Respecting Patient Autonomy: Legal and Medical Aspects of End-of-Life Care

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Objectives

- Understand the medical and legal implications involving end-of-life decisions, including Medical Aid in Dying (MAID), Voluntary Stopping of Eating and Drinking (VSED), and Stopping Eating and Drinking by Advance Directive (SED by AD)
- Share a hospice and nursing home medical director's clinical perspective on end-of-life care;
- Explore legal cases involving MAID where physicians and hospitals have been parties;
- Consider wrongful life, wrongful death, and other actions targeting SNFs, hospices and other healthcare providers.

Legal and Regulatory Underpinnings in LTC

Patient Self-Determination Act of 1990 (PSDA)

The PSDA recognizes patient autonomy as a protected interest

All patients in Medicare/Medicaid certified facilities must be given written information about their right to have an advance directive

The PSDA codified a person's right to accept or refuse medical and/or surgical treatment

Pub. L. No. 101-508 §§4206, 4751 (codified in scattered sections of 42 U.S.C. especially §§ 1395cc, 1396a (West Supp. 1991)

42 C.F.R. § 483.10 Resident Rights (F578)

- The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility, including those specified in this section. 42 C.F.R. § 483.10(a)

- The resident has the right to request, refuse, and/or discontinue treatment, to participate in or refuse to participate in experimental research, and to formulate an advance directive. 42 C.F.R. § 483.10(c)(6)

- Nothing in this paragraph should be construed as the right of the resident to receive the provision of medical treatment or medical services deemed medically unnecessary or inappropriate. 42 C.F.R. § 483.10(c)(8)

42 C.F.R. § 483.10 Resident Rights (F578)

§483.10(g)(12)* The facility must comply with the requirements specified in *42 CFR part 489,* subpart I *(Advance Directives).

i. **These requirements include provisions to inform and provide written information to all adult residents concerning the right to accept or refuse medical or surgical treatment and, at the resident's option, formulate an advance directive.**

ii. **This includes a written description of the facility's policies to implement advance directives and applicable State law.**

iii. **Facilities are permitted to contract with other entities to furnish this information but are still legally responsible for ensuring that the requirements of this section are met.**

iv. **If an adult individual is incapacitated at the time of admission and is unable to receive information or articulate whether or not they have executed an advance directive, the facility may give advance directive information to the individual's resident representative in accordance with State Law.**

v. **The facility is not relieved of its obligation to provide this information to the individual once they are able to receive such information. Follow-up procedures must be in place to provide the information to the individual directly at the appropriate time.**

Voluntary Stopping (of) Eating & Drinking (VSED)

Voluntary Stopping Eating & Drinking

- VSED – just what it sounds like!
- Available in every state (but be aware of risks)
- Considered ethically sound and defensible, manner of death generally certified as natural
- Any person with decisional capacity can do this—but important to rule out significant mental illness clouding decisional capacity
- Support from hospice, or at least good palliation by the primary team, is advisable (symptom relief measures/Rxs)

VSED (cont'd)

- Unlike MAID, people can change their minds after they begin
- Main symptom is thirst for a few days, OTC products can help
- Usually asleep after the first several days, essentially comatose within a week
- Body systems shut down completely, death almost always within 14 days—but even a small amount of fluid can substantially delay death
- May be necessary to help LTC staff work through this—but important that staff respect the decision and NOT go in offering fluids, etc.—fear of regulatory actions may be a challenge

VSED: Illustrative Cases

Bouvia v. Superior Court (1987)

- She has a right to refuse the increased dehumanizing aspects of her condition created by the insertion of a permanent tube through her nose and into her stomach….

- A patient has the right to refuse any medical treatment or medical service, even when such treatment is labeled "furnishing nourishment and hydration."

- The right to refuse medical treatment is basic and fundamental.

Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 241 Cal.Rptr. 239 (1987)

Cruzan v. Dir. Mo. Dep't of Health: Landmark case re: right to refuse treatment

- 1/11/83 Nancy Cruzan in serious MVA, resuscitated by paramedics
- Dx: Persistent Vegetative State (PVS), feeding tube inserted
- 1988: Parents seek removal of feeding tube, hospital refuses
- Parents receive court order to remove feeding tube
- Trial court: fundamental right to refuse, withhold, or withdraw life-prolonging procedures when person is in PVS and recovery not possible
- Missouri Supreme Court reverses trial court (4-3)
- Holding: Parents cannot refuse tx for Nancy absent "clear and convincing evidence"
- 1989 SCOTUS agrees to hear case
- SCOUTS uphold Missouri's "clear and convincing evidence" standard
- 1990 SCOTUS acknowledges "protected liberty interest in refusing unwanted medical treatment"

- *Cruzan v. Dir. Mo. Dep't of Health*, 497 U.S. 261 (1990)

Cruzan

Due process clause of the 14th Amendment supports right to refuse medical treatment

"Substituted judgment" not accepted in this instance

"Clear and convincing interest" required by Missouri

"Best interests" not an issue in Cruzan

Life support was terminated in December 1990 after parents presented clear and convincing evidence.

Cruzan case gave rise to Patient Self-Determination Act (1990)

> must inform patients about state's law re: self-determination; recognizes advance directives

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Stopping Eating and Drinking by Advance Directive

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Stopping Eating & Drinking by Advance Directive (SED by AD)

- Dementia directives becoming more common—some instruct caregivers and healthcare professionals not to hand-feed when loss of self-feeding ability occurs
- Criteria for when to cease assisted feeding vary—bringing up some ethical issues
  - "Now-self" versus "Then-self"—precedent autonomy
  - Does assent to feeding constitute consent? Did the person change their mind?
  - Justice, very vulnerable population. Ageism/discrimination against persons with dementia?
- AMA Code of Ethics (Opinion 2.20): "The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail."

SED by AD (cont'd)

- AMDA – The Society for Post-Acute and Long-Term Care Medicine's White Paper/Policy A19 recommended against ever giving orders in PALTC for SED by AD (except in cases of patient distress or refusal)
  - Although a majority of surveyed AMDA members would want SED by AD for themselves
- AMDA Board of Directors rescinded this policy in 2022:
  - *AMDA encourages all practitioners to carefully consider and evaluate each request for SED by AD individually in the context of clinical and biopsychosocial factors, within the ecosystem of facility, local, state, and federal policy.*
- Another equity issue: people with resources can place their loved one in a different level of care to do SED by AD—those without resources cannot

Medical Aid in Dying (MAID)

Medical Aid in Dying (MAID) is a still-controversial topic that lies at the intersection of law, medicine, and ethics.

Views about MAID among professional organizations, courts and state legislatures (and in the public) are evolving.

Value-laden language: Some organizations (and federal law) still refer to it as Physician-Assisted Suicide, while many state laws use euphemistic phrases: “Death with Dignity” or “End of Life Options”

States Where MAID is Legal

California (End of Life Option Act; 2016)

Colorado (End of Life Options Act; 2016)

District of Columbia (Death with Dignity Act; 2017)

Hawaii (Our Care; Our Choice Act; 2019)

Maine (Maine Death With Dignity Act; 2019)

Montana (Supreme Court decision, not statute)

New Jersey (Medical Aid in Dying for the Terminally Ill; 2019)

New Mexico (Elizabeth Whitefield End-0f-Life Options Act; 2021)

Oregon (Oregon Death with Dignity Act; 1997)

Vermont (Patient Choice and Control at the End-of-Life Act; 2013)

Washington (Washington Death with Dignity Act; 2008)

States that Considered MAID Legislation in 2023

Nevada
Arizona
Kansas
North Dakota
Minnesota
Iowa
Indiana

Kentucky
Virginia
Pennsylvania
New York
Massachusetts
Connecticut
Rhode Island

MAID Prerequisites

- Age 18 (or older)
- Decision-Making Capacity and legally competent (not suffering from a mental health condition that impairs their decision-making capacity for MAID)
- Terminally ill (irreversible disease with prognosis of 6 months or less)
- Attending and consulting physicians must agree on the above
- Residency (not required in Oregon, as of March 2022)
- Ability to self-administer MAID medications

MAID Facts

- More than 8000 prescriptions written since 1997 in U.S.
- 6378 people have died from ingestion of MAID drugs
- Majority of participants had cancer or ALS
- 63% of prescriptions taken
- Average age: 74, male/female about 50/50
- 87% of pts. on hospice
- 90% die at home
- <1% of total deaths in each state were via MAID

Equity issues? Agency? Access?
Most were college-educated, white

Source: Compassion & Choices, Medical Aid-in-Dying Utilization Report, [*https://bit.ly/MAIDutilization2022*](https://bit.ly/MAIDutilization2022)

Opposition to MAID

- ✓Unnecessary with good palliative care
- ✓Recognize nonmaleficence—lethal Rx can be interpreted as doing harm
- ✓Sanctity of life
- ✓Physician's job is not to assist in ending a patient's life—undermines relationship
- ✓Hippocratic Oath
- ✓Inconsistent with physician's role as healer
- ✓Potential for abuse, "slippery slope"
- ✓Passive vs. active distinction
- ✓Many medical societies still oppose
  - ✓Including AMDA & AMA

Support for MAID

- ✓An act of compassion that recognizes patient autonomy
- ✓Individual rights vs. State interest
- ✓Our job is to walk the path with our patients, wherever it takes them
- ✓Alleviates unnecessary suffering (beneficence)
- ✓It has always been done, just not always identified as such (high doses of opioids, palliative sedation, etc.)
- ✓Honesty, transparency

Common Reasons Why Patients Request MAID

- ***Fear of loss of independence***
- Fear of unrelieved pain or other physical symptoms
- Desire to avoid being a burden on family (physically or financially)
- Desire to avoid indignity
- Desire to avoid leaving tarnished memories
- Desire to avoid institutionalization (prefer to die at home)
- Desire to be in control of the dying process (autonomy)
- Fear of losing decisional capacity/memory

- Multiple reasons often coexist

No Obligation to Participate in MAID

- No obligation for physicians (or other health care providers) to participate in any aspect of MAID (e.g., performing eligibility assessments, writing prescriptions).

- Generally considered unethical to refuse to refer a patient, even if the physician opposes the notion of MAID

- Not permissible to refuse to transfer patient’s medical record (with appropriate HIPAA disclosure authorization).

No Consensus in Medical and Legal Communities

MAID: Illustrative Cases

Dale v. University of California Board of Regents, et al.

Background

- May 2016, Judith Dale diagnosed by MD with inoperable Stage IV colorectal cancer, with metastases to liver and lungs. Ms. Dale enrolls in hospice.
- California "End of Life Option Act" became effective June 9, 2016 "allows patient with terminal disease (with life expectancy of six months or less) to request life-ending drug prescription from their doctor."
- Ms. Dale met all legal requirements for MAID

Dale v. University of California Board of Regents; UCSF Health; UCSF Medical Center; Chloe Atreya, MD; and Does 1-100, SF Sup. Ct. July 2017 (Complaint)

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Dale v. UCSF, et al.

- Ms. Dale was told or led to believe that she would be provided the lethal prescription for MAID.
- Medical record documents conversations with MDs, SWs, staff.
- After D/C, readmitted June 28, 2016 - August 6, 2016.
- Palliative care team note, "very motivated to pursue EOLA options." (August 3, 2016)
- August 18, 2016, Ms. Dale learns from MD at UCSF that MAID would not be available through them, despite numerous conversations with staff as inpatient and outpatient indicating that they would.

Dale v. UCSF, et al.

- UCSF Symptom Management Services Team promise (in website marketing material):

- "Your social worker will assist you in finding a doctor who has agreed to participate in the act [EOLOA]." Not true, per Complaint.

- When Ms. Dale was informed that UCSF would not assist, it was "too late in her terminal illness for her to transfer care to a new provider… fulfill requirements of EOLOA and obtain the medications in time to use them."

Dale v. UCSF, et al.

Significant allegations:

- After Dx, Ms. Dale "clearly and repeatedly requested aid in dying under EOLA, and told DEFENDANTS she would not start treatment with them unless they would respect and help facilitate her right to achieve a more peaceful death via aid in dying."
- "DEFENDANTS' staff repeatedly agreed to respect and assist with her request for aid in dying." Documentation evidences multiple conversations with UCSF physicians, social workers, other staff.

Dale v. UCSF, et al.

Ms. Dale's "wish for a peaceful death through aid in dying was denied by the decision of the DEFENDANTS not to participate in EOLA … with knowledge of the serious harm this would cause her…Judy's final weeks were brutal…She did not want to die in a diaper, bleeding from her rectum and urinary tract, in pain unless sedated to the point she was too confused to say goodbye to her family. But this horrific death was forced upon her by DEFENDANTS' actions." (Verbatim from Complaint.)

Dale v. UCSF, et al. - Causes of Action

- Elder Abuse/Neglect
- Misrepresentation/Fraud
- Negligent Infliction of Emotional Distress
- Negligence
- Survivorship

Plaintiffs requested: general damages, special damages, costs of suit, attorneys' fees, and punitive damages.

Kligler v. Healy (Massachusetts)

- Dr. Kligler is a legally competent adult with metastatic prostate cancer. He sought a prescription for a lethal dose of medication to end his life peacefully. Dr. Steinbach was willing to prescribe the lethal dose, but does not want to be charged with manslaughter. They sought the court's recognition of their respective constitutional rights.
- The doctors asserted that terminally ill adults have both a constitutional and common-law right to medical aid in dying (MAID), because there is no criminal statute barring the practice.

Kligler v. Healy

Issue: Whether a physician may be criminally prosecuted for manslaughter for prescribing medication used by a competent, terminally ill person to end their life.

Decided 12/19/22, Massachusetts Supreme Judicial Court rejects MAID – no constitutional right to MAID, which is also prohibited by MA State law.

Kligler v. Healy

“I agree with the court that there is no fundamental right to physician-assisted suicide…such a right finds no support in our history, in our evolving traditions and understandings of equality and fairness, or in our judicial precedent.”

“Physician-assisted suicide …is a quintessentially legislative matter.”

~Justice Dalila Wendlandt

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Washington v. Glucksberg, 521 U.S. 702 (1997)

- “The asserted ‘right’ to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause.”
- “Washington’s assisted suicide ban [is] rationally related to legitimate government interests.”
- ”There is no reason to think the democratic process will not strike the proper balance between the interests of terminally ill, mentally competent individuals… and the [s]tate’s interest in protecting those who might seek to end life mistakenly or under pressure.” *Id*. at 737

Note: Since 2008, Washington has permitted MAID

Takeaway: Laws evolve

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Morris v. Brandenburg (2015)

- “Even were aid in dying suited for a determination of constitutional importance, it would squarely conflict with the State’s own important and legitimate interests.”
- The “legislative process is the superior means by which aid in dying might achieve legality are the three statutory enactments nationally [Oregon, Vermont, Washington].”

New Mexico legislature subsequently approved MAID in 2021

Morris v. Brandenburg, 376 P.3d 836 (2015)

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Baxter v. Montana (2009)

- Montana Supreme Court drew the distinction between a physician unplugging life support (e.g., a ventilator) and providing a lethal prescription ("the final death-causing act lies in the patient's hands.")

- As a matter of law, "a physician [can] assist a mentally competent, terminally ill person to end their life."

- A physician who assists a suicide, and is charged with a crime for doing so, may assert the defense of consent.

Baxter v. Montana, 244 P.3d 1211 (2009)

Trends in LTC/EOL Litigation & Regulatory Actions

Wrongful Life/Wrongful Death Cases

Alicia v. Doctor's Hospital of August, et al., 299 Ga. 315 788 S.E. 2d 392 (2016)

O'Donnell v. Harrison, No. CDV 2017-850 (Mont. Dist. Ct. Lewis & Clark County, May 23, 2019)

Greenberg v .Montefiore New Rochelle Hospital, 205 A.D.3d 47 (2022)

John J. Kane Regional Center – Glen Hazel v. CMS, CRD CR1394 (2006)

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Actions Against Hospices

- Historically, hospices have not been frequent defendants in civil litigation—unlike nursing homes
- Recent negative media coverage and regulatory scrutiny have changed that
- FCA litigation, other regulatory actions (inappropriate admissions/recertifications), wrongful death (a bit of a challenge given patient population), inadequate symptom management
- Common themes
  - Euthanasia: “They put my mother down like a dog”
  - Lack of informed consent to hospice election: “They just told us it was ‘another layer of care’; not that they’d just let my husband die.”
  - Delayed or insufficient treatment: “She was suffering and it took 12 hours to get the pain medicine delivered” or “They did nothing to treat the bedsore as it got worse and worse.”

Conclusions

- End-of-Life Care, and legal issues surrounding it, remain in evolution—with wide variation among states
- Autonomy is of central importance—especially to Boomers—but there may be competing interests and ethical conflicts in achieving goal-concordant care
- Failing to honor advance directives/POLST can result in legal and/or regulatory actions
- VSED is a viable option to relieve suffering in terminal illness in all states; MAID is available to some terminal patients in some states (and D.C.) but is not widely embraced by doctors
- Nursing homes continue to be a target of litigation and regulatory actions; cases involving hospices are increasing