Lifelong Education & Aging Resource Network

Facing Hard Conversations: Aging, Decline, and End-of-Life Care

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Jan 8, 2026

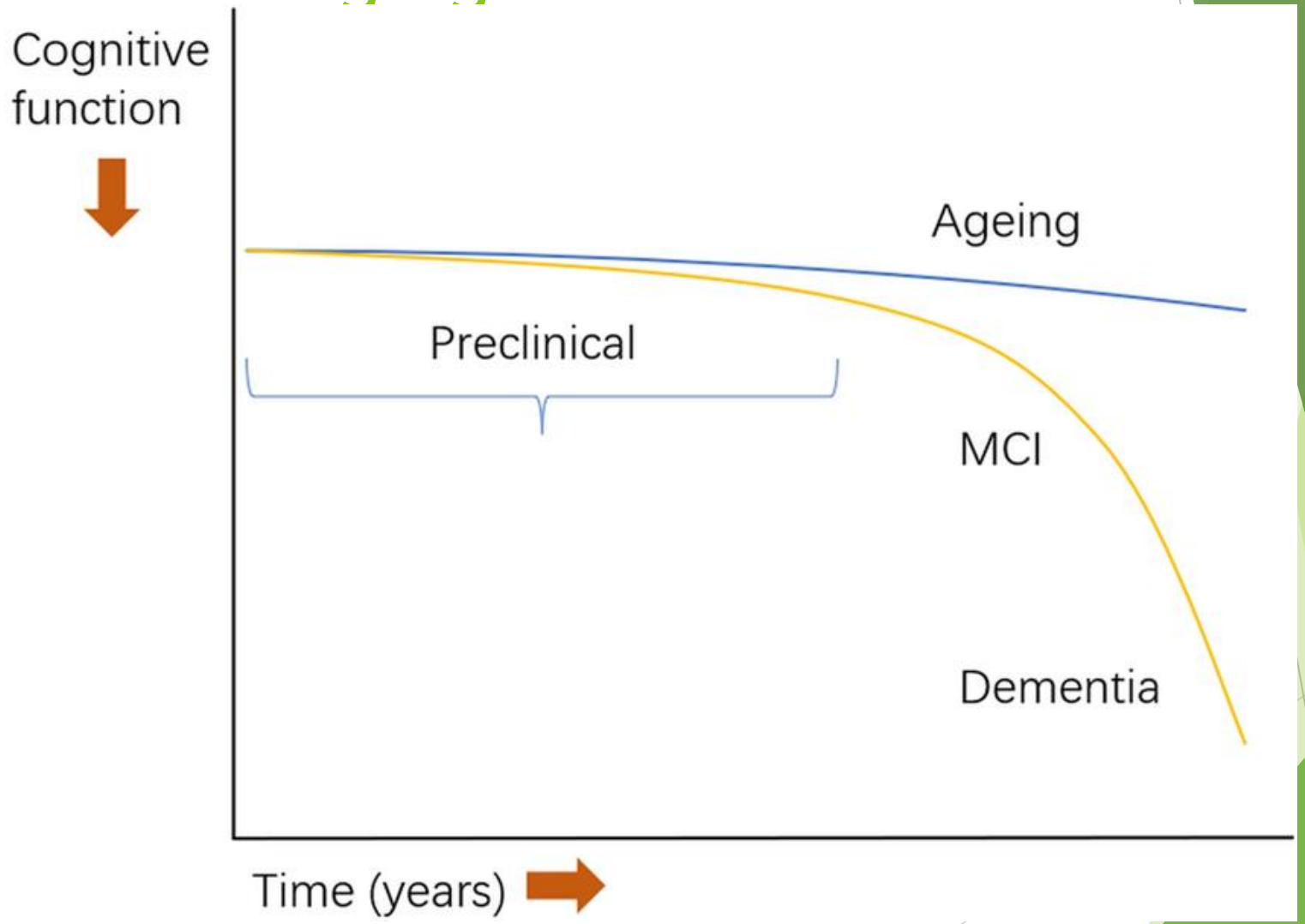
Learning Objectives

- Identify clinical, ethical, and safety considerations in the care or older adults.
- Describe important medical and legal considerations relevant to serious illness and end of life care in adults.

Why These Questions Matter

- Most crises arise when conversations happen too late
- Different professions see different pieces of the same problem
- Asking the right questions earlier improves outcomes

Normal Aging vs Dementia:



Cognitive impairment

- Orange vs Red flags for neurocognitive disorder or dementia
- Medical evaluation important as many conditions can mimic "dementia"
  - e.g. depression/anxiety, delirium, hearing loss, medication effects, drugs, alcohol, organ dysfunction, vitamin deficiencies, electrolyte derangements, seizures, infections, brain tumors

Signs of Alzheimer's and Dementia	Typical Age-Related Changes
Poor judgment and decision-making	Making a bad decision once in a while
Inability to manage a budget	Missing a monthly payment
Losing track of the date or the season	Forgetting which day it is and remembering it later
Difficulty having a conversation	Sometimes forgetting which word to use
Misplacing things and being unable to retrace steps to find them	Losing things from time to time

When to Seek Cognitive Evaluation

- Concerns warrant testing: when poor judgement impacting function and safety
- What testing can and cannot determine
- Using results for planning, not just diagnosis
  - Primary care, neurology, geri-psychiatry, neuropsychiatric evaluations
  - Labs, imaging, cognitive assessments
  - Important not to ignore testing as there are some reversible conditions that can cause cognitive impairment.
- Importance of caregiver education, do's/don'ts, support groups, legal/financial planning, etc

ALZHEIMER'S® ASSOCIATION

When to Step In: Care and Finances

- Warning signs of declining capacity
- Gradual vs urgent intervention
- Preserving autonomy while reducing risk
- Most important thing to do is plan and complete as many documents your loved one will allow as recommended by clinicians and estate planners

Documents: Must have capacity

- Types of Power of Attorney
  - General durable; financial; attorney-in-fact
  - Health care; who, when, where
- Living Will
  - Road map for health care proxy, surrogate
  - Only applicable while you are alive, except for funeral arrangements
  - Views on life-sustaining treatments → Portable Orders
  - Preferences for independence and location of care
- Standard Will
  - Part of estate planning, executor, beneficiaries.
  - Only takes into effect after you die
- Living Trust
  - Avoids probate, court distribution and involvement, more tax implications

Portable Orders: POST

A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse or is not breathing.

Pick 1

- ☐ NO CPR: Do Not Attempt Resuscitation. (May choose any option in Section B)
- ☐ YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion. Requires choosing Full Treatments in Section B)

B. Treatment Orders: Follow these orders if patient has a pulse and/or is breathing.

Reassess and discuss interventions with patient or patient representative regularly to ensure treatments are meeting patient's care goals. Consider a time-trial of interventions based on goals and specific outcomes.

Pick 1

- ☐ **Comfort-focused Treatments.** Goal: Maximize comfort through symptom management; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital only if comfort cannot be achieved in current setting.
- ☐ **Selective Treatments.** Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.
- ☐ **Full Treatment (required if you choose CPR in Section A).** Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.

C. Additional Orders or Instructions. These orders are in addition to those above (e.g., blood products, dialysis).
[EMS protocols may limit emergency responders ability to to act on orders in this section]

D. Medically Assisted Nutrition (Offer food by mouth if desired by patient, safe and tolerated)

Pick 1

- ☐ Provide feeding through new or existing surgically-placed tubes
- ☐ Trial period for artificial nutrition but no surgically-placed tubes
- ☐ No artificial means of nutrition desired
- ☐ Not discussed or no decision made (standard of care provided)

Conservatorship vs Guardianship

Lacking competency, court appointed, costly, time intensive

Conservatorship

Controls: the money

- Bills & banking
- Property & assets
- Contracts & legal affairs
- Benefits & income

Guardianship

Controls: the person

- Medical decisions & consent
- Living situation (home, ALF, SNF)
- Safety & daily care

Is It Still Safe to Live Alone?

- Safety, function, and support systems
- Falls, medications, meals, and isolation
- Home safety assessments and care management
  - Early-stage care: food/pantry, spoiled food, increased home clutter, unopened mail, bills paid, bathing/grooming, driving
  - Middle and late-stage: dressing, bathing, grooming, fed, falls, unsafe living environments, caregiver burnout

Future Living Arrangements

- Health insurance does not want to pay the mortgage or buy the groceries
- Aging in place vs living with family
  - Caregiver burnout
  - Personal care services
    - Minimal hours through Medicaid
    - Contracted ~$30/hr
- Assisted living: $4,000-$10,000/month
  - Levels and layered costs, meals, medications
- SNF (skilled nursing facility): $8,000-$12,000/month
  - Rehab vs custodial care

When Treatment May Be Doing More Harm Than Good

- Benefit vs burden framework
  - No current medications make meaningful changes to risk of mortality or prevent institutionalization
  - Benefits limited to delaying progression or institutionalization on the order of months not years, slight reduction in caregiver burnout, behaviors
  - Risks: slow heart rates, passing out, GI upset, brain bleeds, polypharmacy
- Cumulative impact of hospitalizations and procedures
- Reframing goals of care conversations as things evolve
  - Geriatrics, palliative care

Big Picture: Helpful

- Interventions impacting outcomes:
  - Treating depression
  - Correcting sensory loss
  - Reducing anticholinergic burden
  - Exercise & mobility preservation
  - Caregiver support
  - Advance care planning
  - Safety planning

Prognostication

Dementia Type	Median Survival	Key Prognostic Notes
Alzheimer's disease	8–10 yrs	Slower early, long tail
Vascular dementia	5–7 yrs	Stepwise decline, ↑ CV death
Lewy body dementia	5–7 yrs	Early hallucinations, falls
Parkinson's disease dementia	4–6 yrs	Post-motor onset
Frontotemporal dementia (FTD)	6–8 yrs	Younger onset, rapid behavior change
Mixed dementia	5–8 yrs	Very common clinically
Prion disease (CJD)	Months	Rapid, fatal

Prolonging Life vs Prolonging Suffering

- Aligning treatment with values and goals
- When less intervention may improve quality
- Shared decision-making across disciplines

Palliative Care: Support at Any Stage

- Symptom management and decision-making support through exploring goals of care
- Working alongside curative treatment
- Benefits for patients and families
  - Family disagreement and conflict: Keeping care centered on patient's values in the current medical reality

Driving: Safety, Independence, and Risk

- Driving risk is assessed medically and functionally
  - Visual and medical components that cause can result in physical and/or cognitive deficits
- Role of clinicians, family, and the state: we all have a responsibility for safety
  - Idaho: Family Request for Re-Evaluation of Driving Privileges: Form ITD 5539. dmv.Idaho.gov
- Planning alternatives before keys and cars have to be taken
  - NegotiAge.com , conflict resolution/negotiation exploring interests, rights, power dynamics.

NegotiAge

Empowering you to negotiate geriatric conflicts.

End-of-Life Choices

- Unrealistic:
  - Take me out back/forest
- Reality:
  - Hospitalizations
  - Hospice
  - Death w/ Dignity
  - VSED

Hospice Care: When and Why

- Philosophy of care vs insurance benefit
  - Insurance language varies
- Eligibility: prognosis <6mo
  - Quality vs quantity
- Wholistic multidisciplinary approach focusing on comfort and support
  - RN, nursing aides, SW, chaplain, doctor, volunteers
- Earlier involvement often improves experience:
  - increased support, education, less complicated bereavement, improved symptom management, reducing hospitalizations, reducing CG burnout

Voluntary Stopping Eating and Drinking (VSED)

- Intentional, voluntary decision to stop intake of food and fluids with goal of hastening death which is legal in all U.S states
  - Intent to end present or imminent suffering
  - Must have capacity at onset
  - Patient driven w/o coercion
  - Distinct from starvation from disease or neglect
  - It is not:
    - Suicide by conventional legal definitions
    - Physician assisted death/suicide
    - Euthanasia
  - Ethics: Basic right of bodily autonomy, equivalent to refusing any treatment (CPR, ventilation, dialysis, artificial nutrition)

end of life WASHINGTON
Your life. Your death. Your choice.

Death with Dignity: Medical Aid in Dying

- Allows for terminally ill (<6mo) adult (>18) patient with capacity and physical abilities to voluntary self administer medication to intentionally hasten death
  - Legal in multiple surrounding states: OR, WA, MT, CA, CO, NM (12 total U.S jurisdictions, ~26% of population)
  - While many states have residency requirement OR and VT do not.
    - Must travel to the state, reside in the state for the process, ingest in the state
    - Multiple requests 2 weeks apart (verbal/written), no coercion, not driven by mental health impairments, OR has removed the requirement for multiple requests, and exceptions exist for the 15 day requirement
    - Multiple clinician involvement

Death with Dignity: Medical Aid in Dying cont…

- It is not:

Practice	Ethical Status
Refusal of treatment	Universally accepted
Withdrawal of life support	Accepted
Palliative sedation	Accepted
VSED	Accepted (controversial but legal)
DWD / MAiD	Jurisdiction-dependent
Euthanasia (clinician administers)	Illegal in U.S.

- L
- E
  - Autonomy, beneficence, non-maleficence, justice

EOLCOR
End of Life Choices
OREGON

Key Takeaways

- These are shared challenges across professions
- Early conversations reduce crisis and conflict
- Collaboration is essential
- Better questions lead to better planning and alignment, and outcomes for aging adults

Citations:

- https://www.alz.org/
- https://www.negotiage.com/faq
- https://endoflifewa.org/end-life-choices/vsed/
- https://floridadeathwithdignity.org/2025/08/10/states-where-maid-is-legal-and-whether-residency-is-a-requirement/
- https://eolcoregon.org/dwd-overview/overview-of-death-with-dignity-process/
- dmv.Idaho.gov