Written Disclosure/Accreditation and Objective Information

Name of Activity: Ellis Medicine – DOIM Medical Grand Rounds Webinar *"A Conversation About End of Life Options for New Yorkers"*

Funding Disclosure: There is NO unrestricted education grant support or commercial funding for this activity.

Date and Time: Friday, October 1, 2021 / 8:00-9:00AM

Location of Activity: Webinar

Objectives: After attending activity, participants should be able to:

- Describe the end of life options legally available to NYS residents currently available.
- Describe the ethical principles underlying medical aid in dying.
- Learn the key elements of the proposed law for Medical Aid in Dying.
- Emphasize the fact that those who object on religious or ethical grounds are under no compulsion to participate in the program whatsoever.
- Describe recommended ways to respond to patient requests for assisted death.

CME Accreditation Statement

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Ellis Medicine designates this live activity for a maximum of 1.0 *AMA PRA Category 1 Credit(s)™.* Physicians should claim only the credit commensurate with the extent of their participation in the activity.

AAFP Accreditation Statement:

Application for CME credit has been filed with the American Academy of Family Physicians. Determination of credit is pending.

American Board of Internal Medicine (ABIM) Maintenance of Certification (MOC) Accreditation Statement:

Successful completion of this CME activity, which includes participation in the evaluation component, enables the participant to earn up to 1 Medical Knowledge MOC points in the American Board of Internal Medicine's (ABIM) Maintenance of Certification(MOC) program. Participants will earn MOC points equivalent to the amount of CME credits claimed for this activity. It is the CME activity provider's responsibility to submit participant completion information to ACCME for the purpose of granting ABIM MOC credit.

Disclosure Statement

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Any discussion of investigational or unlabeled uses of a product will be identified.


Internal Medicine
Grand Rounds
Fall 2021

Information on CME

- www.elliscme.org
  - Recordings
  - Resources

Nothing to Declare as Conflict of Interest

From all Speakers and Planners of Presentation

George Giokas MD

- Palliative Care Partners & Inpatient Consultation Services, Ellis Medicine
  - Founder of Palliative Care at EM
- Boarded in Hospice & Palliative Medicine and Internal Medicine

David Pratt MD

- **Private Consultant in Preventive Health & Public Health**
- **Experience in both clinical practice and public health locally, nationally and Internationally.**
- **Dr. Pratt served with the US Public Health Service as an Epidemic Intelligence Officer at CDC.**
- **Boarded in Pulmonology and Preventive Medicine**

“A Conversation About End of Life Options for New Yorkers”

A Conversation About End of Life Options for New Yorkers

Ellis Medicine Grand Rounds

October 1, 2021

George J. Giokas, MD
David S. Pratt, MD, MPH

Learning Objectives

After attending activity, participants should be able to:

1. Describe the end of life options legally available to NYS Residents

2. Describe at least 2 ethical principles underlying medically assisted death

3. Describe recommended ways to respond to patient requests for assisted death

Dr Giokas is an employee of St Peter's Health Partners, a Catholic Healthcare Institution. His comments reflect his own professional opinion.

What Is Medical Aid in Dying?

A two-decade old, safe and trusted medical practice in which a terminally ill, mentally capable person over 18 with a prognosis of six months or less to live, has the option to request from their doctor a prescription for medication which he or she can choose to self-ingest to end unacceptable suffering and to die peacefully at a time and place of their choosing.

This medical practice is also known as death with dignity.

Memento Mori

Institute of Medicine Dying in America 2014 “To Do” list for Health Care System

1. Delivery of Person-Centered, Family-Oriented Care
2. Clinician–Patient Communication and Advance Care Planning
3. Professional Education and Development
4. Policies and Payment Systems
5. Public Education and Engagement

Improving Care for ALL patients 4 C's

CONVERSATIONS patient- family patient - doctor

COMPETENCIES conversations, prognosis, quality of life

(with the needed time and reimbursement)

COORDINATION multiple providers & interdisciplinary care

CARE-GIVER SUPPORT

Box 2. The Continuum of Physician Involvement at the Very End of Life[a]

Prescribing symptom-directed care, educating patients and families about what to expect, advance care planning, counseling about end-of-life goal attainment

Withdrawing or withholding life-extending technology

Prescribing sedation (potentially to unconsciousness) for intractable symptoms

Counseling regarding voluntarily stopping eating and drinking

Prescribing self-administered medication meant to hasten death

Administering medication to hasten death at patient's request

[a] In decreasing order of societal agreement.

Quill, Back & Block JAMA Jan 2016

Box 1. Exploring Inquiries About Physician-Assisted Death

Patient Concerns and Useful Clinician Questions

Patient is worried about future suffering: "I can see what's going to happen and I don't like it."

- What are you most worried about?
- Tell me more about exactly what frightens you.
- What kinds of deaths have you seen in your family?
- How are you hoping I can help you?

Patient feels quality of life is intolerable: "I've suffered enough."

- What makes your situation most intolerable right now?
- Tell me more about the worst part.
- How do you think your family feels or would feel about your wish?
- Exactly how are you hoping I can help you?

Quill, Back & Block JAMA Jan 2016

States Permitting MAiD

- Oregon
- Washington
- Montana
- California
- Colorado
- Hawaii
- New Mexico
- DC
- New Jersey
- Maine
- Vermont

I/5 Americans now covered

What Is Medical Aid in Dying?

A two-decade old, safe and trusted medical practice in which a terminally ill, mentally capable person over 18 with a prognosis of six months or less to live, has the option to request from their doctor a prescription for medication which he or she can choose to self-ingest to end unacceptable suffering and to die peacefully at a time and place of their choosing.

This medical practice is also known as death with dignity.

Currently, public health departments in seven authorized jurisdictions have issued reports regarding the utilization of medical aid-in-dying laws: Oregon, Washington, Vermont, California, Colorado, Hawai‘i and the District of Columbia. Based on that data, we know the following:

- Cumulatively, for the past 20 years, across all jurisdictions, only 3,521 people have taken a prescription to end their suffering.
- A third of people (34%) who go through the process and obtain the prescription never take it. However, they derive peace of mind from simply knowing they would have the option if their suffering became too great.
- Less than 1% of the people who die in each state will decide to use the law each year.
- The vast majority of terminally ill people who use medical aid in dying — more than 85% — received hospice services at the time of their deaths.
- There is nearly equal utilization of medical aid in dying among men and women.
- Terminal cancer accounts for the vast majority of qualifying diagnoses, with neurodegenerative diseases such as ALS or Huntington’s Disease following as the second leading diagnosis.
- Ninety percent of people who use medical aid in dying are able to die at home. According to various studies, most Americans would prefer to die at home.

A Case against Medical Aid in Dying

- What's in a name ?
- Balancing Autonomy
- Recognizing and respecting boundaries
- Concerns regarding the European experience
- Will this distract from our primary responsibilities

Physician-Assisted Suicide

ACP Position Paper 2017

AMA Code of Medical Ethics

Physician Assisted Dying

AAHPM 2016

Medical Aid in Dying

Respect for Patient Autonomy

Beneficence

Non-maleficence

Justice

Veracity

Fidelity - NonAbandonment

Integrity of the Medical Profession

Patient Autonomy

Independence and Control

> "represent lifelong values and characteristics, not transient illness based perspectives" Ganzini QUT Law Review 2016

Limits ... Nonbeneficial or futile therapies

Anticipation **of pain & future suffering, loss of control**

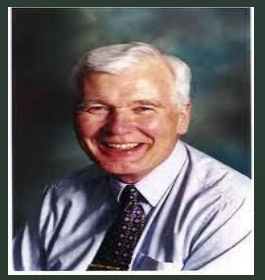
	Primary Intent	Primary Cause of Death
Palliative Sedation	Symptom Control	Illness Unintended medication effect
Voluntary Stopping Eating & Drinking	End Life	Dehydration
Physician Assisted Death	Relief of existential suffering and future state	Medication

Balancing
Having Compassion
&
Recognizing Boundaries

NonAbandonment /
Integrity of the Medical Profession

“I have met many patients over the years that I thought would be better off if they were to die soon. I have been tempted to end more than one suffering person’s life. That is precisely why our profession has developed formal standards of practice and statements of ethical practice— to remind us that such acts are wrong.”

Dr. Robert Twycross,
Professor of palliative medicine at Oxford University
As quoted Ira Byock Best Possible Care 2014



"Certainly, suffering at the end of life is sometimes unavoidable and unbearable, and helping people end their misery may be necessary. Given the opportunity, I would support laws to provide these kinds of [physician-assisted suicide] prescriptions to people. They are reassured just to know they have this control if they need it.

Dr. Atul Gwande Being Mortal 2014

“All the same, I fear what happens when we expand the terrain of medical practice to include actively assisting people with speeding their death.
I am less worried about abuse of these powers than I am about the dependence on them.”

Atul Gwande Being Mortal 2014

Death on demand? An analysis of physician-administered euthanasia in The Netherlands

Robert Preston*

Director of Living and Dying Well, UK

British Medical Bulletin, 2018, **125**:145–155
doi: 10.1093/bmb/ldy003
Advance Access Publication Date: 12 February 2018

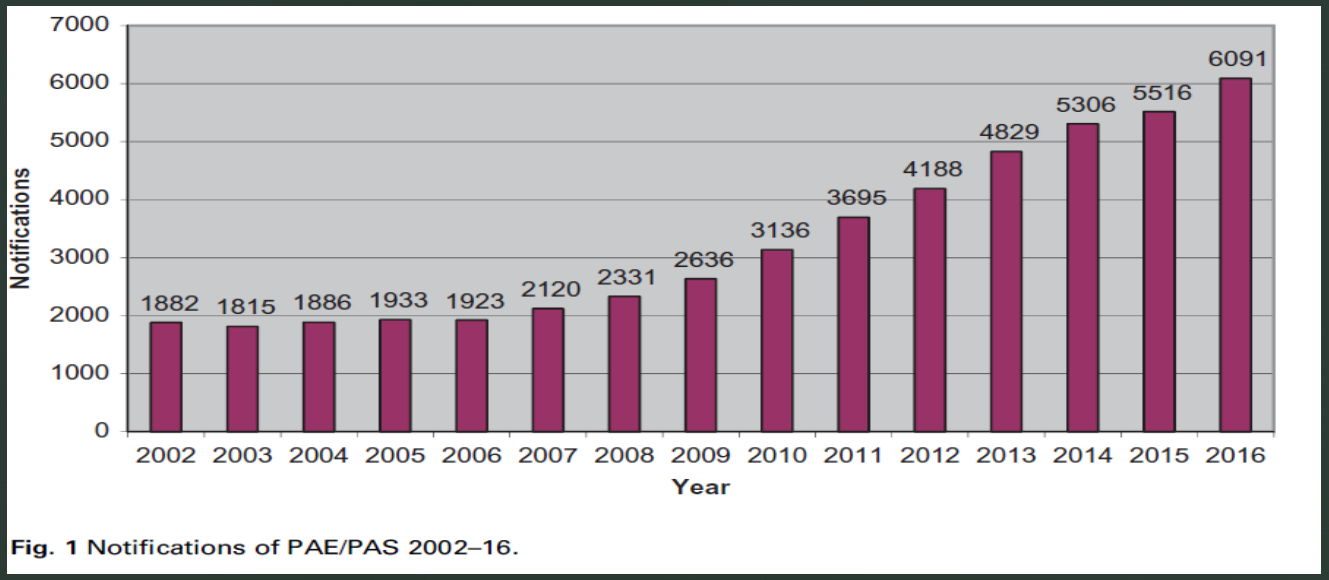


Fig. 1 Notifications of PAE/PAS 2002–16.

Table 2 Incidence of PAS/PAE in The Netherlands in 2010 and 2015 as recorded by RTEs and Statistics Netherlands

	PAE		PAS		PAS + PAE		Total	
	RTEs	Stats NL	RTEs	Stats NL	RTEs	Stats NL	RTEs	Stats NL
2010	2910	3859	182	192	44	N/A	3136	4051
2015	5277	6672	208	150	31	N/A	5516	6822

“**These increases are not easily explained**. Has the willingness to report increased among physicians? Are physicians more inclined to grant patients’ requests for euthanasia? Are patients more resolute when discussing their wish for euthanasia with their physician? Is the …fact that people in the Netherlands are living longer a possible explanation for the rise in the number of notifications? Or is it also related to the demographic composition of the Dutch population?”

R Preston, British Medical Bulletin 2018

JAMA Internal Medicine | Original Investigation | HEALTH CARE POLICY AND LAW

Euthanasia and Physician-Assisted Suicide in Patients With Multiple Geriatric Syndromes

Vera van den Berg, MA; Ghislaine van Thiel, PhD; Margot Zomers, MSc; Iris Hartog, MA; Carlo Leget, PhD; Alfred Sachs, MD, PhD; Cuno Uiterwaal, MD, PhD; Els van Wijngaarden, PhD

- Most cases in the Netherlands involve cancer patients
- an increase in EAS performed in patients with dementia, psychiatric disorders, or multiple geriatric syndromes(MGS).
- geriatric syndrome sight impairment, hearing impairment, osteoporosis, osteoarthritis, balance problems, or cognitive deterioration
- Dutch guidance for physicians states that these geriatric syndromes … “cause unbearable suffering without the prospect of improvement in conjunction with the patient’s medical history, life history, personality, values and stamina”

van den Berg, et al JAMA IntMed Dec 2020

“In summary, in most cases, experiences in the social and existential dimensions are intertwined with the medical dimension of suffering.

The variety of relevant elements in these complex cases raises the question of what the role of these different elements should be in the assessment of requests for EAS and which expertise is needed for optimal care for these older persons.”

van den Berg, et al JAMA IntMed Dec 2020

HEALTH CARE POLICY AND LAW

The Treatment of Patients With Unbearable Suffering—The Slippery Slope Is Real

Diane E. Meier, MD

- Countries where PAD has been legal for considerably longer than the US have revised their original laws to remove prognostic requirements, eliminate psychiatric exclusions, broadly define unbearable suffering and reduce reporting requirements.
- Only 75% of EAS cases are reported to regional committees as required by law, and nonreporting is rarely punished

JAMA Internal Medicine Published online December 7, 2020

“Regulations on PAD assume that
practitioners have both the training and the time to carefully explore the meaning of the request with patients and families,
to understand the sources of the despair,
to offer and try alternative approaches to reduce suffering,
to be present during that suffering,
and to provide encouragement and validation
to the patient regarding the value and meaning of their continued life.

Most do not”

Diane Meier MD, The Treatment of Patients With Unbearable Suffering—The Slippery Slope Is Real. JAMA Internal Medicine December 2020

Conversation Stopper:
What's Preventing Physicians from Talking With Their Patients About End-of-Life and Advance Care Planning

Telephone survey (Feb- March 2016) of primary care physicians and specialists who regularly see patients 65 and older

736 total physicians 202 California physicians

470 primary care providers/internists

266 specialists – oncologists, pulmonologists, cardiologists

What gets in the way of end of life and advance care planning?

(frequently and sometimes)

66% Don’t have the time

65% Disagreement between patient & family

60% Not sure the time is right

50% Might be an uncomfortable conversation

48% Don’t want patient to feel I’m giving up

46% Don’t want patient to lose hope

How should we think about the balance of benefits and burdens of easier access to PAD in the current context of the increasing numbers of older persons, increasing income inequality and poverty, resource stresses on families and health systems, and the already well documented inadequacy of government-funded health care in ensuring high-quality medical care for older persons in our society?

Will legal access to PAD serve as a quick, easy, and inexpensive means of handling the needs of an increasing aging population here and around the globe?

The Treatment of Patients With Unbearable Suffering—The Slippery Slope Is Real. JAMA Internal Medicine December 2020

“There is a generation coming up, the post-war generation, which is now coming to the life stage in which they will die, and this generation has a far more clear and expressed opinion about how to shape their own life end. I expect far more growth in the years to come. “

Steven Pleiter, Director, Levensiende (End of Life Clinic)

“I know lots of people who now say that there is only one way they want to die and that’s through injection. It’s getting too normal.”

Professor Theo Boer Netherlands Regional Review Committee

R Preston, British Medical Bulletin 2018

“But we damage entire societies if we let providing this capability divert us from improving the lives of the ill. Assisted living is far harder than assisted death, but its possibilities are far greater, as well."

Atul Gwande Being Mortal 2014

Reverence for life does not include hastening death, nor does it include forcing people to suffer as they die. As a clinician, it does require me to show up -- with all the resources and skills my training and experience provide -- and to lean forward, listening to the persons before me and learning how I can best be of service.

Dr. Ira Byock

Proponent Agenda

1. What is Medical Aid in Dying?
2. Why I support MAID
3. Ethical underpinnings
4. Safeguards
5. Barriers to introduction

Why I support Medical Aid in Dying

- All medicine has limitations
- It honors autonomy, shared decisions and beneficence
- Ethicists support the practice (Arthur Caplan et al.)
- Enabling suffering may be harm by omission
- MAiD is the moral equivalent of VSED or palliative sedation
- Safeguards have proven ample for 20 years
- Religious intrusion in medical practice limits autonomy
- New Yorkers support it

Patient Autonomy

Patient autonomy: The right of patients to make decisions about their medical care without their health care provider trying to influence the decision.

Beneficence

Is action that produces benefit, does good, offers the kindest thing, and always acts in the patient's best interest. All actions should benefit the patient. Beneficence requires honesty and limiting useless treatments or interventions

Shared Medical Decision Making

Shared decision making is a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences.

Safeguards

- Terminal illness confirmed by two doctors
- Two witnesses to the written request from the patient herself
- Penalties for fraud and coercion
- Referral to mental health professional if doctors believes the patient lacks ability to make their own decisions
- The person must be counseled on all feasible treatment options (pain management, hospice, palliative care)

Safeguards

- Neither age nor disability by themselves qualify
- Any unused medication must be disposed of according to health department guidelines
- The cause of death is listed as the underlying illness or disease
- **Immunity** from civil & criminal penalties, and professional malpractice
- Anyone who alters, destroys, conceals, or forges a person's request commits a felony
- Insurance companies cannot deny payment on an annuity or life insurance policy
- **No physician required to participate**

Barriers to Medical Aid in Dying

The battle paradigm – our role is to fight

The rejection of death's place in life

The assumption that in dying there is no more work to be done

Difficulty facing our own mortality

A close bond with patients distorts prognostication

A Sad Love Story

Testimony of Scott Barraco regarding Kathy Quinn

https://www.youtube.com/watch?v=0Pufm5EphmU&t=11385s

Kathy Quinn's Blog:
http://owmytongue.blogspot.com/2014/06/dying-with-dignity.html

Conclusion:

MAiD is an ethical, humane, compassionate medical practice. A tiny minority of dying patients need this care. Those with religious or ethical objections need not participate. Don't confuse the US with the Netherlands or Switzerland.. their care of the dying is culturally and legislatively different*.

* Reference: The Inevitable: *Dispatches on the Right to Die*, Katie Engelhart St Martin's Press 2021

Let’s All Remember….

But at my back I always hear

Time’s wingèd chariot hurrying near;

And yonder all before us lie

Deserts of vast eternity.

Andrew Marvell