Getting Healthcare to Which You are Entitled and Not Unwanted Care-What You Should Know

Senior Law Day Collaborative

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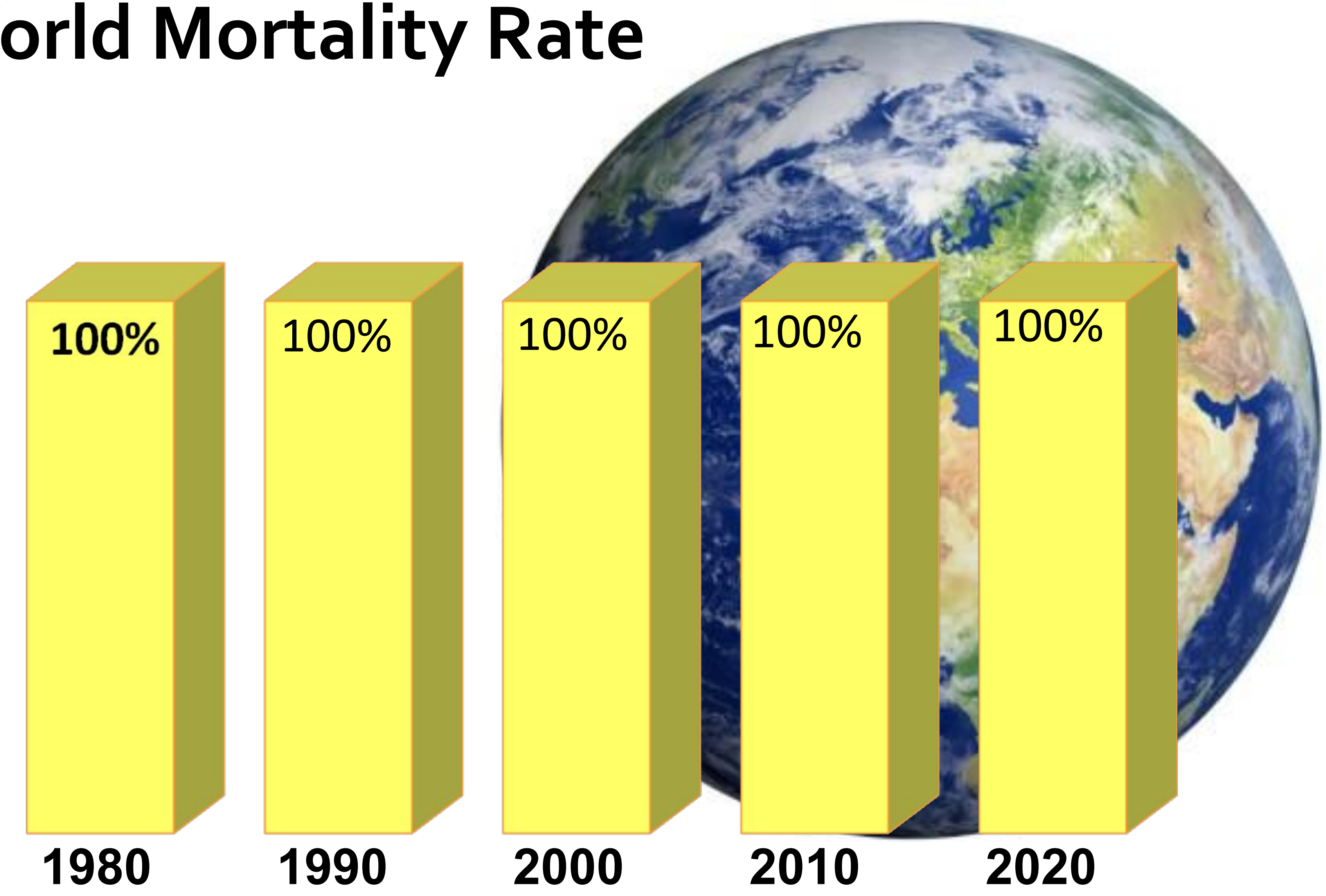
World Mortality Rate



Dying

“For all but our most recent history, dying was typically a brief process . . . . These days, swift catastrophic illness is the exception; for most people, death comes only after long medical struggle with an incurable condition . . .” Atul Gawande, NEW YORKER (Aug. 2, 2010)

https://www.youtube.com/watch?v=LcPqcrZPFBc

Dying

About 90% of Americans now die from chronic, progressive, incurable diseases. People live longer now but not necessarily better.

- Many chronically ill, seriously ill and terminally ill patients have, among other things:
  - Poorly controlled symptoms, particularly pain.
  - Psychiatric disorders and psychosocial and spiritual distress.
  - Concrete needs in the home.
  - Challenges in care coordination, communication, decision making, goal setting.

A Problem

- “The relief of suffering, it would appear, is considered one of the primary ends of medicine by patients and lay persons, but not by the medical profession.”
- Eric Cassell, MD, <u>N Engl J Med.</u> 1982 Mar 18;306(11):639-45.
- “The quote is still valid!” Eric Cassell, 9/27/12

Another Problem

- A 2021 study by Duke University found that the US ranked 43 of 81 countries on how well health centers “provide for the physical and mental well being of patients at the end of life”.

Journal of Pain and Symptom Management

https://www.jpsmjournal.com/issue/S0885-3924(22)X0003-1

Advance Care Planning

- It is never too early to do advance care planning to plan for your future health care based on your priorities and values.
- Leading cases all involve young women, (Cruzan, Quinlan, Schiavo). It really is never too early to plan.

Advance Care Planning

Questions to Consider:

- Do you want to have your health care wishes respected?
- Do you know that many people do not have them respected, particularly at the end of life, often because no one knows their wishes?
- Did you know that most people, usually near the end of life, lose the ability to make their own health care decisions?
- Did you know that by doing what we call advance care planning, that this can be a gift to you and your loved ones and that conflicts can be avoided, which otherwise frequently arise?

Advance Care Planning

- Most important is to consider what makes life meaningful and what does not, and making a statement about the balance between quality of life and quantity of life.
- The Conversation Project offers excellent guidance, www.theconversationproject.org
- Please visit it.

Advance Care Planning

- Conflicts can and do arise when there is **no** health care agent appointed pursuant to the completion of a health care proxy.

Advance Care Planning

Choosing a health care agent

- Choose a person who:
  1. You trust will be comfortable making decisions even if their own wishes are different;
  2. Understands your wishes;
  3. Will not be too emotionally involved to make important life and death decisions;

Advance Care Planning

4. Communicates and interacts well with people;
5. Will speak up on your behalf and be a strong advocate for your wishes with doctors and other health care providers;
6. Can manage potential conflict between family members.

Advance Care Planning

Avoid the Family Health Care Decisions Act. It is necessary for those who do not have a health care agent, or have not made their health care wishes known by other means so that a surrogate can make decisions. But,

1. It is very complicated;
2. Conflicts can easily arise;

Advance Care Planning

3. It is unlikely that the surrogate will know your wishes and, even if they do;
4. There are very difficult standards for making decisions to withhold or withdraw life sustaining treatment;
5. The person who is the surrogate may not be the best person to make decisions.

Questions About Diagnosis and Treatment

- It order to make sure that you have adequate information understand your situation, especially if you are diagnosed with a serious illness, and to make informed decisions about your treatment, consider asking the following questions (from Live with Care)
- Can you please explain my diagnosis?
- Is it acute and can I expect to be cured, or is it chronic?

Questions About Diagnosis and Treatment

- What symptoms may I experience from the illness, and when?
- How do you expect the illness to affect my day-to-day functioning and life?
- What are my treatment options?
- What can I expect from the different options, and what are the risks and benefits of each?

Questions About Diagnosis and Treatment

- What option would you choose for yourself if you were in my situation?
- How long will the treatment take? Can I stop if I feel better?
- What is my prognosis with or without the suggested treatment options?
- What activities should, if any should I avoid?
- If you determine that I am terminally ill, will you please tell me, as required by law?

Questions About Diagnosis and Treatment

- If possible bring someone (family member of friend) with you. Two sets of ears are better than one.
- Bring pen and paper and take notes
- If you do not understand something, ask that it be explained again.

Medical Orders for Life Sustaining Treatment (MOLST)

Medical Orders for Life Sustaining Treatment (MOLST) is a document created jointly between patient or health care agent or surrogate, if the patient does not have decision making capacity, and physician/nurse practitioner/physician assistant

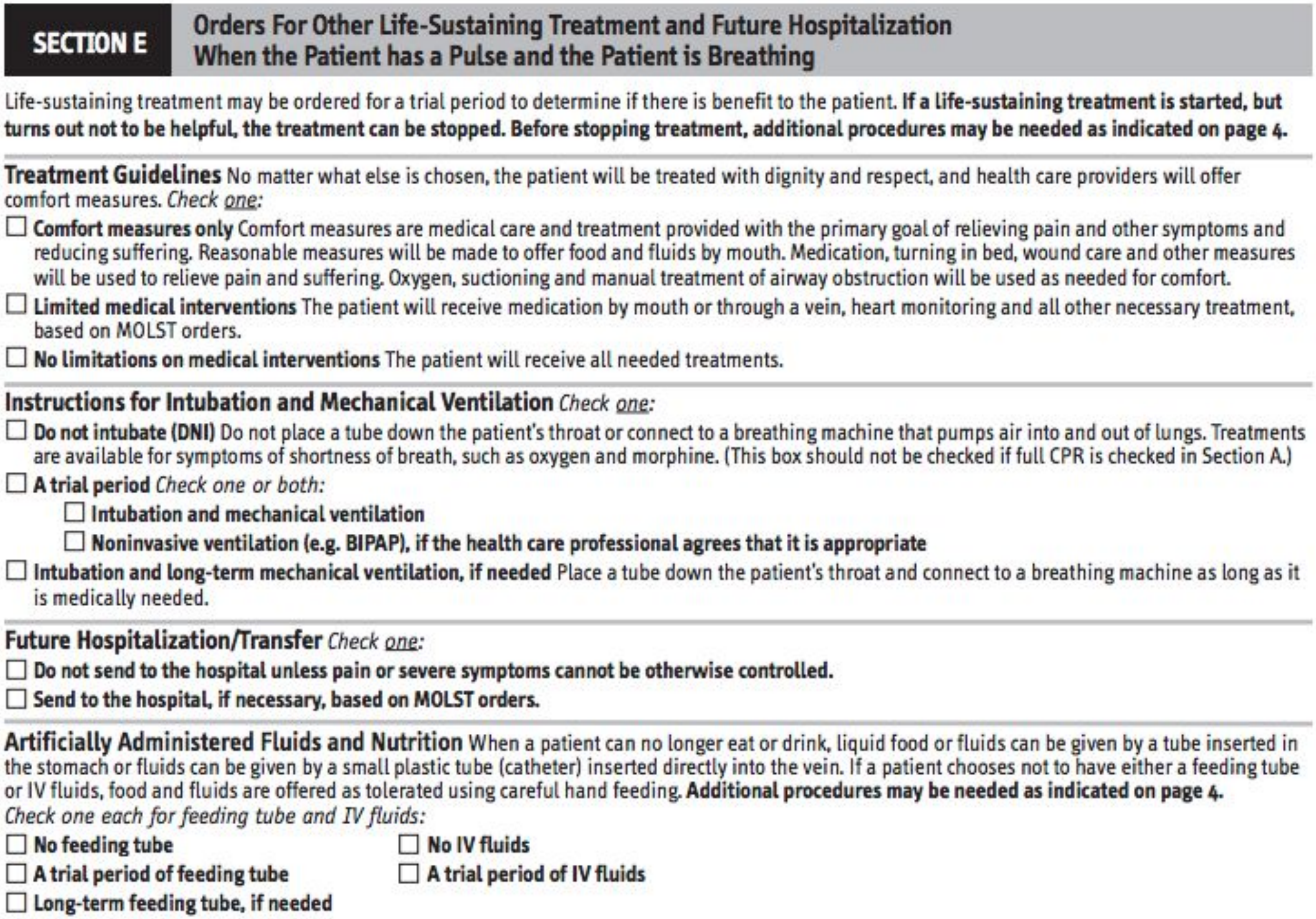
…The only authorized form in New York State for documenting both nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders, as well as other life sustaining treatment preferences.

MOLST

Who is this for? Patients who

- Reside in a long-term care facility or require long-term care services;
- Might die within the next year;
- Want to avoid or receive any or all life-sustaining treatment;

MOLST



SECTION E **Orders For Other Life-Sustaining Treatment and Future Hospitalization When the Patient has a Pulse and the Patient is Breathing**

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. **If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped. Before stopping treatment, additional procedures may be needed as indicated on page 4.**

Treatment Guidelines No matter what else is chosen, the patient will be treated with dignity and respect, and health care providers will offer comfort measures. *Check one:*

☐ **Comfort measures only** Comfort measures are medical care and treatment provided with the primary goal of relieving pain and other symptoms and reducing suffering. Reasonable measures will be made to offer food and fluids by mouth. Medication, turning in bed, wound care and other measures will be used to relieve pain and suffering. Oxygen, suctioning and manual treatment of airway obstruction will be used as needed for comfort.

☐ **Limited medical interventions** The patient will receive medication by mouth or through a vein, heart monitoring and all other necessary treatment, based on MOLST orders.

☐ **No limitations on medical interventions** The patient will receive all needed treatments.

Instructions for Intubation and Mechanical Ventilation *Check one:*

☐ **Do not intubate (DNI)** Do not place a tube down the patient's throat or connect to a breathing machine that pumps air into and out of lungs. Treatments are available for symptoms of shortness of breath, such as oxygen and morphine. (This box should not be checked if full CPR is checked in Section A.)

☐ **A trial period** *Check one or both:*
  ☐ **Intubation and mechanical ventilation**
  ☐ **Noninvasive ventilation (e.g. BIPAP), if the health care professional agrees that it is appropriate**

☐ **Intubation and long-term mechanical ventilation, if needed** Place a tube down the patient's throat and connect to a breathing machine as long as it is medically needed.

Future Hospitalization/Transfer *Check one:*

☐ **Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled.**

☐ **Send to the hospital, if necessary, based on MOLST orders.**

Artificially Administered Fluids and Nutrition When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have either a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. **Additional procedures may be needed as indicated on page 4.**

Check one each for feeding tube and IV fluids:

☐ **No feeding tube**
☐ **A trial period of feeding tube**
☐ **Long-term feeding tube, if needed**

☐ **No IV fluids**
☐ **A trial period of IV fluids**

MOLST

Benefits of MOLST:

- Required discussion with physician, nurse practitioner or physician assistant.
- Clearly stated preferences of patient or lawful person making decisions and agreed upon with physician, nurse practitioner or physician assistant.
- Signed medical order.
- More likely to be respected.

Palliative Care

- The Center to Advance Palliative Care definition of palliative care:

  “Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness – whatever the diagnosis.

Palliative Care

- The goal is to improve quality of life for both the patient and family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient’s other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.”

Palliative Care

- Palliative care is delivered throughout the course of an illness along with curative or life-prolonging care regardless of prognosis.
- Palliative care is provided by many different types of providers in various settings including: hospitals, nursing homes, home health agencies, and concludes with hospice care when life expectancy is limited.

Palliative Care

- Addresses:
  1. Physical symptoms, pain, nausea, breathlessness, fatigue, constipation, loss of appetite, etc.
  2. Anxiety and depression
  3. Psycho-social issues
  4. Spiritual issues
  5. Can also address legal and other difficult issues

Palliative Care Surveys

A 2018 survey in Journal of Palliative Medicine found that an estimated 71% of US adults had never heard of palliative care.

A Center to Advance Palliative Care 2011 Survey found:

-70% of public was “not at all knowledgeable” about palliative care;

-Once informed about palliative care 95% agreed it was important that patients with serious illness, as well a families, be educated about palliative care;

Palliative Care Surveys

-92% said they would be likely to consider palliative care for a loved one if they had a serious illness;

-92% said it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.

- "Physicians tend to either equate palliative care with "hospice" or "end of life" care and they are very resistant to believing otherwise."

Palliative Care

Barriers to the provision of palliative care include:

- Doctors and other healthcare professionals not knowing that palliative care is provided at the hospital.
- Doctors and other health care professionals not understanding what palliative care is and the difference between it and hospice.

Palliative Care

- Unwillingness of doctors and other health care professionals to refer appropriate patients either at all or in a timely fashion.
- Not enough palliative care professionals; there are only about 7,600 physicians who are board certified in palliative care nationwide.
- No palliative care service listed on many hospital websites.

Palliative Care

- CAPC provided physicians with the same definition of palliative care that they did to consumers. After reading the definition, more than six in ten physicians said they are more likely to consider referring patients with serious illness to palliative care.

Palliative Care

- **“Home-Based Palliative Care Can Improve Quality of Life”** Research has shown, says the article, that home-based palliative care enables patients to: decrease ER visits, inpatient days, needs for skilled nursing, and physician visits. And, the total cost of care for these patients is lower.
- Nevertheless, home-based palliative care is not yet available for most U.S. patients. Most palliative care is provided in hospitals. (*Next Avenue,* 5/9, https://www.nextavenue.org/how-home-based-palliative-care-can-improve-quality-of-life/)

Palliative Care Access Act

- In New York we have a law re the provision of palliative care Palliative Care Access Act (PCAA) effective in 2011;
  1. Public Health Law, Section 2997-d
  2. Applies to hospitals, nursing homes, home care agencies and enhanced and special needs assisted living residences.

Palliative Care Access Act

3. Applies to patients with advanced, life limiting conditions and illnesses who might benefit from palliative care.
4. Requires providers to establish policies and procedures to provide these patients:
    a. Services with access to information and counseling concerning palliative care and pain management appropriate to the patient, and
    b. Facilitate access to appropriate palliative care and pain management consultations an services
    c. Provide the information and counseling to those lawfully authorized to make decisions for patients who lack capacity to make medical decisions.

Palliative Care Information Act

- The Palliative Care Information Act, Public Health Law, Section 2997-c, (effective, 2011) requires that: If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner must offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient and information regarding other appropriate treatment options should the patient wish to initiate or continue treatment.

Palliative Care Information Act

Information and counseling offered shall include but not be limited to:

- The range of options appropriate to the patient;
- Prognosis;
- Risks and benefits of the various options;
- Patient’s legal rights to comprehensive pain and symptom management at the end of life;
- May be provided orally or in writing;
- If patient lacks capacity, information and counseling is to be provided to the health care agent or surrogate.

Unwanted Medical Care

- Far too much unwanted medical care is being provided to patients. The wishes of patients are too often ignored.
- This must change.

Unwanted Medical Care

According to a national survey (2014) conducted by Purple Strategies:

- About one in four Americans 50 and over say that they or a family member experienced excessive or unwanted medical treatment. That is about 25 million people. This is unacceptable.
- Nearly two thirds of those surveyed support withholding payments to health care providers who do not honor their end of life wishes.

Unwanted Medical Care

- Four out of 10 said they would "take legal action" (41%) or "not pay for the treatment" (40%) in response to unwanted medical treatment.
- Not surprisingly, 95% said it is important for healthcare providers to respect their end-of-life medical wishes.

Unwanted Medical Care

Dr. Gerald Greenberg, a retired periodontist, age 63, who had been diagnosed with Alzheimer’s 6 years before receiving unwanted medical treatment;

- Patient had completed a health care advance directive (AD) that provided “that he was to be given ‘comfort measures only, no intravenous fluids and no antibiotics,’ if his condition became incurable . . . .”

Unwanted Medical Care

- Patient was receiving care in a nursing home when he was found lying on the floor for over a day.
- He was transferred to a hospital, where his son provided a copy of the patient’s Living Will.
- He was tentatively diagnosed with “life-threatening sepsis.”

Unwanted Medical Care

- The family agreed that the patient’s AD should be honored because “he would never be able to regain any type of normal mental or physical function.”
- He was expected to survive for no more than four days without treatment.

Unwanted Medical Care

- A doctor ordered intravenous antibiotics to be given to the patient for three days, along with tests and other treatments.
- The family attempted to intervene, but the hospital prevented them from speaking to the prescribing doctor.
- The patient remained in the hospital for several weeks.

Unwanted Medical Care

- During that time he had "to endure the pain and discomfort of dying from a lack of hydration/nutrition. . . ."
- He was moved from the hospital to a hospice facility on Dec. 2, 2016, and died Dec. 5.
- "There are times when Gerry was crying. He was not a man who cried, but he was suffering," asserted his widow, Elaine Greenberg

Unwanted Medical Care

Unwanted Medical Care

- For more on this case see article,

Filing Suit for ‘Wrongful Life’ - The New York Times (nytimes.com)

Unwanted Medical Care

- "*The right to refuse life-sustaining treatment has been established for decades. But, as with many principles in bioethics, like the related doctrine of informed consent, there remains a wide chasm between legal and ethical principles, on the one hand, and the reality of clinical practice, on the other" Prof. Thaddeus Pope.*

Unwanted Medical Care

- Professor Pope has identified “Twelve Leading Causes of Unwanted Life-Sustaining Treatment”–

1. *Inadequate Advance Care Planning*
2. *Clinician Misinterpretation of, and*
3. *Confusion on, Advance Directives*
4. *Uncertain Validity of Advance Directive*
5. *Uncertain Applicability of Advance Directives*

Unwanted Medical Care

5. *Demanding or Conflicting Surrogates*
6. *Uncertain Status of the Surrogate Decision Maker*
7. *Uncertain Patient Decision-Making Capacity*
8. *Inadequate Informed Consent*
9. *Negligent Maintenance of Medical Records*
10. *Vitalistic Philosophy of Medicine*
11. *Conscience-Based Objections*
12. *Financial Incentives*

Hospice

- Hospice is a system of care for individuals who have a life-limiting illness that is no longer responsive to curative treatment and life expectancy is approximately 6 months or less.
- Hospice is covered by most commercial insurance and is fully covered under the Medicare Hospice Benefit.

Hospice

- Hospice care provides an interdisciplinary team of professionals and volunteers who are experts in end-of-life care, and focuses on symptom management needs and the quality of life of the patient.
- Hospice is not a specific place. Although hospice facilities or hospice homes may be in your community, hospice care is routinely provided at home, in nursing homes, and in hospitals.

Hospice

What specific services does hospice provide?

- Patient support and comfort including pain and other symptom control;
- Medical and social assessment;
- Nursing visits;
- Individual, family and group psycho-social and spiritual counseling;
- The provision of necessary equipment and supplies;

Hospice

- Support for caregivers;
- Physical, occupational, speech or other types of therapy which might include pet or music therapy as appropriate;
- Dietary and nutritional advice;
- Homemaking and home health aide assistance; and
- Grief and bereavement support up to a year (or longer) for family members following the death of the patient.

Hospice

- Hospice is not sufficiently utilized. Under 50% of patients nationwide and only 30% in NY are enrolled in hospice at the end of life.
- And there are late referrals even when patients die in hospice; the vast majority die within a month and one third within a week.

Hospice

Steps to increase hospice utilization:

- Provide detailed information about the benefits of hospice and how it is a system of care to ensure a better quality of life while the patient continues to live until he or she dies.
- Explain that hospice is as much about living as about dying and remind loved ones that the patient is living until the last breath is taken.

Hospice

- Explain that hospice does not mean giving up hope. The time when hospice care is appropriate is usually the time when hope turns from curative goals to goals of maintaining or having the best quality of life possible, time with family and loved ones, comfort care and finding dignity in each day.

Hospice

- Explain that hospices can be contacted by patients or loved ones for an assessment of eligibility.

  This is important, particularly when referrals are not made by physicians in situations where it seems the patient is or may be eligible.

Palliative Sedation

- Palliative sedation (PS), as defined in this statement, is the intentional lowering of awareness towards, and including, unconsciousness for patients with severe and refractory symptoms.
- AAHPM Statement 2014

Palliative Sedation

Basic criteria for choosing palliative sedation:

- Presence of a terminal illness with a refractory symptom(s)
- A do-not-resuscitate (DNR) order
- Exhaustion of all palliative treatments, including treatment for depression, anxiety, delirium, and familial discord
- Consideration of ethical and psychiatric consultations

Palliative Sedation

- Consideration of assessment for spiritual issues by a skilled clinician or clergy member
- Discussion regarding the continuance of nutritional support or intravenous or subcutaneous hydration in patients receiving such treatments
- Obtaining informed consent
- Consideration of a trial of respite sedation in selected cases

Stanford School of Medicine

Palliative Sedation

Position Statements Addressing PST

- American Academy of Hospice and Palliative Medicine
- Hospice/Palliative Nurses Association
- American Medical Association
- National Hospice and Palliative Care Organization

Voluntarily Stopping Eating and Drinking

- VSED is a decision made by a competent adult to stop further intake of food and fluids with the goal of hastening her/his death. It is an intentional and voluntary (non-coerced) choice to hasten death by a decisionally capable person who suffers intolerably from an incurable and progressive, or terminal illness.

Voluntarily Stopping Eating and Drinking

- VSED is distinguished from the usual diminished appetite often experienced by persons close to death in that it is a conscious decision to speed the dying process. It has been a traditional means of dying in the home for generations and is often thought of as a ‘natural’ way of dying.
- While it is rarely a suffering person’s ‘first choice’ to hasten death, it often is the only legal means available to patient-controlled dying.

Voluntarily Stopping Eating and Drinking

What is the definition of a successful VSED death?

- A successful VSED ‘outcome’ is understood as a peaceful death that occurs with a minimum of discomfort and occurs within a predictable period of days or weeks following the start of the fast.

Medical Aid in Dying

- Life is precious, but it ends eventually for all of us, including about 150,000 New Yorkers each year.
- No dying person should have to endure more suffering than he or she is willing to endure.
- Every dying person who is mentally competent should have the right to die, if possible, in a way that she or he decides and controls, consistent with his or her values and beliefs.

Medical Aid in Dying

- For those who are dying the issue is not whether they will die, but how they are going to die and who makes decisions at life’s end.
- Medical aid in dying should be an available option in addition to stopping or never starting treatment, VSED, and Palliative Sedation.
- It occurs when a terminally ill, mentally competent adult patient, who is likely to die within six months, takes prescribed medicines, which must be self-administered, to end suffering and achieve a peaceful death.

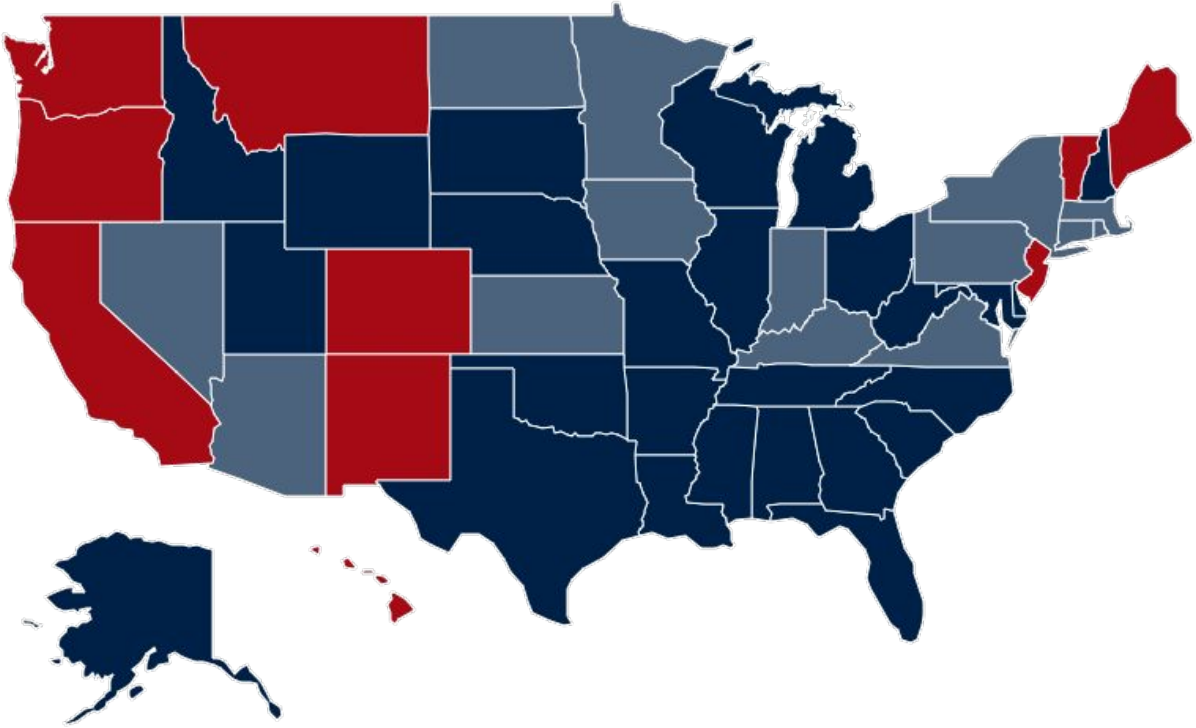
Medical Aid in Dying

- Medical aid in dying is not just a reasonable end-of-life option, but a better choice for some terminally ill patients than other ways in which death may be hastened.
- Most importantly it has been proven to be a safe, ethical medical practice which benefits patients and families and causes no harm.

Medical Aid in Dying

- Medical aid in dying occurs throughout the country, but in states other than those where it is now authorized, it is done underground, is unregulated and may not be legal.
- The practice should be legal, above ground and reasonably regulated. Physicians and family members should not be at risk of punishment.

Medical Aid in Dying (courtesy of Compassion & Choices



Medical Aid in Dying

Medical aid in dying is not assisted suicide

- Terminally ill patients who consume life ending medicines are not suicidal. Stark differences exist between suicides and medical aid in dying.
- People who die by suicides can continue to live, but choose not to; are done in isolation, often impulsively and violently; and they are tragic.

Medical Aid in Dying

- To the contrary, medical aid in dying is available only to terminally ill patients who will soon die; their disease is killing them; the process usually takes at least several weeks from the time the first request for medication is made; it occurs after consultation with two physicians and almost always with family support; and it is empowering.

Medical Aid in Dying

The term “assisted suicide” is rejected by the:

- American Public Health Association,
- American Academy of Hospice and Palliative Medicine,
- American Medical Women’s Association,
- American Psychological Association,
- American Academy of Family Physicians, among others, and
- state laws that permit medical aid in dying.

Medical Aid in Dying

- In 2017 the American Association of Suicidology issued this statement:

"*Suicide is not the same as physician aid in dying*".

https://www.thegooddeathsocietyblog.net/2018/05/06/statement-of-the-american-association-of-suicidology-suicide-is-not-the-same-as-physician-aid-in-dying/

Medical Aid in Dying

- The laws allowing medical aid in dying have worked as intended.
- None of the problems expected by opponents have emerged.
- And there is widespread support for medical aid in dying by the general pubic and physicians.
- The Medical Aid in Dying Act, A. 4321, S. 6471 should be enacted in NY.

Questions-Comments-Concerns?

Contact David Leven at:

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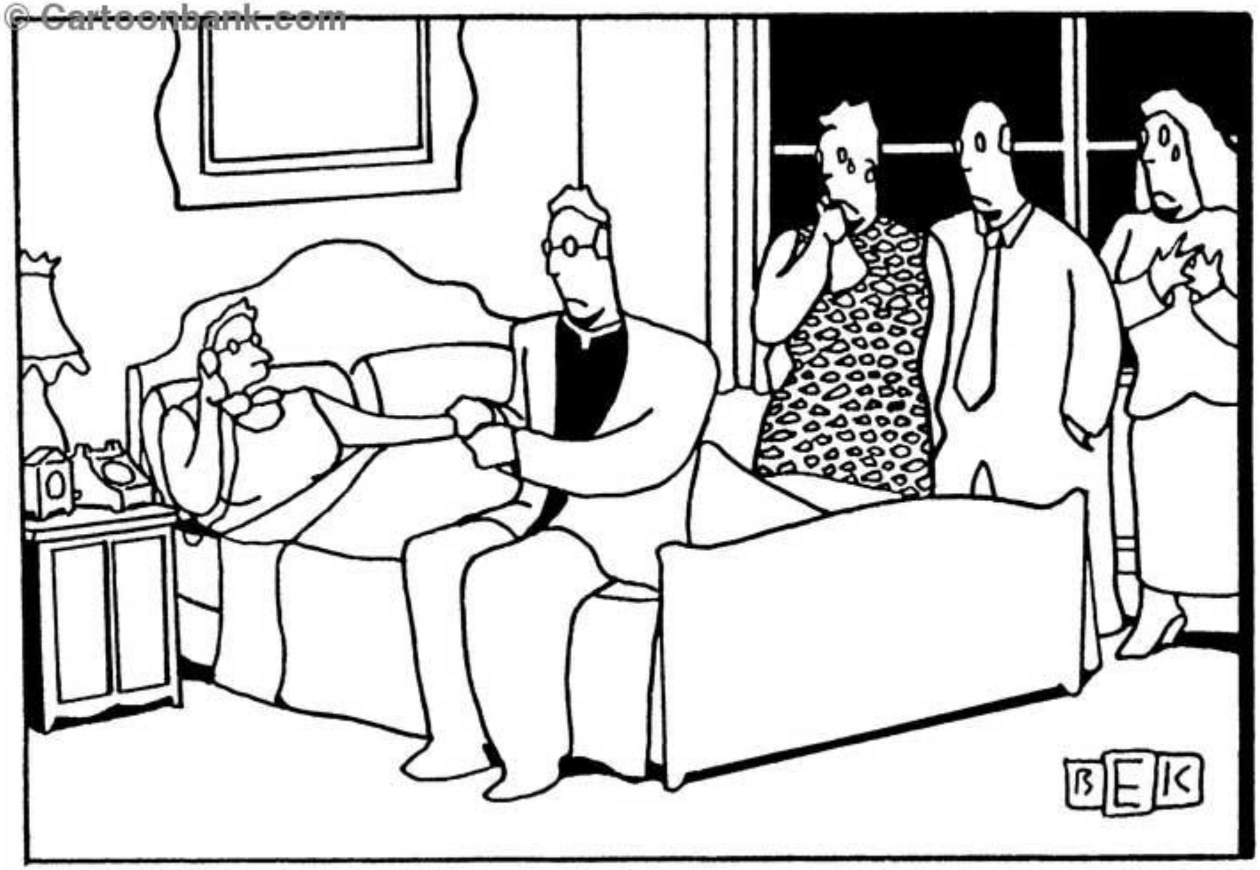
For clinical issues or to refer patients for counseling, contact Judith Schwarz RN, PhD judy@eolcny.org, 212 252 2015

End of Life Choices NEW YORK



"Look, I'm dying. Gotta go."