

Equitable Access to Palliative and End-of-Life Care in New York and New Medical Aid in Dying Law

Public Health Law Article 28-F Medical Aid in Dying
Sections 2899-d to 2899-s
[Effective August 5, 2026]

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Good morning!

***I am a health and public health law attorney,
an aging and health researcher, and a resident of
Westchester County for many years.***

***My research focuses on experience of suffering
among older adults.***

***I welcome the opportunity to speak with you today as
we grow old together here in Westchester County!!***

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Agenda:

Making Sense of Medical Aid in Dying Law in New York

- Introduction to topic (10 mins):
 - Pain and suffering in serious/terminal illness
 - Person-Centered Care
 - Rights to Health/Health Care
 - Palliative & End-of-Life Care Continuum
- Background on NYSBA MAID Task Force Report (10 mins)
- Key Provisions of New York MAID Law (20 mins.)
- Implementation Challenges (10 mins.)
- Q&A/Discussion (10 mins)

Our primary focus today is the problem of pain and suffering in serious illness.

Pain and suffering are multi-dimensional and go beyond experience at the physical level.

Spiritual and social suffering often accompany physical pain and suffering.

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Ethical Frame: *Person-Centered Care and Understanding Goals of Care*

- The *human person* is the center of all health and mental health care, palliative care, and social services, *even when the person with serious illness may no longer have capacity.*
- Personhood is inalienable and ground of human rights and care, as embedded in our laws and regulations on person-centered care (e.g., as mandated under regulations applicable to nursing homes (42 CFR 483.21).
- Starting point: *Goals of Care*

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Our Human Rights to Health & Palliative Care and Pain Management

- United Nations Committee on Economic, Social & Cultural Rights Comment 14: *Normative content of Right to Health as highest attainable standard of health, including rights to palliative care and pain management* (Gostin, 2014)
- Work being done to advocate for *Convention on Rights of Older Persons* (INPEA)

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My Approach to Implementation:

”Leading with palliative care”

- The New York MAID statute is framed in the end-of-life continuum of care, including palliative care and hospice.
- Patients must be informed of their rights to palliative care and hospice (type of palliative care). § PHL 2899-f(1)(f)

Transformations in Our Environment

Healthcare Environment Transformations:

- Private Equity Presence
- Palliative Care Financing/
Funding Challenges
- Intersectionality of age, disability, race, health and mental health; patterns of *ageism, ableism, stigma, and racism; and elder abuse.*

+ What Is Palliative Care?

See New York State
Department of Health:
https://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/practitioners/questions_and_answers.htm#q_1

Palliative care, as defined under NY Public Health Law, is "health care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice care.."

... Many people assume that palliative care and chronic disease management or disease-modifying therapies are mutually exclusive, but they are not. Palliative care may be provided concurrently with life-prolonging care or as the main focus of care.¹

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History of Rights to Palliative Care in New York: Palliative and End-of-Life Care Continuum

Palliative Care Information Act (2010):
PHL §2997c: *Requires the "attending health care practitioner" to offer to provide patients with a terminal illness with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including:*

- *Prognosis;*
- *Range of options appropriate to the patient;*
- *Risks and benefits of various options;*
- *Patient's "legal rights to comprehensive pain and symptom management at the end of life."*
- *The information and counseling may be provided orally or in writing.*

History of Palliative Care in New York: Palliative and End-of-Life Care Continuum

Palliative Care Access Act (2011): PHL §2997d

- Requires that ***hospitals, nursing homes, home care agencies, special needs assisted living residences, and enhanced assisted living residences***, provide access to information and counseling regarding options for palliative care appropriate to patients with advanced life limiting conditions and illnesses.
- These providers and residences must also facilitate ***access to*** appropriate palliative care consultation and services, including associated pain management consultation and services, consistent with the patient needs and preferences.

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History of Palliative Care in New York Cont'd: Palliative and End-of-Life Care Continuum

- **Types of Palliative Care**
- ***Specialist Level Care:*** Palliative care physician or nurse practitioner in hospital settings
- ***Primary/Ambulatory Care*** (e.g. Westmed, White Plains, NY): Non-specialist palliative care integrated into non-hospital/non-institutional care settings such as physician offices or clinics.
- ***Generalist Level Palliative Care:*** All clinicians have some level of training in non-specialist palliative care/pain management.
- ***“Palliative Environments:”*** Pushing out boundaries of palliative care to relieve pain and suffering across domains of care, and in settings and communities as applicable.
- (Morrissey et al., 2015)



Palliative Care: Public Health Priority and “*Secret Sauce*” during COVID

- Social determinants of health, including considerations of equity, diversity, and culture
- Racial/ethnic/educational inequities in access to palliative care across Black & Brown communities (Bullock et al., 2023)
- Income, housing, food insecurity
- Structural/systems barriers including ownership types



Research Data: Inequities and Disparities

- Educational and racial and ethnic disparities:
 - Over 23 years, 95.6% of MAID deaths were Non-Hispanic White and 4.4% were Non-white
 - Profile of MAID users: Older, white, educated and diagnosed with cancer

Kozlov et al.(2022)

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NYSBA MAID Task Force Appointment

- President Richard Lewis appointed MAID Task Force: June 2023.
- Dr. Mary Beth Morrissey, Task Force Chair
- Members brought deep knowledge and expertise in diverse areas of the law, and hailed from hospital systems, private practice, the academy, upstate and downstate, bioethics, and other milieux.

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Task Force Charge

Examine: *legal, ethical, health and public health, and broader policy considerations concerning medical aid in dying, including legislative proposals in New York...risks and benefits; financing; potential inequities and disparities; and the impacts upon families and caregivers; providers and residential and correctional care facilities; professional and informal workforces; and structural vulnerability and social determinants of health across diverse communities.*

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Task Force Process: June 2023 – January 2024

- The Task Force conducted a ***balanced and thorough evidence-based process of inquiry*** over many months in its examination of and deliberations on the pending MAID bill.
- Meetings were held with NYS Legislators/Bill Sponsors; palliative, hospice, and end-of-life care leaders, physicians, and advocates; and professionals in related fields such as social work, ethics, and bioethics.
- An Open Forum was held November 17, 2023.



MAID Bill Sponsors

A995A/S2445A

Assemblymember Amy Paulin and Senator Brad Hoylman-Sigal, Bill Sponsors, appeared before Task Force



Key Statutory Provisions

The MAID statute allows an **adult patient** who is a NYS resident and 18 or older under care of physician with:

- a *“medically confirmed terminal illness or condition”*; AND
- *“decision-making capacity”*;
- to make *an oral request (audio or video recorded)*; AND
- *a signed and witnessed written request; based on an informed decision;*
- *to request(s) voluntarily and without coercion* to receive from their physician a prescription for medication that they would *self-administer by ingestion* and take at a time of their own choosing to bring about their own death.

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Key Provisions and Safeguards in MAID Bill

- i) a qualified individual must have a medically confirmed terminal illness or condition that is incurable and irreversible and will likely cause death within 6 months; and who has decision-making capacity;
- ii) individuals are not eligible for medical aid in dying *solely* because of age or disability;
- iii) **Attending Physician** (2899-f), and **Consulting Physician** (2899-h) must examine patient and medical records and confirm that the person has a terminal illness or condition with a prognosis of 6 months or less to live; is making an informed decision, has decision making capacity; ***and is acting voluntarily and not being coerced;***
- iv) ***Attending physician required to offer patient opportunity to rescind request.***

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Key Provisions and Safeguards in MAID Bill

iv) there is a mandatory mental health evaluation, 2899-i (*Hochul amendment*); mental health professional (2899-d(11)) is defined as:

- individual licensed to practice medicine in NYS who is diplomate of American board of psychiatry & neurology or eligible to be certified by that board,
- or by American osteopathic board of neurology & psychiatry or eligible for;
- or licensed to practice psychology under Title Eight of Education Law;

v) Prescription cannot be filled until 5 days after written, unless attending physician medically confirms that patient may die before waiting period expires;

vi) the attending physician must inform the requesting patient about all of their end-of-life care options, including palliative care and hospice, 2899-f(f)

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Last Set of Changes to MAID Bill before Hochul Amendments

Changes included:

- Making even more explicit a prohibition that *a health insurance company cannot deny coverage* for care because a person requests, or fails to request the procedure
- Expanding the list of people who cannot serve as a witness to a dying patient who requests the procedure to include the patient's domestic partner, health care proxy, or anyone who has power of attorney for the patient.
- Extending immunity from adverse action to those who refuse to participate in the procedure by adding a new section explicitly providing immunity from "employment, credentialing, or contractual liability or penalty for any reasonable good-faith action or refusing to act under" the law.



Key Provisions & Safeguards

- *There is no surrogate decision making under the statute and no planning in advance via advance directive.*

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Safe Disposal of Unused Medications

"§ 2899-o. Safe disposal of unused medications. A person who has custody or control of any unused medication prescribed under this article after the death of the qualified individual shall personally deliver the unused medication for disposal to the nearest qualified facility that properly disposes of controlled substances or shall dispose of it by lawful means in accordance with regulations made by the commissioner, regulations made by or guidelines of the commissioner of education, or guidelines of a federal drug enforcement administration approved take-back program. **The commissioner may make regulations as may be appropriate for the safe disposal of unused medications prescribed, dispensed or ordered under this article** as provided in this section."

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**Private Health Care
Facility Opt Out
-Policy and prior
notification to
patient
-If MAID request,
prompt transfer
-Sanctions if
violations**

2. (a) A private health care facility may prohibit the prescribing, dispensing, ordering or self-administering of medication ...while the patient is being treated in or while the patient is residing in the health care facility if:

- (i) ...contrary to a formally adopted policy of the facility that is expressly based on sincerely held religious beliefs or moral convictions central to the facility's operating principles; and
- ii) the facility has informed the patient of such policy prior to admission or as soon as reasonably possible.

(b) Where a facility has adopted a prohibition under this subdivision, if a patient who wishes to use medication under this article requests, the patient shall be transferred promptly to another health care facility that is reasonably accessible under the circumstances and willing to permit the prescribing, dispensing, ordering and self-administering of medication ...

3. ...any health care provider or employee or independent contractor of the facility who violates the prohibition may be subject to sanctions otherwise available to the facility, provided the facility has previously notified the health care provider, employee or independent contractor of the prohibition in writing.

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Opting Out

❖ ***No physician, health provider or pharmacist is required to participate in medical aid in dying***

❖ Those who do and comply with all aspects of the law receive civil and criminal immunity.

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Role of Ethics Committees

Adapting ethics committee knowledge and applicable guidance for purposes of MAID education/training:

- “Discuss the role and responsibility of the ethics review committee in addressing conflict and assisting in resolving conflict;
- Formulate consensus about adoption of best practices to assure ethically competent functioning of the ethics review committee, and consultation and communication with family members and health care professionals.”

Morrissey, M.B. (2011). **Educating ethics review committees in a more humanistic approach to relational decision making.** *NYSBA Health Law Journal, Special Edition: Implementing the Family Health Care Decisions Act, 16(1)*, pp. 65-70.

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Next Steps

- Providers drafting policies
- Regulatory Process: Regulations have not yet been issued but will be critically important
- Training the workforce across professions, providers, and systems
- Providing education to communities
- Understanding experience and concerns of older adults

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Role of Collaborative for Palliative Care, and IAPCPH Cert. Program in Workforce Development

Developing workforce education and training across professions:

- Medicine and Palliative Medicine, Nursing, Social Work, Psychology, Chaplaincy, Therapists, Aides and Non-professional staff, Administrators
- Generalist level and specialist level
- Ethics Committee Members
- Family Members

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Questions

Let's reflect on how this new law may impact you or your family members and discuss questions you may have.



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- Rogers, C.R. (1995). *On becoming a person*.

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Thank you for your attention!

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