

**ASSEMBLY COMMITTEE ON HEALTH**

**PUBLIC HEARING**

A2383-A

Medical Aid in Dying Bill

**WRITTEN TESTIMONY BY**

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19<sup>th</sup> Floor, 250 Broadway

My name is David Hoffman and I am grateful for the opportunity to address the New York State Assembly Health Committee on the important topic of medical aid in dying. I appear before you today to express my support for adoption of Assembly Bill 2383, and to respond to some of the comments and observations made by witnesses who have testified previously, concerning which I believe there is a need for clarification or context.

My analysis of the arguments in favor of, and in opposition to, the medical aid in dying legislation is informed by over 35 years of involvement in the healthcare delivery system in a variety of capacities. I am, variously, a healthcare lawyer, clinical ethicist, hospital administrator, healthcare compliance officer, bioethics teacher and, for 17 years, an advocate for the adoption of the Family Healthcare Decision Act. My areas of practice, and of teaching, focus on the intersection of law, medicine and ethics. In fact, I often describe my role as that of an

interpreter acting to connect those disciplines in a meaningful manner for the benefit of my patients and clients. My opinions are also informed by my experience as an advanced emergency medical technician, founder of the ambulance service at the State University of New York at Buffalo, service on numerous committees on legal and medical ethics and as a volunteer panel member for the New York State Surrogate Decision Making Committee. Having viewed all 4 hours of the testimony given in Albany on April 23, 2018 I was impressed by all of the speakers and I respect each of them for their concern for patient welfare including the support provided to patients facing end-of-life decisions.

And yet I must take exception to some of the collateral attacks, hyperbolic and inaccurate descriptions and misconceptions of the progress that we have made since the decision of the United States Supreme Court in *Vacco v. Quill*, in providing all patients who are confronting end-of-life decisions with the fullest possible support.

I am fortunate to have begun my formal training in bioethics over 24 years ago when I was invited to participate in the pilot program in bioethics and the medical humanities created by Columbia University and the Albert Einstein College of Medicine with funding and support from the United Hospital Fund. Since that time, in addition to my work as a clinical ethicist and healthcare lawyer I have devoted a substantial amount of time to teaching bioethics, and specifically the intersection of law and bioethics, in law school, medical school and graduate school settings. At around the same time that I began my bioethics training I connected with an ad-hoc group of healthcare providers and advocates to support the adoption of the Family Healthcare Decisions Act. During the course of the many years that we advocated for the

importance of family participation in healthcare decision making, we encountered many of the same speculative arguments in opposition to that law as have been advanced in opposition to the medical aid in dying legislation we are here to discuss today. In both cases the arguments can be broken down into three broad categories, first the risk of coercion, second the potential adverse impact on vulnerable populations and third the potential for a slippery slope impact, under which the law is applied to an ever-increasing group of people. In short, I am pleased to advise this committee that none of those fears have been borne out by the practical experience of those of us who are daily engaged with patients, their families, and healthcare providers who are responsible for implementing the provisions of the Family Healthcare Decisions Act. It is based upon that experience, and my familiarity with the processes and structures built into the medical aid in dying legislation, that I can express my confidence in the ability of the healthcare delivery system to implement this law in a manner that is patient centered and respectful of all of the concerns raised by witnesses who have testified previously.

It is important to recognize at the outset 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. This is at its heart an effort to remove physicians from a historic gatekeeper function which has no particular relevance to physician aid in dying. We are only having a discussion today about the need for Physician involvement in prescription of lethal doses of medication because, in 1938, for a very good reason, the United States Congress adopted the Food, Drug and Cosmetics Act creating, for the first time, a standardized system for regulating public access to selected medications. While that legislation was very well

intentioned and largely effective in accomplishing its goals of protecting the public from what is euphemistically referred to as snake oil, that protection, in the form it takes today, produces an unnecessary burden for patients for whom possible side effects are no longer a relevant consideration.

Several of the prior witnesses who testified before this committee raised concerns about the requirement in this bill that medical aid in dying only be made available to individuals who are deemed by their physicians to have 6 months or less to live. Several of those who testified earlier focused on the inability of healthcare providers to ascertain with precision which patients had 6 months to live, potentially resulting in individuals who had longer than 6 months to live being subject to premature death. While these concerns were undoubtedly sincere, this objection ignores the fact that the requirement for determination of terminal illness and 6-month life expectancy is only a **necessary**, but not a **sufficient** condition for authorizing the use of medical aid in dying. It could, and should, never be the case that a patient would be provided with a prescription for a lethal dose of medication solely because a clinician had determined that, in all likelihood, they would expire within 6 months. That determination is only the start of an evaluation of the patient's clinical circumstances, which then turns to the clinical indication for medical aid in dying and the availability of alternative courses of treatment that might relieve the patient's physical pain and existential suffering.

While this legislation removes the barrier to accessing lethal doses of medication created by the passage of the Food, Drug and Cosmetics Act, it does not create a **positive right** of patients to receive a lethal dose of medication. Rather this law creates a **negative right**, that is, the right not

to be obstructed in seeking clinician support for medical aid in dying. However, the law does not, and should not, create an affirmative obligation (the natural consequence of a positive right) compelling any physician to provide medical aid in dying if they do not believe that it is clinically indicated, or if they believe it violates the clinician's own conscience. The removal of legal barriers to medical aid in dying merely enables clinicians to make their own judgment about whether medical aid in dying is both appropriate and necessary.

It is a fool's errand to attempt to legislate the standard of care for clinicians, with regard to medical aid in dying, or any other clinical judgement, each of which must be made by a clinician on the basis of their evaluation of all of a particular patient's individual circumstances. The proper role of the law is to define socially acceptable parameters within which clinicians exercise their professional judgment.

Dr. Sally White testified earlier that she supports more and better end-of-life care. I wholeheartedly join her in that mission. However she then went on to speculate that there was nothing in the medical aid in dying bill to stop abusive relatives from using medication to end the life of unwell patients over their objection. Though it is true that this bill does not, and cannot, provide a legal standard for provision of medical aid in dying which protects every patient from the homicidal behavior of a family member or caregiver, the bill establishes that it is one of the unquestionable responsibilities of a clinician contemplating provision of a prescription for medical aid in dying to consider and evaluate the safety of the patient's personal circumstances and to consider whether the patient is at risk of abuse in their final days, whether in relation to medical aid in dying or other aspects of their palliative or hospice care. Nothing in this bill

relieves any clinician of their moral and legal obligation to act as advocates for their patients and to consider the ability of the patient to safely and appropriately utilize medical aid in dying in an environment that is free of coercion or criminal conduct.

Dr. White also observed that the bill contains no mandate for training of clinicians on determinations of decision-making capacity or the obligation to make a referral for that purpose. She asserted that doctors need training in order to properly assess a patient's decision-making capacity in regard to medical aid in dying. I am pleased to advise this committee that there is no necessity of mandating availability of such training because it is already being provided and will no doubt be expanded in order to meet the demands of healthcare professions to prepare themselves to assume this important clinical responsibility.

I am privileged to teach currently in the Master's Program in Bioethics at Columbia University and in the Albert Einstein College of Medicine – Cardozo School of Law Bioethics Master's Program. In those programs I teach my students about the importance of proper assessment of decision-making capacity in all clinical contexts including decisions about end-of-life care. Our program includes among its numbers: physicians, nurses, nurse practitioners, psychologists, therapists and virtually every other category of health care provider. I teach classes in: Bioethics and the Law, Managing Patients with Diminished Capacity, and Organ Transplantation Ethics. This Fall I will be offering a new class at Columbia: Advanced Clinical Ethics at the End of Life.

Far too often, in the testimony given by others during the earlier session of this hearing, reference was made to the presence or absence of decision-making capacity as an absolute unitary phenomenon. In contrast, I train my students that the only proper response to the

question: “does the patient have decision-making capacity?”, is to ask: “capacity to make what decision?” Capacity determinations are always decision specific. Several of the witnesses who testified in Albany expressed concern that the law does not address the possibility that a patient's decisional capacity might change during the course of their illness, between the time that a physician issues a prescription for a lethal dose of medication and the time that a patient decides to utilize that medication. It is true that the law contains no such provision, and of course the law doesn't have to. Clinicians have a professional ethical obligation to recognize that capacity is variable, and that it must be anticipated that patients nearing the end of life may experience a diminution in capacity to make different types of decisions. However, several of those witnesses failed to acknowledge that a patient does not necessarily need the same level of decisional capacity to affirm continuing commitment to an earlier decision as they needed to make that decision in the first place. Consideration of that circumstance ought to rest in the sound discretion of the clinician who is exercising their judgement to either prescribe, or decline to prescribe, medication to achieve medical aid in dying.

Other witnesses expressed concern that a clinician's determination that a patient is “terminal”, as that phrase is defined in the statute, might be influenced by a patient exercising their right to refuse available medical interventions. While it is true that even terminal patients have the prerogative to accept or reject treatment offered by their attending clinicians, it is also true that a clinician authorized to provide medical aid in dying is entitled to take that refusal of treatment into consideration in evaluating both the patient's decisional capacity, and the clinician's willingness to provide the medical aid in dying authorized by this bill. The bill clearly creates a responsibility on the part of the treating clinician to ascertain whether the patient is suffering

from an **incurable** illness or condition. It is therefore soundly within the range of authority and exercise of judgment by the clinician to determine whether, by virtue of the patient's refusal of a particular intervention that might cure the patient's underlying illness or condition, the patient is disqualifying themselves from receiving medical aid in dying because the patient is not in fact incurable.

I took exception to the sarcastic statement made by one of the earlier witnesses that perhaps there is a need to create a “profession for professional executioners.” This is both clinically inaccurate, as nothing in this bill empowers anyone to act as an executioner, and technically irrelevant to this committee's considerations, because each clinician authorized to act under the bill is empowered to make their own decision about whether medical aid in dying is something that they believe is appropriately within the scope of their clinical practice.

Dr. Omega Silva opined that a risk is presented when patients are provided with medication to achieve aid in dying and then experience a “moment of crisis.” It is quite impossible, but fortunately wholly unnecessary for this piece of legislation to address that clinical contingency. Here again, it is not the function of this law to define and dictate a standard of care. Clinicians who chose to participate in the evaluation of patients who seek medical aid in dying will exercise their own professional judgement to determine how, and at what point in treatment, a patient is provided with a lethal dose of medication. It will also be appropriate for that clinician to assess the support available to the patient through family and friends, to create a plan of care that anticipates the circumstances under which a patient might experience such a "crisis". Be that as it may Dr. Silva's concerns must be evaluated in comparison to other alternatives available to an

“end-of-life patient” who is experiencing such crisis, where the patient, without access to guidance from a clinician, might well resort to other extraordinary and less reliable interventions that might actually leave them worse off than when they started.

Several witnesses expressed concern about coercion and the potential slippery slope effect of providing patients with access to medical aid in dying. The slippery slope and coercion are arguments that were frequently made by opponents to the Family Healthcare Decisions Act who were concerned that surrogates would act in furtherance of their own self-interest, and not in advancing the interest, values and priorities of the patient for whom they were a surrogate. In the 8 years since the adoption of the Family Healthcare Decisions Act I have seen no evidence of a slippery slope phenomenon in surrogate abuse of their decision-making authority. I am confident that clinicians understand their responsibility to ensure that patients are making treatment decisions without the coercive influence of third parties. It is a basic rule of bioethics consultation, one that I drill into all of my students, that no decision to accept or refuse treatment can be considered a reliable expression of the patient's wishes unless they have had the opportunity to independently express that treatment preference, without any other individuals present. This is true, for example, when a patient who self-identifies as a Jehovah's Witness is approached about consent for blood transfusion, when other members of their family or their faith are present for the consultation. Likewise, it is ethically impermissible to discuss consent to treatment for venereal disease or consideration of the use of birth control with a patient under the age of 18 with any other individuals present. The medical aid in dying law does not need to have, as part of its legal dictate, protections related to the influence of coercion. That obligation is already incorporated in the professional responsibility of all clinicians.

In fact, I teach my students that in each instance where bioethics consultation is being provided the consult should be structured around four considerations which I characterize as the four “Cs” of clinical bioethics: capacity, confidentiality, consent and coercion. We evaluate patient decision making, whether regarding end-of-life care or other treatment decisions, on the basis of those four criteria in that order, in order to ensure that a patient is free to make an independent and autonomous capacitated decision when warranted, while at the same time having the support of family members and surrogates when necessary.

Dr. Thomas Madejski indicated in his testimony to the committee his desire to "eliminate the desire of patients to contemplate ending their lives due to inadequate care." I concur in Dr. Madejski's assessment that no patient should decide to accept medical aid in dying because the curative or palliative care provided to them has been inadequate. That is appropriately part of the consideration that a clinician should undertake in determining whether to provide medical aid in dying. Dr. Madejski also opined that the medical aid in dying bill might exacerbate a patient's fear of abandonment at a time of greatest need. I don't think that Dr. Madejski meant to suggest that any clinician, whether a member of the Medical Society of the State of New York or not, would under any circumstances issue a prescription for a lethal dose of medication to a terminally ill patient and then abandon them. We have a term for that type of behavior by a treating clinician, and that term is medical malpractice. No clinician, physician or otherwise, should even consider exercising their professional authority to issue a prescription for medical aid in dying if that clinician is not satisfied that they are able to provide appropriate ongoing consultation and support throughout the course of managing the patient's terminal illness. Even

mentioning the possibility of abandonment by a physician who has written a prescription for a lethal dose of medication is indicative of the doctor's willingness to promote irrational fear of negative consequences in order to achieve a political defeat of this legislation. That intent is further manifest in Dr. Madejski's repeated reference to "participation in euthanasia or support of assisted suicide." In repeating that phrase throughout his testimony Dr. Madejski is attempting to conflate the responsibility of a clinician to respect the patient's exercise of their autonomous right to control their treatment with a fictional concern that doing so would constitute euthanasia, which in New York is a form of homicide.

Dr. Madejski also seemed not to appreciate the distinction between the double effect, which results when a patient is given a dose of pain medication for the express purpose of relieving pain (but which might depress the patient's respiratory drive resulting in earlier demise) from the impact of palliative sedation which is not merely management of physical pain in the first instance, but is instead the medical induction of a deep sleep state which renders the patient unaware of the conditions which are productive of suffering. While it is true that palliative sedation for patients who have exercised their lawful right to refuse artificial or oral nutrition and hydration is a viable alternative to medical aid in dying for some patients, the existence of that modality of care at the end of life does not in any way negate the importance of medical aid in dying as a legal, safe and reliable alternative at the end of life. It should not be the intention of either the legislature or the Medical Society of the State of New York to dictate to patients and clinicians, including the medical society's physician members, that one form of end-of-life intervention is preferable in all cases to another form of intervention. It is the object of the medical aid in dying legislation to remove obstacles to clinicians, including physicians,

providing patients with information about all of available palliative and end-of-life care options and offering to patients the intervention which the clinician feels is most appropriate under that patient's individual circumstance.

Finally, I would be remiss if I didn't comment upon the so-called survey of the medical society membership which Dr. Madejski indicated was a basis for his objection to the medical aid in dying legislation. In the first instance, it was inappropriate for Dr. Madejski to introduce conclusions about the results of the survey when he was not prepared or willing to share the data itself. By conducting an electronic survey which is in no sense a statistically valid random sampling of his members, in the context of a legislative hearing on an important piece of end-of-life legislation, Dr. Madejski has undermined the reliability of his entire testimony. He was not able or willing to identify how many of the respondents self-identified as: medical students, medical residents or fully-licensed physician members of his organization. In addition, some questions posed in the survey, specifically Questions No. 8 and 10 are disingenuous, and beside the point. Question No. 8 asks: "Do you believe that this activity should be a right of patients or should not be a right that patients can claim?". This question is objectionable because it suggests that the bill being contemplated confers a right on a patient which creates a corollary obligation for physicians to provide medical aid in dying. This is entirely inaccurate. Question No. 10 asks "Would you support or not support other physicians engaging in this activity if it were legally permitted?" This question is also ill conceived and beside the point because - whether a responding physician is supportive or not supportive of another physician's activity - has no bearing on whether this modality ought, as an ethical and legal matter, to be available as an option for individual patients? Physicians, regardless of whether they are members of the

Medical Society of the State of New York. A more appropriate question, one that gets to the heart of the matter would be: “Do you believe that physicians who support the practice of providing medical aid in dying should be legally prohibited from doing so?” In evaluating the testimony of Dr. Madejski in regard to his so-called “survey of members” the committee ought to consider the absence of such a straightforward and relevant question in the Medical Society’s survey. (The full text of the survey is attached).

Given that the survey was sent out to the members of a single professional organization and the medical society’s president failed to report to the committee the number of respondents, it is difficult to credit even the anecdotal conclusions shared by Dr. Madejski regarding the potential for a change in the medical society's position on medical aid in dying. Regardless of the statistical validity of this survey, which is highly doubtful, given the lack of a random selection of respondents, the conclusions of that survey are entirely beside the point. Questions regarding the validity of the survey aside, no single professional society, not the Medical Society of the State of New York, or any other professional organization should be permitted to define the standard of care for the practice of medicine. That is the appropriate role of physicians practicing in a particular discipline, based on accumulated medical insights, as shared through peer reviewed medical journals and other forums for development of clinical consensus.

The Medical Society, like any professional organization, has an appropriate role in advocating for its members. MSSNY's active membership is reported to be 10,111. Since there are 74,992 physicians in New York - MSSNY represents about 13% of our physicians. In that regard, it is entirely legitimate for the Medical Society and other professional medical organizations to take

positions as advocates for the legal rights of its members. So for example, if the medical aid in dying law were to require physician members of the medical profession to provide a prescription for a lethal dose of medication when demanded by a patient, it would be entirely appropriate for the Medical Society to oppose that requirement, on behalf of its physician members, regardless of the percentage of the total medical profession that that organization might represent, on the grounds that no such affirmative duty ought to be imposed upon physicians or any other class of healthcare provider. It is something altogether different and objectionable, for the medical society to urge the withholding of medical aid in dying, as a treatment option from physicians and their patients who do not support the Medical Society's position.

Justice Benjamin Cardozo declared in 1914, in his decision in *Schloendorff* that: ..."[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body..." *Schloendorff v. Society of New York Hospital*, 211 N. Y. 125, 129 130, 105 N. E. 92, 93 (1914). In the circumstance presented by the Medical Aid in Dying bill, what is needed by patients who are suffering at the end of life is simply for the laws of New York State to respect that earliest expression of the cherished right to bodily autonomy – that is, the right of consent and the right of refusal of treatment. Cardozo drafted those now famous words more than 20 years prior to the adoption of the Food Drug and Cosmetics Act which ushered in the age of prescription medications and with it, physicians, and now other licensed independent practitioners', role as gatekeepers for access to certain classes of medication. While that gatekeeper role remains an important one in situations where medications are being utilized in a curative or palliative application, that gatekeeper function has limited relevance to the use of

those same medications in the end of life circumstances contemplated by the Medical Aid in Dying bill.

I urge you to respect the rights of patients and clinicians by voting to approve the Medical Aid in Dying bill.

Respectfully submitted,

David N. Hoffman