ECHO IDAHO

Special Session

Ethical Decision-Making in Dementia Care:

Balancing the Caregiver's Needs and Patient's Best Interests

09/08/2026

None of the planners or presenters for this educational activity have relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.

University of Idaho
School of Health and Medical Professions

Project ECHO

Learning Objectives

- Identify common ethical tensions in dementia care involving autonomy, dignity, safety, capacity, and caregiver needs.
- Differentiate the roles of legal requirements, professional ethics, institutional policies, and personal values in clinical decision-making.
- Apply a structured ethical decision-making framework to complex dementia-care scenarios.

University of Idaho
School of Health and Medical Professions

Project ECHO

Disclosures

- All cases have been de-identified to protect the privacy of the caregivers/PLWD
- Some illustrations were generated with AI tools; all content was reviewed and edited by the primary presenter (Dr. Black).

University of Idaho
School of Health and Medical Professions

Project ECHO

Case 1

Mid 80-year-old, widowed, female diagnosed with Major Neurocognitive Disorder due to possible Alzheimer's Disease with behavioral disturbance with worsening cognition (severe STM loss, disorientation), worsening sundowning, paranoia with delusions, and impaired decision making. Referred by PCP for neuropsychological evaluation to help clarify decision-making capacity, cognitive staging of dementia, and to assist with caregiver education due to increasing caregiver distress.

- **Key stakeholders**
  - Patient
  - Adult Daughter (Primary Caregiver and DPOA for HC and $)
  - Concerned neighbors / personal trainer
- **Central conflict**

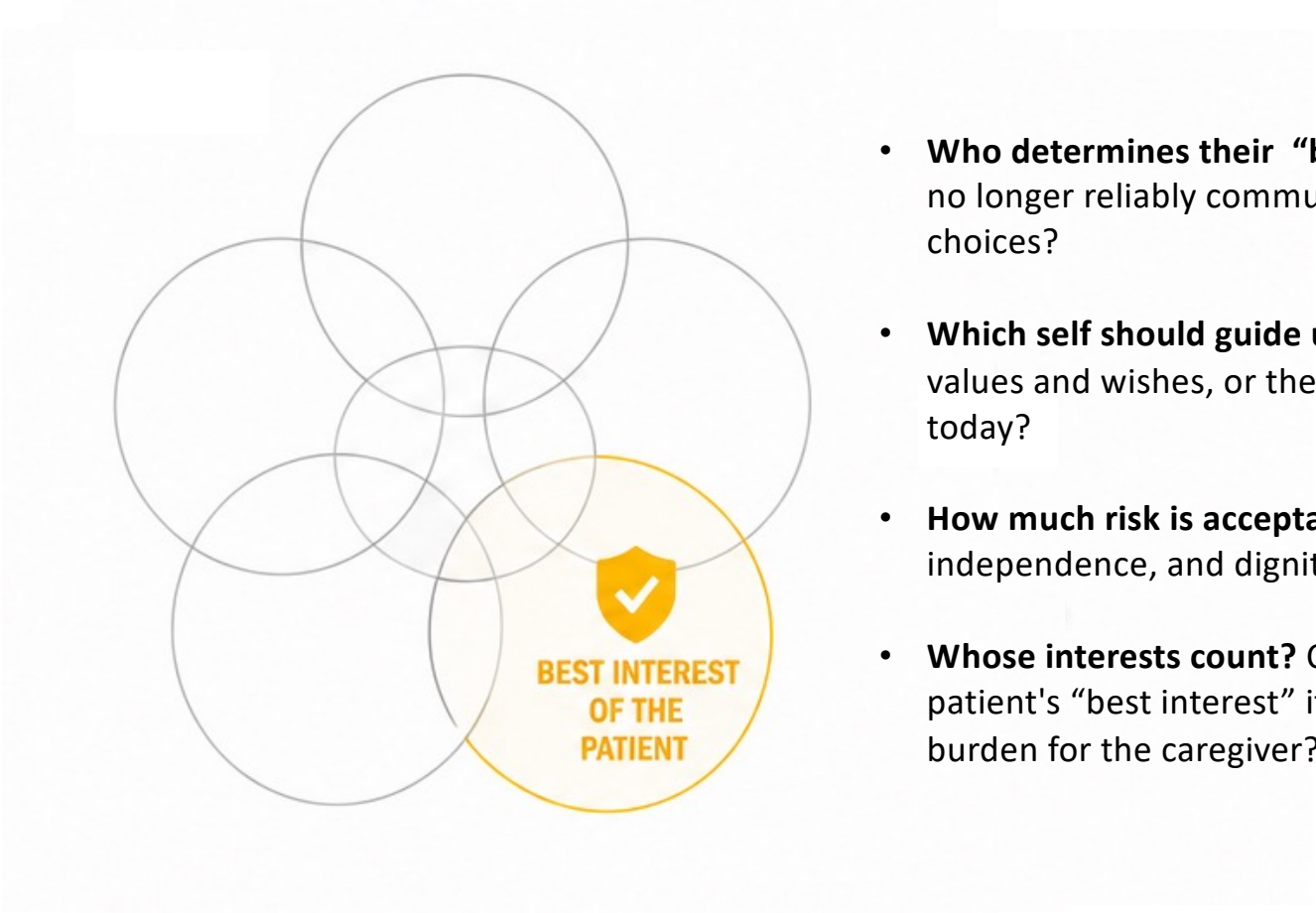
Patient is adamant she will remain in place at home despite being isolated on a rural farm. Local neighbors and personal trainer have expressed increasing concern regarding the patient's ability to live independently and have repeatedly contacted the daughter with increasing alarm. Daughter (POA) provides exceptional support but lives a couple hours away.

- **Unresolved questions**
  - Does the patient retain cognitive decision-making capacity for determining her own place of residence?
  - What are the least restrictive supports that could be put in place today to manage current concerns around self-neglect while also honoring her dignity and autonomy?
  - How to prepare for future care needs, which will increase over time and potentially soon?

Core Tensions for Caregivers/Families/PLWD

Person Living With Dementia	Primary Caregiver	Broader Family System
Autonomy ↔ Safety: *How much independence should I give up to reduce risk?*	**Protection ↔ Paternalism**: *When should I override their wishes to protect them?*	**Different Values of Risk ↔ Consensus**: *Who decides what is "safe enough"?*
Agency ↔ Dependence: *How can I remain involved as I increasingly need help?*	**Caregiving Commitment ↔ Personal Limits**: *How much can I reasonably sacrifice to continue providing care?*	**Shared Responsibility ↔ Unequal Burden**: *Who should provide the care and how much?*
Past Wishes ↔ Present Preferences: *Which matters more: what I wanted then or what I want now?*	**Surrogate Authority ↔ Moral Uncertainty**: *Am I making the decision they would want or what I believe is best?*	**Individual Values ↔ Family/Cultural Values**: *Whose values should guide care when we disagree?*

Core Tensions for Providers

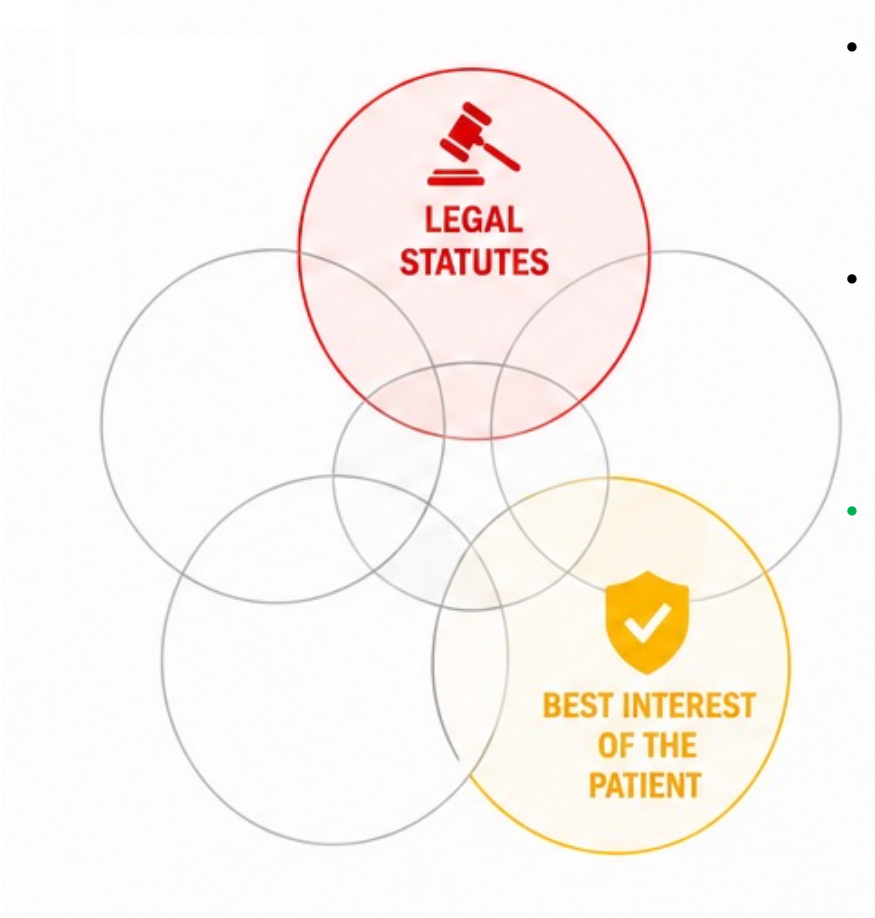


- **Who determines their "best interest"** when the person can no longer reliably communicate or reason through their choices?
- **Which self should guide us?** Their previously expressed values and wishes, or their preferences and expressed wishes today?
- **How much risk is acceptable** in preserving autonomy, independence, and dignity?
- **Whose interests count?** Can something truly be in the patient's "best interest" if it creates unsustainable harm or burden for the caregiver?

University of Idaho
School of Health and Medical Professions

Project ECHO

Core Tensions for Providers



- **Capacity ≠ diagnosis:** Dementia does not, by itself, automatically eliminate an individual's healthcare decision-making rights; authority may shift depending on capacity, the particular decision in question, advance directives, etc.
- **Advance directives & surrogate authority:** Idaho law governs instruments such as healthcare directives and surrogate decision-making; federal requirements generally recognize representatives authorized under state law.
- **NEW — Idaho guardianship reform (effective Jan. 1, 2027):** Idaho's adoption of the **Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA)** modernizes the state's framework, emphasizing **less-restrictive alternatives, proportionality, and preservation of autonomy** before or within guardianship (Idaho S.B. 1240, 2026)

University of Idaho School of Health and Medical Professions

Project ECHO

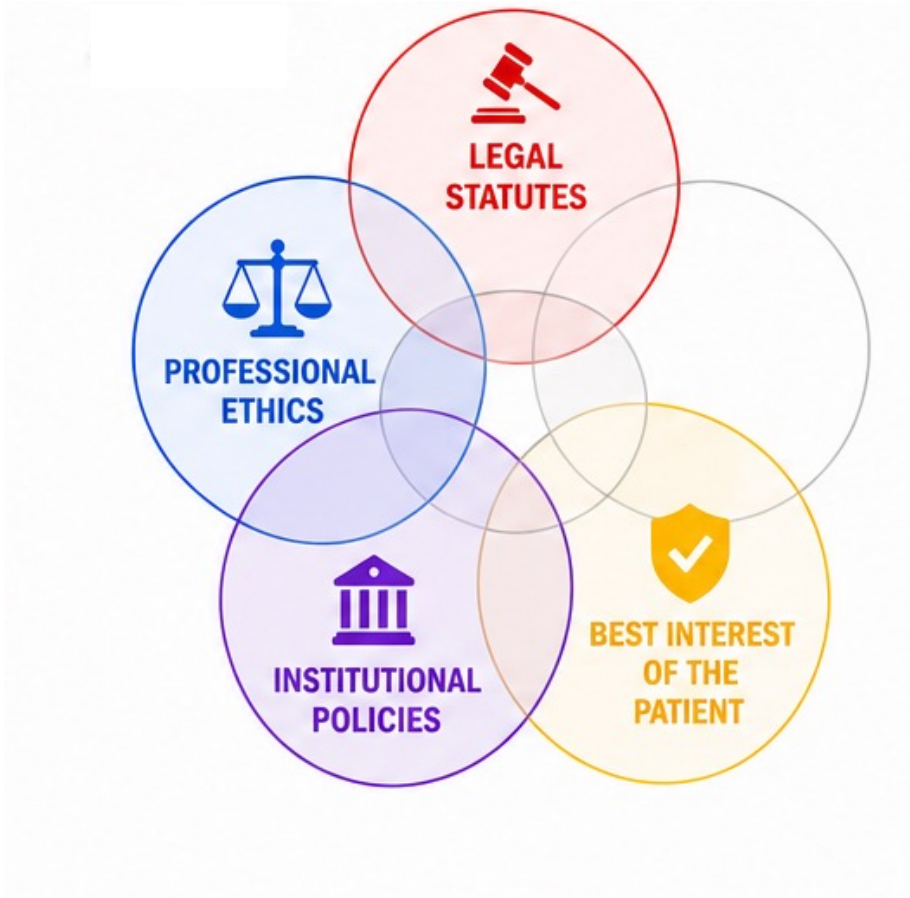
Core Tensions for Providers

- **Different professions → different ethical duties:** Social workers, psychologists, physicians, nurses, and other disciplines operate under distinct professional codes, not one universal healthcare ethics code.
- **Reasonable professionals may disagree:** Two team members can approach the same dementia dilemma differently without either behaving unethically.

University of Idaho School of Health and Medical Professions

Project ECHO

Core Tensions for Providers



YOUR Professional Setting Matters

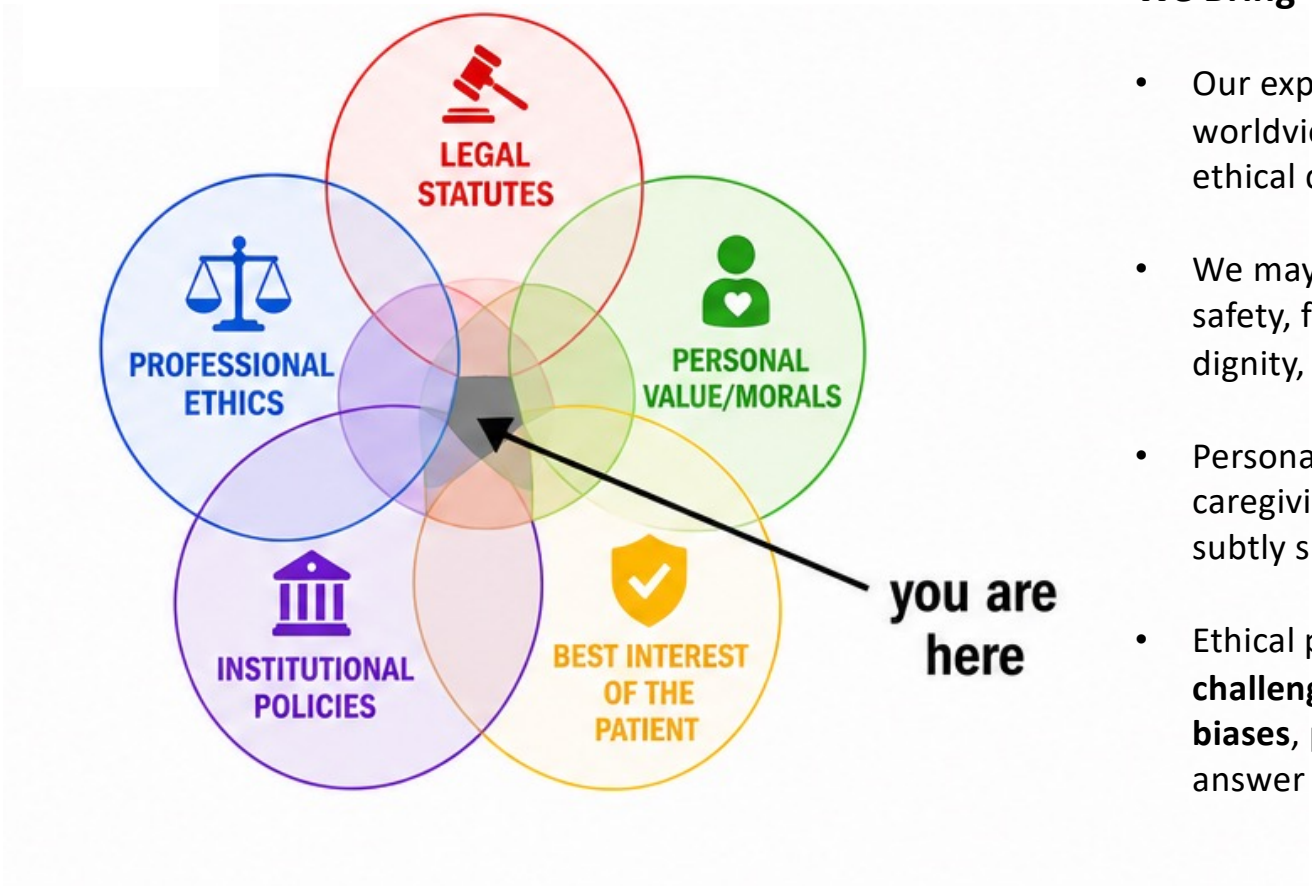
- **Where you practice can radically change the required course of action.**
- **Different settings carry different mandates:** hospital • government agency • law enforcement • community mental health • private practice • long-term care.
  - Policies may govern confidentiality, reporting, safety interventions, discharge, consent, documentation, and use of institutional resources.
- **What is permissible in one setting may be restricted, or even required, in another.**

To Ponder: *What happens when your institution's policy conflicts with what you believe is ethically best for the patient?*

University of Idaho School of Health and Medical Professions

Project ECHO

Core Tensions for Providers



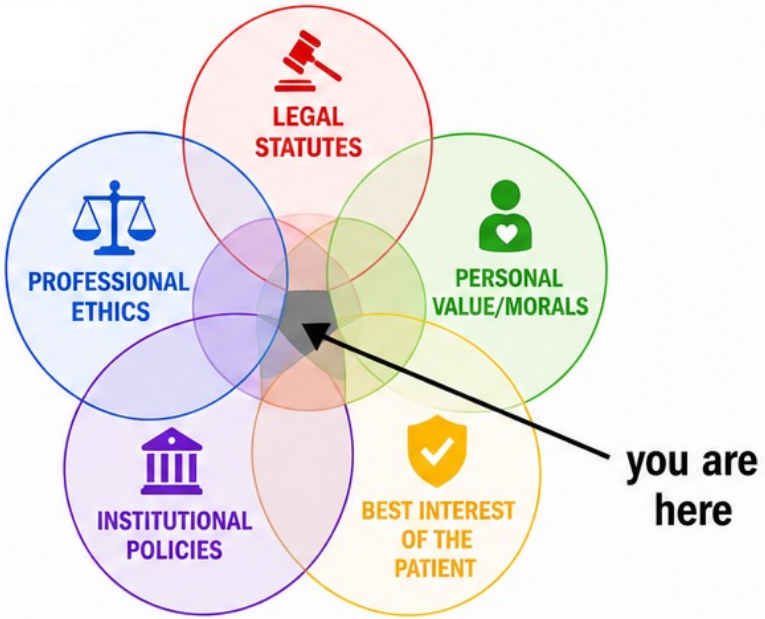
We Bring Ourselves Into the Room

- Our experiences, culture, beliefs, and worldview influence how we perceive an ethical dilemma.
- We may differ in how we value autonomy, safety, family responsibility, quality of life, dignity, and acceptable risk.
- Personal experiences with dementia, caregiving, disability, aging, or death can subtly shape recommendations.
- Ethical practice requires **us identifying and challenging our own assumptions and biases**, particularly when the “right” answer feels obvious.

University of Idaho School of Health and Medical Professions

Project ECHO

Common Reactions to Ethical Tensions



University of Idaho
School of Health and Medical Professions

Project ECHO

Why Ethical Dilemmas are Hard

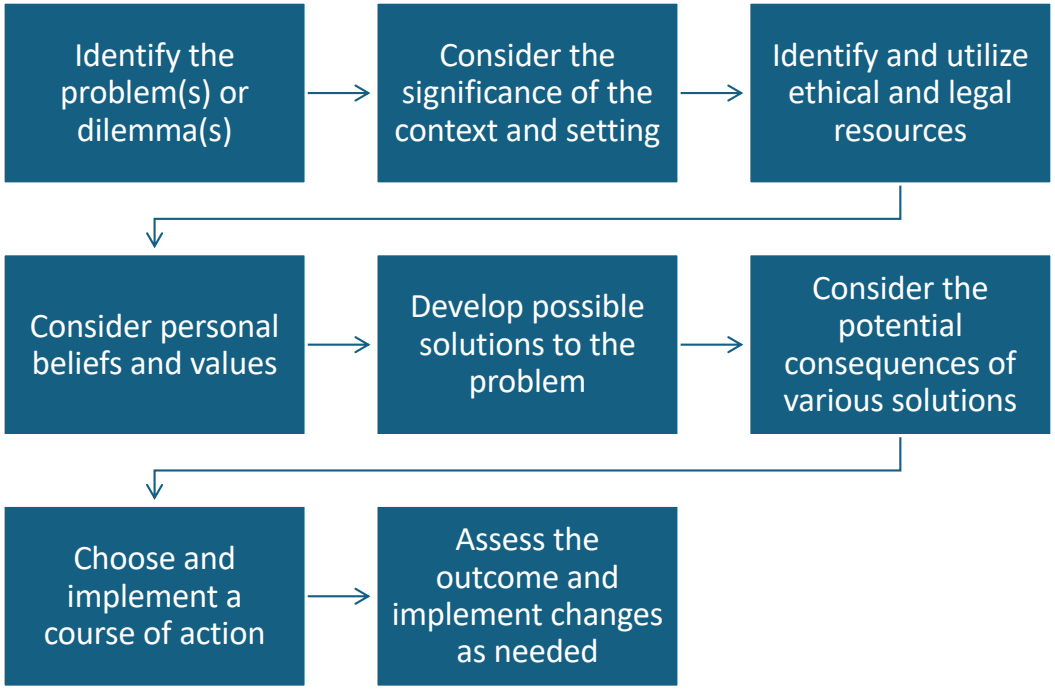
Core tensions in dementia caregiving become ethical dilemmas when legitimate obligations (legal, institutional, professional), values, or courses of action conflict (e.g., Bush, 2007)

- **Clashing Principles:** Prioritizing autonomy directly competes with ensuring caregiver safety and patient well-being (e.g., Schou-Juul et al., 2026).
- **Procedural Traps:** Legalistic "capacity binaries" restrict clinicians from navigating fluid, borderline cognitive decline and personality/behavioral changes (e.g., Wong & Yap, 2025).
- **Harms of Safety:** Physical and social restrictions meant to protect patients (positive intent) often accelerate depression and isolation (e.g., Chiong et al., 2021).
- **Relational Strain:** Care choices are heavily strained by cultural filial duties, gendered labor burdens, and caregiver burnout (e.g., Wong & Yap, 2025).
- **No Universal Formula:** Ethical care is highly context-sensitive, offering no "one-size-fits-all" prescriptive resolution (e.g., Serrat et al., 2026).

University of Idaho
School of Health and Medical Professions

Project ECHO

Bush, Connell, & Denney's (2006) Ethical-Decision Making Model

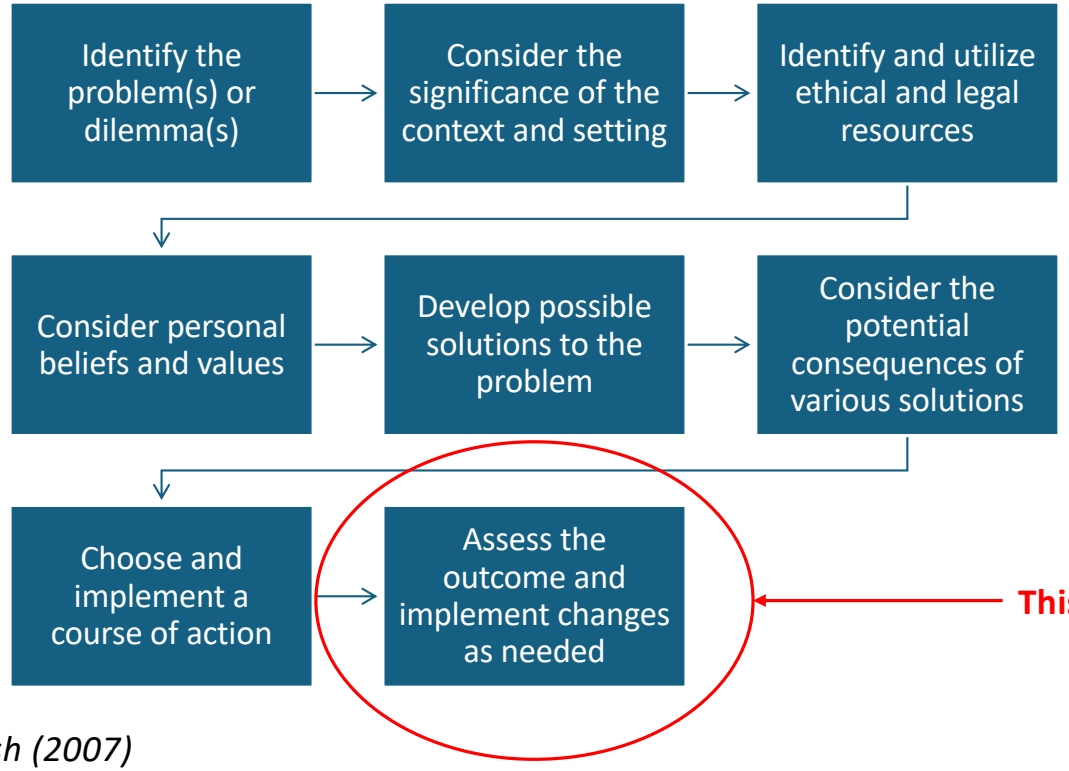


-As adapted in Bush (2007)

University of Idaho School of Health and Medical Professions

Project ECHO

Bush, Connell, & Denney's (2006) Ethical-Decision Making Model



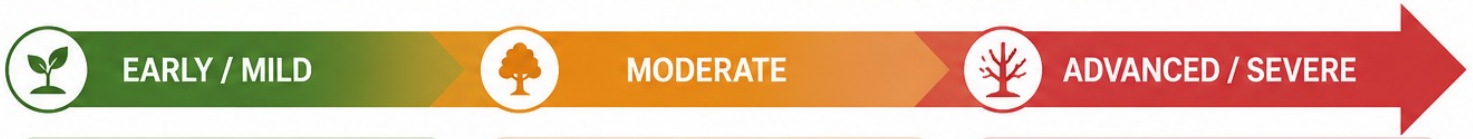
-As adapted in Bush (2007)

University of Idaho School of Health and Medical Professions

Project ECHO

The Ethical Landscape Shifts as Dementia Progresses

Core tensions evolve over time across the three perspectives



	EARLY / MILD	MODERATE	ADVANCED / SEVERE
Person Living with Dementia (PLWD)	**Autonomy ↔ Protection** Driving • Finances • Disclosure Independent living *"How much risk is acceptable?"*	**Agency ↔ Increasing Dependence** Supervision • Medication • Personal care • Living arrangements *"When and how much should others step in?"*	**Prior Wishes ↔ Present Experience** Goals of care • Comfort • Quality of life Treatment burdens *"What would honor this person now?"*
Primary Caregiver	**Preserve Independence ↔ Prevent Harm** Encouraging self-care • Monitoring Safety planning *"How involved should I be?"*	**Caregiver Burden ↔ Personal Limits** Time • Stress • Health • Finances Work • Relationships *"How much can I keep giving?"*	**Surrogate Decisions ↔ Moral Uncertainty** End-of-life choices • Feeding Hospitalization • Restraints *"Am I doing the right thing?"*
Broader Family System	**Different Views of Risk ↔ Reaching Agreement** Assessing needs • Sharing concerns Planning for the future *"What is the right plan?"*	**Shared Responsibility ↔ Unequal Burden** Dividing tasks • Decisions • Time Financial pressure *"Who should do what—and how much?"*	**Individual Values ↔ Family / Cultural Values** Honoring values • Conflicting beliefs Legacy • Cultural expectations *"Whose values should guide us?"*

PLWD independent decisional authority — *generally decreases over time*

Caregiver / surrogate responsibility — *generally increases over time*

Personhood, dignity, preferences, and relational agency remain ethically relevant throughout.
Our task is to respond with compassion, proportionality, and continual reassessment.

ty of Idaho
h and Medical

Project ECHO

Example: *"Dad Insists He Can Still Drive"*

Bush et al. (2006) Steps	Example Application
1. Identify dilemma	Autonomy ↔ Safety: respect his independence or intervene to reduce risk?
2. Consider context	Objective cognitive/functional status, recent driving history (e.g., dents, dings, near-misses), level of insight, passenger observations
3. Ethics & law	Professional obligations, Idaho law/reporting requirements, relevant institutional policies
4. Personal values	*"Am I allowing my own tolerance for risk, beliefs about aging, or views about independence to drive the recommendation?"*
5. Generate options	Continue driving; restrict driving; formal driving evaluation; transportation supports; voluntary or involuntary cessation
6. Consider consequences	Injury to patient/others ↔ loss of autonomy, identity, mobility, and social participation
7. Choose & implement	Select the most proportionate/least restrictive defensible intervention given the evidence
8. Reassess	Did the solution work? Has risk, cognition, or the patient's response changed as dementia advances?

University of Idaho
School of Health and Medical Professions

Project ECHO

Case 2 – Laura LaForte, LCSW

Mid-70s married (several times) female diagnosed with Major Neurocognitive Disorder probably due to Alzheimer's Disease without behavioral disturbance. Client is emotionally struggling with the choice of aligning with her spouse vs. her adult children, after significant familial discord resulted in a stop of all communication and visits with adult children and their families.

- **Key stakeholders**
  - Client
  - Spouse
  - Adult Children
  - Grandchildren (teens)
- **Central conflict**
  - Client is conflicted and suffering after longstanding unresolved hurt feelings and mistrust between husband and her biological adult children led to major family argument and permanent no contact from her children based on her choice to align with her husband and stay married with husband being the primary caregiver. Client's worsening symptoms now evidencing concern from children with thoughts the couple should divorce so they can take over all financial affairs and "take care of her" as her symptoms progress.

Unresolved questions

- How best to support the autonomy, wants and needs of the client with conflicting loyalties?
- What treatment plan could meet the needs of each person in the client's Dementia Ecosystem to create shared understanding in support of her?

Case 3 – Karen Kouba-McIver, LSW

Spouse (caregiver) is experiencing burnout, depression, stress, health, and safety issues due to 24/7 care of spouse (care recipient)

Key Stakeholders:

- Patient (care recipient)
- Caregiver-spouse
- 2 adult children who live out of state

- **Central conflict:** Caregiver or care recipient consideration with patient autonomy or caregiver well-being in ethical, legal and practical rights of ability or safety.

- **Unresolved Questions:**
  - How should caregiver burden influence recommendations about placement?
  - What community resources could delay or prevent institutional placement?

Case 4 – Kennette McWilliams, LCSW

Mid 70s woman with recurrent metastatic lung cancer (bone mets), progressive dementia (poor STM), and GAD; requires support with healthcare management.

Stakeholders:

- Patient
- Daughter (nearby support)
- Twin sister
- Interdisciplinary healthcare team

Central Concerns:

- Determining decision-making capacity while balancing autonomy, safety, self-determination, and potential surrogate decision-making.

Unresolved Questions:

- How can autonomy be preserved as cognition declines?
- How should conflicts between patient wishes and family recommendations be addressed?

References

American Medical Association. (n.d.). *AMA code of medical ethics*.

American Psychological Association. (2017). *Ethical principles of psychologists and code of conduct (2002, amended effective June 1, 2010, and January 1, 2017).*

Bush, S. S. (2007). An ethical decision-making model. In *Ethical decision making in clinical neuropsychology* (pp. 23–34). Oxford University Press. https://doi.org/10.1093/oso/9780195328226.003.0003

Chiong, W., Tsou, A. Y., Simmons, Z., Bonnie, R. J., & Russell, J. A. (2021). Ethical considerations in dementia diagnosis and care: AAN position statement. *Neurology, 97*(2), 80–89. https://doi.org/10.1212/WNL.0000000000012079

Idaho Legislature. (2026). *Senate Bill 1240: Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act*. https://legislature.idaho.gov/sessioninfo/2026/legislation/S1240/

References

National Association of Social Workers. (2021). *Code of ethics of the National Association of Social Workers*.

Schou-Juul, F., Gordiijn, B., Morais, A., Fonseca, M., Scerri, A., Hinrichsen, C., Porteri, C., Sperling, D., Kelly, B., Bobrowicz-Campos, E., Dogru-Huzmeli, E., Jarašiūnaitė-Fedosejeva, G., Thygesen, H., Stončikaitė, I., Alexandre, I. M., Rymaszewska, J., Irving, K., Zajdó, K., Johansson, L., . . . Lauridsen, S. (2026). Development and pilot validation of a European ethical framework for decision-making in dementia care (EDEM). *BMC Medical Ethics, 27*(1), Article 171. https://doi.org/10.1186/s12910-026-01551-y

Serrat, R., Lauridsen, S., Bobrowicz-Campos, E., Brandão, T., Brites, R., Cannella, V., Celdrán, M., Chacur-Kiss, K., Cin, A., Fabà, J., Jarašiūnaitė-Fedosejeva, G., Korkmaz-Yaylagul, N., Pons-Vila, J., Porras, Y., Radenkovic, M., Thoft, D. S., Silva, R., Stončikaitė, I., Szcześniak, D., . . . Schou-Juul, F. (2026). Ethical principles and frameworks in dementia care: A scoping review. *Neuroethics, 19*, Article 29. https://doi.org/10.1007/s12152-026-09655-3

Wong, G. H. Z., & Yap, P. L. K. (2025). A person-centred approach to decision-making and care for persons living with dementia. *Annals of the Academy of Medicine, Singapore, 54*(4), 252–256. https://doi.org/10.47102/annals-acadmedsg.2024377

University of Idaho School of Health and Medical Professions

Project ECHO