

Dying in America Care Options at the End of Life

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How Do Most People Want Their Lives to End

- At home with loved ones
- As free from pain and suffering as possible
- Their social, emotional, and spiritual needs addressed
- Their wishes, values, and well-being supported



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Dying in America

- Unfortunately, the majority of us do not die at home
 - Approximately 60% of people die in a hospital or other medical facility
 - ER visits and hospitalizations are frequent near end-of-life
 - 75% seen in ER in last 6 months; 50% in last month
 - 75% seen in ER are admitted
 - One in five have major surgery in the last month of their life
 - One in five die in a Critical Care Unit

Institute of Medicine – Dying in America, 2014

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The Medicalization of Dying in America

- **Why**
 - Mismatch between what is needed and what is provided
 - Poor communication leads to poor informed consent
 - Poor to no Advance Care Planning
 - Poor understanding and misperceptions regarding Palliative Care and Hospice Care

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Why?

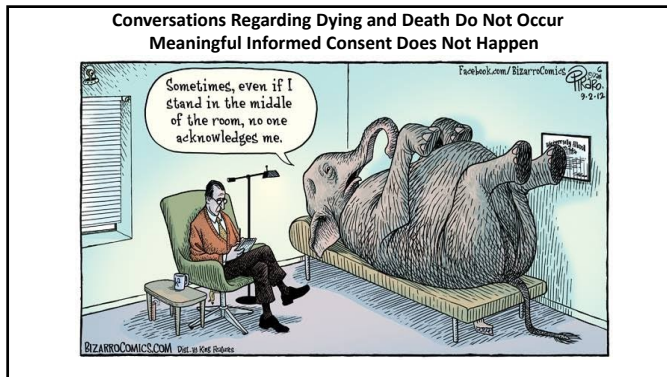
- Huge mismatch between what is needed by patients and families and what is provided by insurance and the state
 - Uninsured rates ~ 20%, higher in some populations
 - Affordable home health and caregiving not available
 - Long term care unaffordable for most
 - Our jails and prisons are our largest psychiatric facilities!
 - There are increasing rates of diseases of despair – mental health, addiction, and suicide
 - Little investment in behavioral health
- Regarding what actually has the greatest impact on our health and outcomes – the US health care system has missed the boat

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Why??

- **Lack of complex communication skills – not taught, never learned**
 - Poor communication between providers and the patient and their family
 - Especially true when the topic is dying and death
 - Far too often this leads to no true meaningful informed consent

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Why??

- **Poor to no advance care planning**
 - Medical power of attorney
 - Advance directive – living will
 - POLST – Physician Orders for Life-Sustaining Treatment
 - Prehospital medical directive (in Arizona – the ‘Orange Form’)
- Personal letter and video – use your phone ☺

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Why??

- **Poor understanding and misperceptions regarding Palliative Care and Hospice Care**
 - We need public **and provider** education regarding the role and benefits of Palliative Care and Hospice Care in the care of patients with advancing life-limiting illness
 - Patients and families should be encouraged to seek providers with expertise in end-of-life-care
 - Palliative Care
 - Patient Advocates Certified in EOLC, EOLC Doulas
 - Hospice Care

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“I am not afraid of dying, I just don’t want to be there when it happens.”

Woody Allen

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Dying in America Institute of Medicine - 2014

- *The overall quality of communication between clinicians and patients with advanced illness is poor, particularly with respect to discussing prognosis, dealing with emotional and spiritual concerns, and finding the right balance between hoping for the best and preparing for the worst. Ample evidence documents structural and financial disincentives for having these discussions. In the absence of adequate documented advance care planning, the default decision is to treat a disease or condition, no matter how hopeless or painful.*

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“The Tyranny of Survival”

- *In the endless efforts to defy death via more and more treatment, the opposite occurs. Relentless disease directed treatments lead to as much and often more pain and suffering than the disease itself, and commonly a shortened survival. Death is allowed an early victory.*
- *How do you define “Do No Harm” ???*

Allen Verhey 2011. The Christian Art of Dying; Walter Eerdmans Publishing

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We Must Acknowledge Our Shortcomings

- We must begin to focus on the morality and ethics of the care we provide for people while they die, especially our advocacy for endless, relentless disease directed therapies. We push treatment after treatment despite: the lack of home health and affordable caregiving, the paucity of meaningful mental and behavioral health; the impotence of the informed consent which is provided; the absence of advance care planning conversations and documentation, and our reluctance to refer patients to palliative care and hospice care. All of this is simply unacceptable and morally bankrupt.

Tom Fitch MD

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End-of-Life Care Options – It Starts With Communication

- ‘Healers’ should enable the **well being** of their patients – i.e. enable that which defines **who** they are as a person and **what** makes their life worth living
- *We should do that by tailoring the medical care of our patients in a manner consistent with **their** wishes, goals, and values*
- *As their illness progresses we should ask them such things as:*
 - *What do you value most in life*
 - *Knowing the likely course of your illness and your prognosis, what are your most important goals*
 - *How do you want to be cared for at a point where you can no longer pursue the things that give meaning to your life?*

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It Starts With Communication

- And ask:
 - *How do you want to be cared for if you reach a point where you are no longer you?*
- *Document in the medical record and ensure the patient completes advanced directives*
- Perhaps we best ‘do no harm’ by not subjecting our patients and their families to ‘The Tyranny of Survival’.
- Perhaps we also best ‘do no harm’ by not overriding our patients’ well-informed and ethically sensible belief of how **they** want to end **their lives** with dignity.

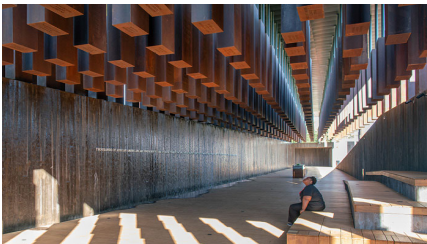
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End of Life Care Options

- Palliative care – expert supportive care *given in conjunction with disease directed therapies*
 - Expertise in symptom management, communication, informed consent, family support, social, emotional, & spiritual support, and advance care planning
- **Stopping ‘disease directed’ therapies**
- Hospice care
- Death more imminent, suffering intolerable
 - Withholding or withdrawing *advanced* supportive therapies and/or devices
 - Voluntarily stopping eating and drinking (VSED)
 - Palliative sedation
 - Medical Aid in Dying (MAID)

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Be Present



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Thank you!
Questions?

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