

Testimony in support of the **Medical Aid in Dying Act**

New York State Assembly Health Committee Hearings

April 23, 2018 in Albany May 3, 2018 in NYC



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FORMER ASSEMBLY MEMBER

Janet Duprey





BIOETHICIST

Art Caplan, Ph.D.

Professor of Bioethics at NYU's Langone Medical Center; Founding Director of NYULMC's Division of Medical Ethics

New York City

"When the state of Oregon began debating the legalization of their Death with Dignity Act in the late 1990s, I was often asked my opinion on the wisdom of enacting such legislation. I said I opposed the proposed legislation ... Since that time ... I have closely followed the empirical evidence gathered in Oregon and later in the state of Washington ... I found no cause for my concerns — none."

Video testimony

Full written testimony



BIOETHICIST

David Hoffman Health Care Attorney and Clinical Ethicist

New York City

"It is important to recognize ... that in advancing legislation which provides patients with the opportunity to end their pain and suffering at the end of life — through the use of safe and reliable medical means — we provide the greatest possible assurance of achieving the patient's goals while producing no additional discomfort."

Video testimony Full written testimony



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CLERGY

Rev. Dr. Richard Gilbert Retired Unitarian Universalist Minister

Rochester

"[Medical aid in dying] is the last right of a human being ... the greatest reverence for life is to end human suffering."

Video testimony

Full written testimony

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COMPASSION & CHOICES

Corinne Carey NY Campaign Director

Troy

"I've traveled the state extensively: from Buffalo to Brooklyn, from Long Island to the North Country, and I've sat with hundreds of family members and people living with terminal illness. These New Yorkers cannot wait. The time is now. I urge this committee to take up and pass the Medical Aid in Dying Act[.]"

<u>Video testimony</u>

Full written testimony





DISABILITY RIGHTS ADVOCATE

Gene Hughes Supporter who lives with a disability

Utica

"This is not a disability issue! A disability or chronic condition alone is clearly not a terminal illness, and therefore does not qualify under this legislation ... my life would be empowered by medical aid in dying. It would give me the autonomy I've worked so hard to maintain since my very first day in a wheelchair."



DISABILITY RIGHTS ADVOCATE

Christopher Riddle

Associate Professor and Chair of Philosophy at Utica College; Director of the Applied Ethics Institute

Utica

"If we want to promote dignity and respect for the disabled, I suggest it is of utmost importance that we do not allow opposition to assisted dying to deny basic autonomy rights at the end of life."

Video testimony

Full written testimony



Video testimony

Full written testimony

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Scott Barraco

Supporter whose girlfriend suffered horribly without options at the end of her life

Rochester

"People not only suffer terrible deaths against their wishes, they suffer the anticipation of it. Cathy was robbed of her ability to plan and make decisions about her death in the same way she did for her life."

Video testimony

Full written testimony



FAMILY EXPERIENCE

Amanda Cavanaugh Compassion & Choices NY Campaign Organizer

Watervliet

"In the midst of coming to terms with Chrissy's mortality ... we discussed moving to Vermont to utilize their Patient Choice and Control at the End of Life Law. But Chrissy didn't want to leave her family, her friends, and the life that we had spent creating together. New York provided so many great memories and opportunities for our lives, but this state failed us, New York failed Chrissy, at the end of her life."

<u>Video testimony</u>

Full written testimony



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Stacey Gibson

Supporter whose husband chose to voluntarily stop eating and drinking to hasten his dying

Garrison

"[Sid] wanted the option of aid in dying so that he could die in peace surrounded by his loved ones. Isn't that the good death we all want? He wanted to live but his body was dying and making him suffer."

FAMILY EXPERIENCE

Laurene Gilbert

Supporter whose husband was driven to extreme measures because he didn't have access to medical aid in dying

Ithaca

"... Steve's attempt failed and he was in a coma for six days before he passed. I honored his request to not save him, but this is not the way he wanted to die. I believe with all my heart that no one should have to go through what he went through."

<u>Video testimony</u>

Full written testimony



Video testimony

Full written testimony

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Janet Green Supporter whose husband asked for help to die

Poughkeepsie

"Hospice came to our home to provide support for me and pain medication for Harry. It was not enough. His pain often broke through and became unbearable ... Harry asked me to shoot him. Those who are terminally ill should have legal options to help them end their lives without prolonged suffering."



Full written testimony



FAMILY EXPERIENCE

Laura Kelly Supporter whose father asked for help to die

Mount Kisco

"Adults with end-stage terminal illnesses, like my independent and funny father, deserve to make their own decision from an array of legal and compassionate choices about how they leave this world ... If I have the misfortune to contract a terminal illness, I fervently hope that I don't have to move away from the enlightened state of New York when I'm deathly ill in order have the peaceful end I desire."

<u>Video testimony</u>

Full written testimony





Peggy Lang Supporter who lost her mother after a needlessly painful death

New York City

"Requests for medical aid in dying are not a failure of hospice or palliative care, they are an opportunity to improve the end-of-life care experience. They are an opportunity to honor the beliefs and preferences of each unique individual and ensure that they have the option to die with dignity when they decide that the pain and suffering from their terminal disease is too great to withstand."

Video testimony

Full written testimony



FAMILY EXPERIENCE

Bonnie Rose Marcus

Supporter whose partner died in agony despite receiving quality palliative care

New York City

"Jay would want us all to know, that his extreme pain in the last hours of his life, was not necessary. If a medical aid in dying law were in place in New York, he wouldn't have had to go through the pain he did, and the pain I witnessed."

Video testimony Full written testimony





Patricia & Ed O'Connor

Supporters whose family members have struggled with limited options

Red Hook

Patty testified about her brother who suffered with a terminal illness for years and died alone because he didn't want to jeopardize anyone in his family when he took his own life. Ed said: "there was only one person who asked us the natural question: 'How did he do it?' And the question was not asked out of morbid curiosity, but out of practicality." Ed asked the committee to pass the medical aid in dying law to give his sister, a New Yorker with ovarian cancer, the peace of mind to know that she could end unbearable suffering and could do so surrounded by the love of her family.

Video testimony Patricia's full written testimony Ed's full written testimony







Rachel Strauber Supporter

New York City

"Medical aid in dying would have given my mother the ability to terminate her life when the pain she suffered became unbearable. It would have allowed her to be surrounded and comforted by the adoring family on whom she had lavished a lifetime of love and care. But without a legal structure in place, my mother was left to the tender mercies of nursing home care that resulted in months of misery and left her to die alone."

FAMILY EXPERIENCE

Lindsay Wright

Supporter whose husband died far from home when the couple moved to Oregon to access its death with dignity law

New York City

"... people from all walks of life, beliefs, and backgrounds want better end-of-life options, including compassionate palliative care, fewer and less invasive end-of-life interventions, and more autonomy in how they will die,especially when they have a terminal illness. And they – we – want that option right here in New York where we live."

<u>Video testimony</u>

Full written testimony



Full written testimony

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FORMER ASSEMBLY MEMBER

Janet Duprey

Former Republican member of the NYS Assembly from the North Country who lost both of her parents after painful death experiences

Peru

"It took eleven agonizing days as my family and I watched our mother and grandmother starve to death ... I can tell you from experience, forcing a person and their loved ones to live through that kind of torture isn't something we should be proud of as a society."

Video testimony

Full written testimony



LIVING WITH TERMINAL ILLNESS

Bernadette Hoppe

Supporter living with a stage 4 cancer

Buffalo

"People like me are dying every day across New York. Maybe their deaths would be less agonizing, maybe they could spend their last days, weeks, and months with the peace of mind knowing that New York has a law that allows medical aid in dying."

<u>Video testimony</u> <u>Full written testimony</u>





LIVING WITH TERMINAL ILLNESS

Susan Rahn Supporter

Rochester

"I want more than anything to live. I will continue to utilize my palliative care team for pain and comfort, but when that stops working, that's when I want another option. I want to be able to choose how I will die when my time comes."

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Full written testimony

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LIVING WITH TERMINAL ILLNESS

Ida Schmertz Supporter living with a life-limiting illness

New York City

"I plan to continue to live actively as long as I possibly can, seek additional treatment options when needed, and definitely support palliative care, hospice care and all other available options for end-of-life care when the time comes. [But when my illness recurs] the Medical Aid in Dying Act would allow me the option to die as we all would wish — at home, surrounded by family and loved ones and on our own terms."

<u>Video testimony</u> <u>Full written testimony</u>





LIVING WITH TERMINAL ILLNESS



Retired physician; first woman president of the Howard University Medical Alumni Association; former president of the American Medical Women's Association

Washington, D.C.

"I love my work ... and my life. But if the time comes that my weekly Thursday chemo treatments are no longer working and my suffering becomes unbearable, I would want medical aid in dying as an option for myself, and for the sake of my loved ones."



LOVED ONE WHO USED MEDICAL AID IN DYING

Richard Friedberg

Supporter whose daughter used Oregon's death with dignity law

New York City

"I doubt that I could ever be as brave as [my daughter] Elinor. But I'm now 82, and cancer is common in my family. The chance of my living more than another ten years is slim. When my turn comes, I would like to be allowed to die in the manner I choose."

Video testimony

Full written testimony



Video testimony

Full written testimony



LOVED ONE WHO USED MEDICAL AID IN DYING

Nancy Murphy Supporter whose sister died gracefully using Vermont's aid-in-dying law

North Country

"[Joan's] loving, beautiful, peaceful and CHOSEN transition allowed us to bond with her and she was with us in a way that is beyond description. Our grieving is mixed with admiration for her courage and determination and with pride that we as a family came together in mutual support of her decision."



LOVED ONE WHO USED MEDICAL AID IN DYING

Rachel Remmel

Supporter whose brother was the youngest to use Washington's aid-in-dying law and blogged about his decision

Rochester

"[My brother] Ethan died at home surrounded by family and friends, for which I am grateful to Washington state's law. In a blog he wrote about his decision: "I feel strongly that [this option] should be legally available to mentally competent and terminally ill people such as myself."

Video testimony

Full written testimony



Video testimony

Full written testimony

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LOVED ONE WHO USED MEDICAL AID IN DYING

Myra Shulman

Supporter whose mother was one of the first to use California's End of Life Option Act

Ithaca

"When the time came, [my mother] lay on her own bed, in her own home, with her daughters at her side — holding her — and swallowed the life-ending prescription. Within a few minutes she slipped gently into unconsciousness. For the following five hours my sister and I, and our husbands, were at her side. It was such a peaceful, gentle, truly beautiful way to end a life."

Video testimony

Full written testimony



PHYSICIAN

Diana Barnard, M.D.

Vermont Family Medicine, Hospice and Palliative Medicine Specialist

Weybridge, VT

"My patient John Roberts, a WWII veteran who had overcome many challenges in his long and full life, died peacefully in his home with his good friend Hal at his side ... he had accomplished his most precious life goals: to live as long and as well as possible with a clear mind, to remain in his own home despite declining health related to advanced prostate cancer, and to die peacefully. All on his own terms."

<u>Video testimony</u> <u>Full written testimony</u>





Maggie Carpenter, M.D. Hospice and Family Practice Physician

New Paltz

"The N.Y. chapter of the American Academy of Family Physicians, of which I am a member, firmly supports this legislation. The majority of providers I know in the hospice and palliative care world overwhelmingly support this legislation, including the sister who acts as our interfaith minister at Hudson Valley Hospice."



PHYSICIAN

Jay Federman, M.D.

Family physician from Saranac Lake; Medical Director for the Tri-Lakes division of High Peaks Hospice

Saranac

"For a variety of reasons, some individuals seek more personal control of their dying process and assurance they will not suffer at the end. This is why the Medical Aid in Dying Act should be supported and enacted into law in New York State."

<u>Video testimony</u> <u>Full written testimony</u>



Video testimony

Full written testimony

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Robert Milch, M.D.

Co-Founder Hospice Buffalo (1978); internationally recognized palliative care provider

Buffalo

"This legislation would allow terminally ill New Yorkers to die without suffering in whatever way is coherent with their own values and beliefs."



PHYSICIAN

Heather Paladine, M.D.

Family Physician; Director of a residency training program in Family Medicine

New York City

"I ask New York lawmakers not to react to fear based on speculation or misinformation, but to hear the pleas of dying patients and the trusted voices of experienced, dedicated clinicians."

<u>Video testimony</u> <u>Full written testimony</u>



Video testimony

Full written testimony

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David Pratt, M.D.

Internist, lung specialist, and primary care physician with experience in outpatient palliative care; former Commissioner of Public Health Services in Schenectady County

Rexford

"Medical Aid in Dying honors autonomy, gives options, affords dignity and is true to the ethical principle of beneficence ... This is an urgent matter for many New Yorkers ... let's honor their autonomy and provide them this crucial option."

Video testimony

Full written testimony



PHYSICIAN

Timothy Quill, M.D.

Physician specializing in palliative care at the University of Rochester Medical Center

Rochester

"...we are asking you to consider authorizing the Medical Aid in Dying Act as a last resort for terminally ill patients who feel they do not otherwise have acceptable options. Twenty years of data from Oregon suggest strongly that this practice can be legally regulated, and that it enhances rather than undermines palliative care and hospice."

<u>Video testimony</u> <u>Full written testimony</u>





Yale Rosen, M.D. Physician; Pathologist

North Bellmore

"Having witnessed the suffering of many terminally ill patients during my medical training, and also within my family and circle of friends, medical aid in dying is a subject which has long interested me and which I support. [My wife Carol, who died from metastatic breast cancer] would have benefited greatly from knowing that she had the option to utilize medical aid in dying if or when her suffering became unbearable."

Video testimony

Full written testimony



REPRESENTING A SUPPORTIVE ORGANIZATION

Guillermo Chacon

President and CEO of the Latino Commission on AIDS; Founder of the Hispanic Health Network

New York City

"... I am blessed today to call myself cancer free. I would want this compassionate law if my cancer ever came back."

<u>Video testimony</u> <u>Full written testimony</u>





REPRESENTING A SUPPORTIVE ORGANIZATION

Beth Haroules Senior Staff Attorney, New York Civil Liberties Union

New York City

"[I]t is the NYCLU's position that no person should be able to deny to another the option to choose medical aid in dying. No person should presume to dictate an agonizing death, or any particular sort of death, for another human being ... Each terminally ill person should have the right to make their own decisions about how to spend their final days and how to face death."

Video testimony

Full written testimony



REPRESENTING A SUPPORTIVE ORGANIZATION

Barb Thomas

Aid in Dying Issues Specialist for the League of Women Voters of New York State; Supporter whose husband asked for aid in dying

Saratoga Springs

"No one should have to die like Bob did. No one should have to face telling the one they love that there's nothing they ca do to help like I did."

Video testimony Full written testimony

