): across three common scenarios in this report, estimated direct paid long-term-care totals range from about \$336k–\$746k in the U.S. and \$529k–\$1.28M in Hawai'i, depending on how early and how long residential/nursing care is used.
- Cheapest U.S. state pathways (illustrative): using state median costs for home health aide + assisted living + nursing home (semi-private) and a 7-year '3-2-2' care mix, Texas, Louisiana and Arkansas emerge as among the lowest-cost states—still far below Hawai'i in this model.

Important note on cost estimates. Medians are not quotes. Actual charges vary by level of dementia-specific supervision, staffing ratios, payer (private pay vs Medicaid), room type, location, and availability. Scenario totals are models, not predictions, and are provided to help families plan ranges and trigger points.

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1. Dementia end-of-life: what typically happens (USA baseline)

Although people die from an immediate cause (e.g., pneumonia), dementia is widely treated clinically as a progressive terminal condition. In later stages, people commonly experience total dependence for activities of daily living, reduced ability to communicate, impaired swallowing (dysphagia), weight loss, recurrent infections, skin breakdown, falls, and complications from immobility. Families often face 'goal-of-care' choices: prioritizing comfort vs hospitalization and aggressive interventions.

1.1 Common end-of-life trajectories (scenarios)

Scenario A — Home-first, family-led care (late placement). Long period at home with unpaid spouse/child caregiving, supplemented by part-time paid help and/or adult day. Transition to assisted living or nursing facility occurs late, often triggered by safety risks (wandering), incontinence, mobility loss, or caregiver burnout.

Scenario B — Earlier assisted living/memory care transition. Family provides early-stage oversight but moves to assisted living/memory care in moderate stage to stabilize supervision needs and reduce caregiver strain. Nursing facility or inpatient hospice becomes more likely in the final 1–2 years.

Scenario C — Early nursing facility pathway. Earlier nursing-facility placement due to severe behavioral symptoms, complex medical comorbidities, lack of available family caregivers, or unsafe housing. Costs are typically highest because the most expensive setting is used for the longest period.

Scenario D — Rapid decline after an acute event. A fall/hip fracture, stroke, delirium, or repeated infections can accelerate functional decline. Families may see a sudden transition from home to hospital to skilled nursing and then hospice.

Scenario E — 'Long duration' dementia (including younger onset). Longer time living with dementia can amplify cumulative cost and caregiver load; planning must account for many years of supervision needs and potential caregiver health decline.

1.2 Hospice and palliative care in dementia

Hospice is designed for comfort-focused care when life expectancy is thought to be about six months or less if the disease runs its normal course. For dementia, hospice eligibility is commonly supported by FAST stage ≥ 7 plus serious complications such as pneumonia, recurrent infections, pressure ulcers, significant weight loss, or dysphagia. Medicare generally covers hospice services, medications and equipment related to the terminal condition, but does not cover room-and-board in a nursing facility; families often pay that privately or through Medicaid if eligible.

2. Care options and annual median costs: USA vs Hawai'i

The table below uses widely-cited 2024 median costs (annualized) for common long-term care services. These are planning benchmarks; local quotes vary.

Care setting / service (median)	Typical use in dementia	USA median annual cost	Hawai'i median annual cost
Homemaker services (44 hrs/week)	Help with meals, housekeeping, supervision (early-moderate stages)	\$75,504	\$91,520
Home health aide (44 hrs/week)	Hands-on personal care + supervision at home (moderate+)	\$77,792	\$97,240
Adult day services (5 days/week)	Supervision, social/therapeutic activities; respite for caregivers	\$26,000	\$22,998
Assisted living (private 1BR)	Residential supervision + personal care; memory-care add-ons often increase cost	\$70,800	\$121,392
Nursing home (semi-private)	24/7 skilled care; common in late-stage dementia	\$111,325	\$196,370

Note: Nursing home private-room medians for 2024 are higher than semi-private. (USA: \$127,750; Hawai'i: \$229,950.)

3. Hawai'i: island-level nursing-facility rate benchmarks

Hawai'i's State Health Planning and Development Agency (SHPDA) publishes facility-reported daily room rates for skilled nursing facilities (SNF) and intermediate care facilities (ICF). These are useful as an 'island benchmark' because they reflect Hawai'i's limited bed supply and geographically distinct markets.

Island group (county)	Average SNF semi-private daily rate	Approx. annual (daily × 365)	Planning note
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Hawai'i Island (Hawai'i County)	\$770/day	\$281,050/yr	Higher rates often reflect limited capacity and staffing/transport costs.
O'ahu (Honolulu County)	\$534/day	\$194,910/yr	Higher rates often reflect limited capacity and staffing/transport costs.
Kaua'i (Kaua'i County)	\$906/day	\$330,690/yr	Higher rates often reflect limited capacity and staffing/transport costs.
Maui Nui (Maui County)	\$624/day	\$227,760/yr	Higher rates often reflect limited capacity and staffing/transport costs.

Interpretation: even within Hawai'i, nursing-facility pricing differs by county. This matters for families considering inter-island moves, waitlists, or Medicaid planning.

4. Modeled cost from onset to end of life (illustrative scenarios)

This section translates scenarios into rough 'from onset to end of life' direct paid long-term-care totals. It excludes medical spending (hospital/physician/drugs) and does not assign a dollar value to unpaid caregiving time unless noted.

Scenario	Illustrative duration	Care mix (years × setting)	Direct paid LTC total (USA)	Direct paid LTC total (Hawai'i)	What typically triggers transitions
A: Home-first (late placement)	≈8 years	3y homemaker (10 hrs/wk equiv) + 2y adult day (3 days/wk)	\$335,605	\$529,152	Safety risk, caregiver burnout, incontinence, mobility loss

		equiv) + 2y assisted living + 1y nursing home			
B: Assisted living earlier	≈7 years	2y home health aide + 3y assisted living + 2y nursing home	\$590,634	\$951,396	Wandering, 24/7 supervision need, spouse health decline
C: Early nursing facility	≈7 years	1y home health aide + 6y nursing home	\$745,742	\$1,275,460	Severe behavioral symptoms, complex comorbidities, no available caregivers

Context: the Alzheimer’s Association estimates the total lifetime cost of care for a person living with dementia at \$405,262 (2024 dollars), with ~70% borne by families as unpaid caregiving and out-of-pocket costs. Scenario totals above are ‘direct paid LTC’ only, so families should plan for additional medical spending, home modifications, legal/financial planning, and caregiver work impacts.

5. What families and spouses typically do (planning patterns)

- Care begins at home. Most people with dementia live in the community for years with spouses/adult children providing the majority of supervision and hands-on help.
- Families add paid help in steps: part-time homemaker support → increased hours → personal-care aides → adult day services (respite) → residential care.
- Transitions are usually crisis-driven: a fall, wandering incident, caregiver illness, or hospitalization often forces a move faster than expected.
- Financing is mixed: Medicare covers acute medical care and hospice services, but not long-term custodial care. Long-term care insurance can help (if purchased earlier). Medicaid becomes the payer of last resort for eligible individuals after spend-down.
- Spousal impact is profound: caregivers often reduce work hours or leave the workforce; stress and health decline are common. Planning for caregiver backup is as important as planning for the person with dementia.

6. Which U.S. states are cheapest for end-of-life dementia care? (modeled comparison to Hawai'i)

There is no single 'cheapest' state for every family. Costs depend on the care setting mix, housing, and eligibility for Medicaid. To give a practical benchmark, we modeled a 7-year '3-2-2' mix (3 years home health aide, 2 years assisted living, 2 years nursing home semi-private) using state median costs from CareScout's state tables.

State	Home health aide (annual median)	Assisted living (annual median)	Nursing home semi-private (annual median)	Modeled 7y total (3-2-2)
Texas	\$68,640	\$65,700	\$85,045	\$507,410
Louisiana	\$50,336	\$89,790	\$91,250	\$513,088
Arkansas	\$59,488	\$85,775	\$92,528	\$535,070
Hawai'i (Genworth medians)	\$97,240	\$121,392	\$196,370	\$927,244

Interpretation: In this simple model, Hawai'i's projected direct paid LTC total is roughly \$350k–\$420k higher than the lowest-cost states—before counting medical spending or unpaid caregiver time.

7. International comparison (high-level): Europe, Asia, Latin America

Internationally, dementia end-of-life experiences are shaped by how long-term care is financed and delivered. Broadly: (1) many European systems provide more publicly financed home and residential long-term care than the U.S.; (2) several East Asian countries (notably Japan) created national long-term care insurance to shift burden from families to a social insurance model; (3) across much of Latin America, families remain the primary caregivers and formal long-term care systems are less developed, producing high informal-care reliance.

Selected contrasts:

- OECD pattern: across OECD countries, a large share of long-term care spending occurs in nursing homes, with substantial variation in home-care support and eligibility rules.
- Japan: universal long-term care insurance (introduced in 2000) provides standardized eligibility and benefits for home/community and institutional care, explicitly aiming to reduce exclusive reliance on family caregiving.
- Global cost: WHO and Alzheimer's Disease International estimate global dementia costs around \$1.3 trillion (2019), with roughly half attributable to informal (unpaid) care; projections rise sharply by 2030.

- Latin America & Caribbean: PAHO reviews highlight a growing need for integrated long-term care systems; currently, families frequently provide care with limited formal respite and residential capacity.

8. References

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