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# Approaching Death: The Journey Through Terminal Illness

FCA 2008 National Conference

**Kathryn L. Tucker, JD**
**Director of Legal Affairs**
**Compassion & Choices**

**Affiliate Professor of Law**

**Lewis & Clark School of Law**

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# Common scenarios

- What are the common junctures on the path of terminal illness?
- Recognize the options that are presented to maximize possibility that the dying process will be consistent with an individual's desires, values, beliefs, wishes.

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# Withdrawal of Care at Patient's Direction

- a mentally competent adult with cerebral palsy wants to direct the withdrawal of a feeding tube, knowing her death will be precipitated.
  - Does she have a right to direct withdrawal?
  - What is the basis for such a "right"?

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# Right to Reuse or Direct Withdrawal of Feeding Tube

- Federal Constitutional
  - Privacy or liberty
- State Constitutional
  - Privacy, liberty, dignity
- State Common Law
- State statute

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# Withdrawal of Care at Surrogate's Direction

Patient is in a vegetative state, connected to a ventilator: her parents want the ventilator removed. Can this be done?

- Agreement among family members
- Conflict among family members
- Surrogate has evidence of patient's wishes
- Surrogate lacks evidence of patient's wishes

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# Right to Removal of Ventilator

- Federal Constitutional
  - Privacy or liberty
- State Constitutional
  - Privacy, liberty, dignity
- State Common Law
- State Statute
  - Post Schiavo landscape

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# Advance Care Planning

elderly resident of a nursing home with many serious medical conditions, does not want CPR or other 'heroic measures' if she has a heart attack or other acute crisis.

- Can she plan to ensure that her wishes are respected?

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# Advance Directive

Margaret has signed an Advance Directive, directing that she not be subjected to CPR or other life extending interventions. She has a cardiac arrest in hospital: should she be resuscitated?

- How useful/effective is her AD?
- Can ADs be made more effective?
- What recourse if AD not honored?

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# End of Life Pain Management

William is dying of lung cancer, a painful condition. He is admitted to hospital in extreme pain.

- Should his pain be treated aggressively?
- Does he have a 'right' to aggressive pain management?
- What might prevent him from receiving aggressive pain management?
- What redress if inadequate pain management?

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# Obstacles to William's Care

- Clinician concern about regulatory oversight, "perceived excessive rx"
- Inadequate education in medical school and in practice
- Lack of accountability for under treatment
  - From medical board
  - From tort system

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# William's Right to Aggressive Pain Management

- Federal Constitutional: G'berg
- State
  - Statutory
  - Regulatory/medical board guidelines
  - Standard of care

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# Terminal (Palliative) Sedation

Peter is dying of a painful condition where conventional methods of pain management are not effective.

- Can his physicians induce unconsciousness via IV medication, and keep him unconscious, withholding fluids and nutrition, until his death ensues?

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# Terminal (palliative) Sedation

- Bases for Peter's right to this treatment
  - Federal constitutional: G'berg
  - State standard of care
- What issues are implicated w/this intervention?

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# Alert: Health Care Refusals

- Provider unwillingness to provide care patient chooses.
- Immunity for health care providers from professional and/or civil liability for refusing to provide care which patient has chosen? **Bad Idea**!
  - These measures **undermine professionalism**
  - **Put interests of provider over patient's**
    - **E.g. Alabama legislation**

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# Alert: Restrictions at Catholic Facilities

- Catholic health care facilities follow ERDs:
  - **Will not honor an advance directive that is contrary to Catholic teaching**
  - The free and informed health care decision of the person or the person's surrogate is to be followed **so long as it does not contradict Catholic principles.**

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# Alert: Restrictions at Catholic Facilities

- There should be a presumption in favor of providing nutrition and hydration to all patients
- Patients experiencing suffering that cannot be alleviated should be helped to appreciate the Christian understanding of redemptive suffering.
  - With increase in hospital mergers: problem grows!
  - At minimum: duty of **NOTICE**

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# Aid in Dying

Char is dying of breast cancer

- She has exhausted curative therapy
- She wants control over the time and manner of her death by having medications she could take to bring about a peaceful death, in her bed at home, surrounded by her family. Can she do this?
  - **What do we call this? : the language issue**

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# Terminology: Aid in Dying

- American Public Health Association(2006)
- American Medical Women's Association(2007)
- American Academy of Hospice and Palliative Medicine(2007)
  - All reject use of term "assisted suicide" to refer to this choice, as inaacurate and value laden

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# Aid in Dying

- Federal constitutional litigation to establish this right: *Washington v. Glucksberg* (1997)
- State constitutional litigation to establish this right: *Baxter v MT*
- Legislative avenues to establish this right: WA Initiative 1000

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# Aid in Dying In OR

- Oregon Death with Dignity Act initiative passes: 1994
- Implementation delays:
  - Lee v. Oregon, 891 F. Supp. 1429 (D. Or. 1995), vacated, 107 F.3d 1382 (9th Cir. 1997)
- Implementation begins: 1998

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# Aid in Dying in OR: A Narrowly Drawn Law with Many Safeguards

- Must be terminally ill (6 mo or less life expectancy)
- Diagnosis confirmed by 2nd MD.
- Must be mentally competent
- Patient must make multiple requests
- 15 day waiting period
- Mandatory provision of info re alternatives
- Patient must self administer medications

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# Aid in Dying In OR

- Use of Aid in Dying is limited
- During the first 10 years, approx. 30 per yr
  - A significant number of patients obtain medications but do not use

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# Aid in Dying In OR

Patients opting for Aid in Dying

- Have health insurance
- Are overwhelmingly enrolled in hospice care
- Almost all die at home
- 10 years of experience in Oregon demonstrate that risks to patients are not realized when a carefully drafted law is in place

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# Not all patients are able to obtain medications

Reasons for not receiving or filling prescriptions include:

- did not meet legal criteria
- died during the 15-day waiting period or before they could fill the prescription
- lost decision making or swallowing ability
- refused to see a psychiatrist

-Id.

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# No Harm to Vulnerable Populations

- The option of physician-assisted dying has not been unwillingly forced upon the disabled, poor, uneducated, uninsured or otherwise disadvantaged
- **No evidence** of harm to 'vulnerable populations'
  - Battin/Ganzini, 2007, **LEGAL PHYSICIAN-ASSISTED DYING IN OREGON AND THE NETHERLANDS: EVIDENCE CONCERNING THE IMPACT ON PATIENTS IN 'VULNERABLE' GROUPS**

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# Improved EOL Care In OR

Rather than posing a risk to patients or the medical profession, the DWDA has galvanized improvements in EOL care

- Increased physician enrollment in CME courses on pain/symptom management;
- Increased physician enrollment in CME courses on recognizing depression and other psychiatric disorders;
- Increase in referrals of patients to hospice programs.

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# Outside Reviews

"It is [quite] apparent from credible sources in and out of Oregon that the Death with Dignity Act has not had an adverse impact on end-of-life care and in all probability has enhanced the other options."

- State of Vermont (2004)

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# GAO Finds:
# EOL Communication Improved

Representatives of a hospice-based palliative care provider in Oregon stated that the physicians they work with are more comfortable discussing end-of-life issues with their patients since the enactment of the Death with Dignity Act.

-GAO Report to the Hon. Ron Wyden, US Senate, 2007, p.14
www.gao.gov/new.items/d0866.pdf

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# GAO Finds:
# EOL Communication Improved

Passage of the Dignity Act "helped create an environment in Oregon where end-of-life issues are discussed more openly."

-Id.

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# Outside OR: The Underground Practice

A significant number of primary care physicians, and an even larger number of oncologists, report having been asked for assistance in a patient's hastened death; one quarter complied.

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# In the Back Alley

When aid in dying occurs outside Oregon, covertly, there are **no** safeguards; AND complications are more likely to occur.

- much higher chance of an extended time until death after consuming lethal medications
- stress and anxiety for the patient and family is much higher

- H. Starks et al, Family Member Involvement in Hastened Death, 31 Death Studies 105–30 (2007).

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# Expanding the Laboratory Beyond Oregon

- **Both statehouse and courthouse will be influenced by OR experience and by policies of groups themselves influenced by OR experience (e.g. AMWA policy on Aid in Dying.)**
  - **Central argument against= risk; risk disproved in OR.**
- **Continued opposition by religious right and factions of disability community**
  - **Disability opposition weak in face of data**

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# American Medical Women's Assoc Supports Aid in Dying

- AMWA supports the right of terminally ill patients to hasten what might otherwise be a protracted, undignified or extremely painful death.

- AMWA believes the physician should have the right to …provide a terminally ill patient with, but not administer, a lethal dose of medication and medical knowledge, so that the patient can, without further assistance, hasten death. This practice is known as Aid in Dying.

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# AMWA Supports Aid in Dying

"AMWA supports the passage of aid in dying laws which empower mentally competent, terminally ill patients and protect participating physicians, such as that passed in Oregon, the Oregon Death with Dignity Act."

- AMWA House of Delegates 2007

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# People's Memorial Association

- Values responsible advanced planning, dignity, privacy and individual choice.
- To promote planning for end-of-life decisions.
- To make available a variety of death care options that are both dignified and affordable.

**These principles support endorsing the Washington Death with Dignity Act**

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# Support for WA Death w/Dignity Act is Strong

- WA State Public Health Association
- American Medical Women's Association
- American Medical Student's Association
- ACLU
- National Women's Law Center
- Northwest Women's Law Center

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# Conclusion

"Making someone dies in a way that others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyranny."

Ronald Dworkin, *Life's Dominion*