End of Life Choices
NEW YORK

AID IN DYING:

AN INFORMATIONAL SUMMARY

VOLUME 22
MAY 2018

TABLE OF CONTENTS

End of Life Choices New York
244 Fifth Avenue, #2010
New York, NY 10001-7604

David Leven, Executive Director Emeritus and Senior Consultant
914.907.6156 or david@endoflifechoicesny.org

www.endoflifechoicesny.org

EXECUTIVE SUMMARY

- **Aid in dying** is the process by which a mentally competent, terminally ill adult patient obtains a prescription of medicines which the patient may ingest to end suffering and achieve a peaceful death.
- **Aid in dying is legal** in CA, VT, WA, MT, CO, Washington, Hawaii, DC, and OR.
- **57% of physicians support aid in dying** according to a 2016 Medscape survey.
- **A 2015 poll in New York State** by Eagle Point Strategies showed:
  - 77% overall support for aid in dying.
  - 72% of Republicans support aid in dying.
  - 67% of self-identified conservatives support aid in dying.
  - 78% of Upstate New Yorkers support aid in dying.
- **75% of Catholics in NYS support aid in dying** (Eagle Point Strategies, 2015).
- **73% of Americans support aid in dying** according to a 2017 Gallup national poll.
- **Americans of every political ideology support aid in dying**, including 67% of Republicans, 81% of Democrats, 60% of conservatives, 79% of moderates, and 89% of liberals (Gallup 2017).
- Gallup's 2017 poll also found that **55% of weekly churchgoers support aid in dying.**
- **Aid in dying already happens.** National physician surveys indicate that 20% of doctors have received at least one request to assist a terminally-ill patient with dying, and that 3%-18% of physicians consent to these requests.
- **Palliative sedation** is another legal strategy to bring a peaceful end to one's life. It is done to commence the dying process when all hope is lost – just like aid in dying.
- **But palliative sedation has none of the protections that aid in dying does**: no written patient consent, no required statutory determination that a patient has capacity, no physician obligation to assess depression, no mandatory reporting of related actions in the patient's medical record, and no reporting to the Department of Health when it occurs. It can also be requested by a health care agent or surrogate for those who lack capacity. It's therefore ironic that some opponents of aid in dying consider palliative sedation an acceptable alternative.
- **Claimed abuses have not been found**. As a 2007 *Journal of Medical Ethics* study (Battin et al) of aid in dying in Oregon and The Netherlands concluded, "…we found no evidence to justify the grave and important concern expressed about the potential for abuse—namely, the fear that legalized physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups." To the contrary, that study found that "people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges."
- **Oregon's experience proves aid in dying works**. From 1997-2017, there were approximately 629,152 deaths in Oregon. Only 1,270 of those deaths were due to aid in dying, or only .20% of all Oregon deaths from 1997-2017.
- **90.9% of Oregon aid in dying patients** had cancer, ALS, AIDS, or heart disease.
- **Patients in Oregon** were primarily motivated by a fear of losing autonomy (87%), not being able to engage in activities that make life enjoyable (88%), a loss of dignity (67%), and losing control of their bodily functions (37%).
- **New York's proposed law has strict safeguards** to ensure patient safety, including: limited to 18 years of age or older; must have legal capacity; must have a prognosis of 6 months or less to live; must make an oral and a written request for aid in dying witnessed by 2 adults who attest that the patient: 1) has capacity; 2) is acting voluntarily and of their own volition; 3) is not being coerced; and 4) must be informed of all other available medical options. Only a patient can administer the medication, and the patient can rescind their decision at any time.
- **Editorial support** for aid in dying has emerged statewide, including from the *New York Times*, the *Buffalo News*, the Albany *Times Union*, the Middletown *Times Herald-Record*, Long Island *Newsday*, the Oneonta *Daily Star*, and the *Scarsdale Inquirer*.
- **Numerous organizations in New York have endorsed A.2383-A/S.3150-A,** including the NYS Academy of Family Physicians, NY Statewide Senior Action Council, NYS Public Health Association, the Rochester Breast Cancer Coalition, Housing Works, ACT-UP NY, Harlem United, NY Civil Liberties Union, and the NY Society for Ethical Culture.

SUMMARY OF A.2383 (PAULIN)/S.3151 (SAVINO)

1. Patient must be at least 18 years of age, have a prognosis of 6 months or less to live, be diagnosed with an illness that is incurable and irreversible, confirmed by an attending and a consulting physician.
2. A patient requesting aid in dying (AID) shall not be considered suicidal, and patients self-administering an aid in dying medication shall not be deemed to have committed suicide.
3. A patient must make an oral and a written request (on a form provided in law) for AID. The written request must be witnessed by 2 adults who attest that the patient: 1) has capacity; 2) is acting voluntarily, of their own volition; and 3) is not being coerced.
4. One witness shall NOT be: 1) a relative; 2) a person entitled to a portion of the patient's estate; 3) an owner, operator, independent contractor or employee of a health care facility where the patient resides or is being treated; or 4) the patient's attending physician, consulting physician or mental health professional, if applicable, who provides a capacity determination.
5. If the attending or consulting physician has any doubt about the patient's capacity, the physician <u>must</u> refer the patient for evaluation by a mental health professional. Only patients subsequently found to have capacity may proceed.
6. A patient may rescind his or her request for medication at any time without regard to capacity.
7. Patients must self-administer the medication.
8. An attending physician must have primary responsibility for the care of the patient requesting AID and the treatment of the patient's terminal illness.
9. Attending physician responsibilities: 1) diagnose that the patient has 6 months or less to live; 2) confirm the patient has capacity, made an informed decision, and requested the medication voluntarily, without coercion, and of their own volition; 3) inform the patient of the need for a consulting physician's confirmation, and refer if requested; 4) if the patient lacks capacity, refer the patient to a mental health professional for evaluation; 5) provide information and counseling regarding the availability of palliative care, hospice, the full range of medical options, and and their right to comprehgensive pain and symptom management; 6) discuss with the patient the patient's diagnosis and prognosis, potential risks and probable result of the medication to be used, feasible alternatives or additional treatment options including hospice and palliative care, the importance of taking the medication with someone else present and not taking the medication in public, and the option to obtain but not take the medication; 7) inform the patient that they can rescind the request for medication at any time; 8) document in the patient's medical records all AID actions; 9) ensure all legally-mandated steps have been taken; 10) offer the patient an opportunity to rescind the patient's request prior to writing a prescription; 11) inform the patient that only may administer the medication, and of the importance of informing their family of their decision; and 12) prescribe the medication if the patient qualifies.
10. Attending physician documentation requirements: 1) date of oral request; 2) patient's written request; 3) the patient's diagnosis and prognosis; 4) that the patient has capacity, is acting voluntarily, of their own volition and without coercion, and made an informed decision; 5) the outcome of the patient's capacity evaluation, if any; and 6) state in the patient's medical record that all requirements of the law have been met and actions taken, including the medication prescribed.
11. The consulting physician must: 1) examine the patient and medical records; and 2) confirm in writing that the patient i) has a terminal illness, ii) has capacity, or provide documentation that the physician referred the patient to a mental health professional for evaluation, iii) is making an informed decision of their own volition, and iv) is acting voluntarily and without coercion. This information must be given to the attending physician and the patient
12. A mental health professional asked to determine the capacity of a patient must, in writing, report to both the attending and consulting physicians the professional's conclusion with regard to capacity. If the patient is determined not to have capacity, the patient may not receive AID.
13. Physicians, other health care providers and health care facilities acting within the law are protected from civil, criminal, and professional liability.

14. Physicians, nurses, pharmacists and other health care providers are under no obligation to participate in AID.
15. Health care providers are not subject to civil or criminal liability or professional disciplinary action for being present when medication is taken, or for failing to prevent the medication from being taken.
16. Private health care facilities may refuse to participate in AID if they find it morally objectionable or if it is against their religion and they have informed the patient of the policy. In such cases, a patient requesting transfer to another reasonably accessible provider must be accommodated, and medical records forwarded.
17. If a health care facility prohibits AID and informs its employees in writing, an employee who violates that prohibition may be subject to sanctions by the employer.
18. No obligation owing under a contract, will or other agreement may be conditioned on using or refusing AID, and no provision in a contract, will or other agreement is valid if it impacts a patient's aid in dying decisions.
19. Insurance benefits cannot be denied based on any AID actions, and insurers can't condition the sale or issuance of life or health insurance policies or set rates on the making or rescinding of a request for AID, nor can insurers provide information on AID medication unless requested by the patient or physician, or communicate both the denial of coverage for treatment and information as to the availability of AID medication.
20. The sale or issuance of physician malpractice insurance or rate charged cannot be conditioned on or affected by whether the insured participates in AID.
21. Actions in accordance with the law shall not be considered suicide, assisted suicide, attempted suicide, promoting a suicide attempt, mercy killing, or homicide.
22. Reiterates that "euthanasia" remains illegal under New York law.
23. Provides requirements for the safe disposal of unused medications.
24. DOH must issue regulations to ensure the safe disposal of unused AID medications.
25. An AID patient's death certificate shall specify the underlying terminal illness as the cause of death.
26. DOH shall: 1) annually review a sample of records to ensure compliance; and 2) issue an annual report on utilization and compliance with the law.
27. Actions contrary to this law may be punished by professional, civil, or criminal means, as appropriate.
28. The law takes effect immediately.

ORGANIZATIONS IN SUPPORT OF MEDICAL AID IN DYING

- ACT UP-NY
- Compassion & Choices
- Death with Dignity Albany
- Death with Dignity National Center
- End of Life Choices New York
- Harlem United
- Hispanic Health Network
- Housing Works
- Latino Commission on AIDS
- League of Women Voters of New York State
- Mobilizing Preachers and Communities)
- New York Civil Liberties Union
- New York State Academy of Family Physicians
- New York State Public Health Association
- New York StateWide Senior Action Council
- New York Society for Ethical Culture
- Rochester Breast Cancer Coalition
- Secular Coalition of America – New York Chapter
- Voters for Change-ADK

FICTION & FACT

FICTION #1: Aid in dying is suicide.

FACT:

- Suicide is the act of ending your life, unrelated to a terminal illness, usually in isolation, and often impulsively and violently, by a clinically depressed person who wants to die.
- Aid in dying is sought by patients with 6 months or less to live. It is the process by which a very small number of mentally competent dying patients obtain prescribed medicines to end their suffering and achieve a peaceful death. They don't want to die, but understand that due to their illness, death is imminent or will occur soon. These terminally ill patients simply want to gain control of their dying process.
- The American Public Health Association, the American Academy of Hospice & Palliative Medicine, the American Women's Medical Association and the American College of Legal Medicine have all concluded that aid in dying is not suicide, as has every state which has a law permitting aid in dying.

FICTION #2: Doctors oppose aid in dying.

FACT:

- While the AMA is opposed to aid in dying, it is currently reexamining its position.
- Supporters include the American Medical Student Association, the American Medical Woman's Association, the American College of Legal Medicine, and the American Public Health Association.
- Prior to aid in dying legislation passing in California, the California Medical Association removed its opposition (in place since 1987) to aid in dying. In doing so, the CMA said,

  > "We believe it is up to the individual physician and their patient to decide voluntarily whether the End of Life Option Act is something in which they want to engage. Protecting that physician-patient relationship is essential."
- According to a 2016 Medscape survey of over 7,500 physicians nationwide, 57% support aid in dying.

FICTION #3: The public doesn't support aid in dying.

FACT:

- A 2015 poll in New York State by Eagle Point Strategies showed:
  - 77% overall support for aid in dying.
  - 75% of Catholics support aid in dying.
  - 72% of Republicans support aid in dying.
  - 67% of self-identified conservatives support aid in dying.
  - 78% of Upstate New Yorkers support aid in dying.
- Recent polls in neighboring states show widespread support for aid in dying from voters, with almost identical support from people with disabilities in those states: MA, 74% and 71%; CT, 66% and 65%; and NJ, 63% and 62%.
- Nationally, Gallup has polled support for aid in dying since 1947. Since 1973, a majority of Americans have supported it. In their most recent poll, 73% of Americans supported aid in dying.
- Gallup's 2017 national polling shows aid in dying is supported across the political spectrum: 67% of Republicans, 81% of Democrats, 60% of conservatives, 79% of moderates, and 89% of liberals.
- Gallup's 2017 poll also found that 55% of weekly churchgoers support aid in dying.
- In a 2016 survey, LifeWay Research—a Christian research firm—found that 69% of Americans support aid in dying, including 53% of African-Americans, and 70% of Catholics.

FICTION #4: No state allows aid in dying, and New York shouldn't either.

FACT:

- Aid in dying is legal in California (2016, legislature), Montana (2009, court decision), Vermont (2013, legislature), Washington (2008, initiative), Colorado (2016, initiative), Hawaii, legislature, 2018), Washington, DC (2016, City Council), and Oregon (1998, initiative).

FICTION #5: The proposed New York law has no safeguards to protect against abuse.

FACT:

- The proposed law has numerous safeguards to protect patients, including:
  - Two doctors must confirm the patient has capacity, is 18 or older, is acting voluntarily, and has 6 months or less to live.
  - Patient must provide an oral and a signed written request for aid in dying, witnessed by 2 adults who confirm the patient has capacity, is acting voluntarily, and is not being coerced.
  - If a patient's capacity is questioned by the attending or consulting physician, the physician must refer the patient for a mental health evaluation to confirm that the patient has capacity.
  - Neither age nor disability may be the sole factor used to determine patient eligibility.
  - Medical records must account for every legally-mandated step in the aid in dying process being recorded.
  - Written and oral contracts, wills, and insurance policies are prohibited from being contingent on/limited due to a patient's desire to use/not use aid in dying.
  - Patients must administer aid in dying medications themselves.

FICTION #6: Rather than enact an aid in dying law, we should expand access to hospice care.

FACT:

- Hospice is a complement to, not a replacement for, aid in dying.
- In Oregon's 20-year experience, approximately 90% of aid in dying patients were enrolled in hospice at the time of their death.

FICTION #7: The medical system doesn't allow people to end their lives, so we shouldn't make aid in dying legal.

FACT:

- The U.S. Supreme Court ruled that patients have the right to refuse unwanted medical treatment, as well as to refuse food and water. All of these actions are legally sanctioned methods for ending your life.
- The practice of "palliative sedation" (originally known as "terminal sedation"), is also legal throughout the U.S, and is practiced in virtually all medical settings, including those managed by the Catholic Church, which supports its use. Palliative sedation is sedating a terminally ill patient, for whom no treatment has been effective at managing the patient's pain, into unconsciousness. Once the patient loses consciousness, food and hydration are withdrawn. Just as with aid in dying, palliative sedation is a proactive action by a physician to commence a process which will lead to the patient's death. A more extensive discussion of palliative sedation can be found on page 13 of this packet.

FICTION #8: Catholics are opposed to aid in dying, so it should not become law.

FACT:

- 75% of Catholics in NYS support aid in dying (Eagle Point Strategies, 2015).
- 65% of Catholics nationally support aid in dying (Gallup, 2014).
- Self-determination is at the core of aid in dying. Catholics and other religious individuals and institutions have a right to decline aid in dying, but not to impose their beliefs on others.

FICTION #9: Some terminally-ill people want every effort made to treat them. If there was an aid in dying law, there would be a strong motivation to deny them that care.

FACT:

- There is no evidence that aid in dying laws have been used to deny anyone the care they desire. Indeed, a nationally-prominent medical ethicist, Arthur Caplan, Director of the Division of Medical Ethics at NYU Medical Center, stated, "I worried about people being pressured to do this. But…the policy in Oregon is working. There is no evidence of abuse or coercion, or misuse of the policy."

FICTION #10: Aid in dying laws lead to poor and disabled people being encouraged to kill themselves.

FACT:

- No study has ever found a link between aid in dying and the disabled or poor being coerced into using it. In fact, studies have proven the opposite to be true.
- In practice, poor and disadvantaged people exhibit the same lack of access to aid in dying as they do to everything else in health care. Studies in Oregon have shown that those who utilized aid in dying are overwhelmingly white (97%), middle class (98% have health insurance), highly-educated (approximately 73% have attended college or have a college degree) individuals capable of maneuvering through the somewhat complex aid in dying process. If anything, Oregon's experience shows that the poor suffer from a lack of access to aid in dying.
- As a 2007 *Journal of Medical Ethics* study (Battin et al) of aid in dying in Oregon and The Netherlands concluded, "…we found no evidence to justify the grave and important concern expressed about the potential for abuse—namely, the fear that legalized physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups." To the contrary, that study found that "people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges."
- In a 19 year period, Disability Rights Oregon, legal advocates for the disabled, has never received a claim of exploitation or coercion pursuant to Oregon's AID law. *(Note: also see pages 17-18)*

FICTION #11: If aid in dying becomes law in New York, depressed or mentally incompetent people will be able to legally obtain drugs to kill themselves.

FACT:

- The only people who could legally obtain drugs under the law are those with capacity and a diagnosis of 6 months or less to live. If you don't have a terminal diagnosis, you are legally prohibited from utilizing aid in dying.
- The proposed NY law explicitly prohibits disability and age as eligibility criteria for aid in dying.

FICTION #12: If aid in dying were legal, people with any kind of disease could kill themselves.

FACT:

- People with any disease <u>could</u> use aid in dying, <u>BUT</u> only if two physicians determine they have 6 months or less to live.
- In Oregon's 20 years of experience, approximately 90% of patients who used aid in dying had cancer, ALS, AIDS, or heart disease.

FICTION #13: If aid in dying becomes law, its use will become widespread.

FACT:

- In Oregon, where aid in dying has been the law for 20 years, it is still rarely used. For example, in 2017, of 36,498 total deaths, only 143 involved aid in dying, or just .39% of all deaths in Oregon that year.
- From 1997-2017, there were 629,152 deaths in Oregon. Only 1,270 of those deaths were due to aid in dying, or just .20% of all Oregon deaths during those 20 years.

FICTION #14: Hospitals, many of whom are Catholic institutions, will be routinely confronted with aid in dying requests if aid in dying were legal.

FACT:

- In Oregon, approximately 90% of aid in dying deaths occurred at home, reflecting the primary motivation of patients who use it: to control how and where they die.

FICTION #15: Aid in dying will lead people facing financial difficulties, or concerned about pain, to kill themselves.

FACT:

- In 2017 in Oregon, concerns about pain (about 21%) or financial difficulties (about 5.6%) were the reasons least cited by patients as a rationale for seeking aid in dying.
- Patients were primarily motivated by a fear of losing autonomy (87%), no longer being able to engage in activities that make life enjoyable (88%), a loss of dignity (67%), and losing control of their bodily functions (37%). Patients who seek aid in dying are motivated by a desire to maintain control of the conditions under which they die, not a fear of uncontrolled pain or a heavy financial burden.
- A New England Journal of Medicine study of hospice nurses and hospice social workers who cared for aid in dying patients in Oregon concluded that financial problems, depression and fears of pain were not what motivated their patients to seek aid in dying. Rather, they said that the primary motivations of their patients were: 1) a desire to control the circumstances of their death; 2) a desire to die at home; and 3) being ready to die.

FICTION #16: The families of aid in dying patients will be devastated by this process.

FACT:

- In Oregon, two studies of family members of aid in dying patients show that they were better prepared for and accepting of the patient's death, had diminished states of denial, had more resolved grief, were more likely to believe the patient's choices were honored, and were less likely to have regrets about the death. Family members of aid in dying patients also rated the quality of the moment of death as better than did the families of patients who didn't use aid in dying.

FICTION #17: Family members will coerce sick relatives to end their life if aid in dying is legal.

FACT:

- A study of 1,384 family members in Oregon found no incidence of aid in dying outside the law.
- The New York legislation has provisions to guard against patient coercion (see Fiction #5 above).

FICTION #18: Aid in dying will irrevocably damage the doctor-patient relationship.

FACT:

- A 2007 US GAO study, comparing Oregon to 3 other states without aid in dying, concluded that Oregon physicians are more comfortable discussing end of life issues since aid in dying was enacted, and that it helped foster a doctor-patient relationship in which end of life options were discussed more openly.

FICTION #19: Because it is illegal, no physicians currently assist their patients with aid in dying.

FACT:

- Researchers estimate that 1 in 250 deaths nationally involve aid in dying.
- National physician surveys indicate that 20% of doctors have received at least one request to assist a terminally-ill patient with dying, and that 3%-18% of physicians consent to these requests.

FICTION #20: The use of "palliative sedation" makes aid in dying unnecessary.

FACT:

- Palliative sedation is used to help terminally ill patients die, as is refusing food and hydration, and refusing treatment, all of which are legal in the U.S. Because it is only used now for the small number of patients who have unmanageable, uncontrollable pain, it is not an option for patients with other conditions who seek aid in dying. And, palliative sedation does not address the needs of patients who want to use aid in dying nearly as well: a desire to maintain control of their body and the dying process until the very end of their lives; a desire to maintain their dignity as they die; and a desire to avoid a radical decline in their quality of life. Aid in dying is a better option too as it is a quicker, more effective method of dying, where patients do not have to linger for days or weeks and where patients can say their good byes to loved ones just before dying and loved ones can be present at the time of death.

SAFEGUARDS:

AID IN DYING
VS
RIGHT TO REFUSE TREATMENT, FOOD, AND HYDRATION

The refusal of treatment, food, and hydration at the end of life are all legal in New York. They are widely-accepted in the medical and religious communities, despite the absence of legal safeguards regulating their use. When a patient is refusing treatment - even life sustaining treatment - physicians may, pursuant to standard of care, do some of the things listed below, but they have no statutory requirement to do so.

By comparison, the Paulin/Savino aid in dying bill has numerous safeguards to protect patients:

Statutory Safeguards	Paulin/Savino Bill	Refusal of Treatment, Food & Hydration
Patient must be at least 18 years old	Yes	No
Patient must provide oral and written & signed request	Yes	No
Patient written request must be witnessed by 2 adults	Yes	No
Witnesses must meet eligibility rules	Yes	No
Witnesses must attest that patient has capacity, is acting voluntarily, and is not being coerced	Yes	No
MD must confirm that patient has capacity	Yes	No
MD must diagnose that patient has 6 months or less to live	Yes	No
MD must confirm patient is making an informed decision voluntarily and without coercion	Yes	No
Patient must seek the opinion of a consulting physician	Yes	No
Consulting MD must confirm the attending MD’s findings	Yes	No
If lack of capacity is suspected, the patient must be found to have capacity by a mental health professional before proceeding	Yes	No
Physician must document every step of the process, and record in the medical record that all steps required by law have been taken	Yes	No
DOH must review a sample of cases annually to ensure compliance and identify abuse	Yes	No
DOH must report on utilization and compliance to ensure compliance and identify abuse	Yes	No

RESPONSES TO OBJECTIONS RAISED BY THE NEW YORK STATE CATHOLIC CONFERENCE CONCERNING AID IN DYING LEGISLATION

The New York State Catholic Conference has issued a memo listing what they perceive as “fatal flaws” in legislation to allow terminally ill patients to seek and receive aid in dying.

The objections they raised, and factual responses to them, follow:

Objection: The Standard for Determining Capacity is Inappropriate

- Paulin/Savino uses a standard for determining patient capacity that exceeds existing requirements for patients making similar medical decisions. When a patient who has decision-making capacity (and this bill only applies to requests by patients with decision-making capacity) is making decisions to refuse or reject even life-sustaining treatment, to voluntarily stop eating and drinking, or to start palliative sedation, there is no statutory requirement for capacity determinations, even though death will result. Paulin/Savino does mandate that the patient’s capacity be determined by the patient’s physician.
- Paulin/Savino would require a second physician opinion for determining capacity. Requiring a second opinion is *two more* physicians than is required for a patient to refuse treatment or food and hydration.
- The Catholic Conference memo has New York law turned upside down. You do not have to get a physician to certify your decision-making capacity in order for you to make a health care decision (including refusing life-sustaining treatment). The high standards of proof the Conference memo refers to are for making a decision that you *lack* capacity so someone else can make decisions for you. It is in fact unusual in New York law that the Paulin/Savino bill requires a physician certification of a patient’s capacity.

Objection: Counseling, Diagnosis and Treatment is Lacking

- Evaluation by a mental health professional IS required under Paulin/Savino, but only if the attending or consulting physician determines, in his or her medical opinion, that the patient may lack capacity. Such a process is standard practice in medicine.

Objection: Patient Coercion is Likely

- Having two witnesses is the standard used in New York’s Public Health Law, including for the designation of a health care agent.
- The bill does not prohibit one witness from being a relative or a person entitled to a portion of the patient’s estate, just as the Health Care Proxy Law does not prohibit such persons from being witnesses to the health care proxy. And, since that law went into effect decades ago there has been no effort to change it because of evidence of or realistic concerns about coercion.
- If a patient with decision-making capacity chooses to refuse life-sustaining treatment, there is no requirement for anyone to witness that decision. This bill only applies to patients with decision-making capacity.
- In over 20 years of experience in Oregon, using the same process proposed in Paulin/Savino, not a single example of patient coercion has been found valid and no effort has been made to change that law.

Objection: Surrogates Will Make Decisions for Patients

- Only a patient – with decision-making capacity – may make aid in dying decisions under Paulin/Savino. There are no provisions that would allow a surrogate or health care agent to do anything relating to aid in dying, such as making a request or decision or administering the medication.
- The Health Care Proxy Law (HCPL) and the Family Health Care Decisions Act (FHCDA) have nothing to do with Paulin/Savino or aid in dying. They both establish protocols for making health care decisions when a patient loses capacity. A patient making an aid in dying decision must HAVE capacity. If the patient does not have capacity, the bill says the process cannot proceed.
- The rules for what decisions can be made for a patient who loses capacity are governed by the HCPL and the FHCDA. Paulin/Savino does not amend those laws, and will have no impact on them.
- The only person authorized by Paulin/Savino to administer the aid in dying medication is the patient. If any other person were to administer the medication, that person would be in violation of the law and subject to criminal prosecution. Where the bill says the patient "may" administer the drug, it does not mean someone else may do so; it means the patient is authorized to administer the drug and may also change his or her mind and choose not to.

Objection: There is a Lack of Accountability & Transparency

- Paulin/Savino tracks existing law, which does not require notice to the family of an adult patient who has decision-making capacity if they decide to stop life-sustaining treatment, start palliative sedation, voluntarily stop eating and drinking, or make any health care decision.
- Paulin/Savino mandates that the attending physician inform the patient of all end-of-life treatment options, as is currently required by the Palliative Care Information Act (Public Health Law, § 2997-c).
- Paulin/Savino requires the Department of Health to collect information on the aid in dying utilization and compliance, and report it annually.
- Paulin/Savino requires that a patient make an oral and a written request for aid in dying, and that two witnesses attest that the patient has capacity, is acting voluntarily, and is not being coerced.
- Paulin/Savino requires that the attending physician keep extensive records related to the aid in dying process, including: all oral and written patient requests; the patient's diagnosis and prognosis; that the patient has capacity and is acting voluntarily; the outcome of any capacity evaluation by a mental health professional, if needed; and note in the medical record that all requirements of the law have been met, including all the steps taken to carry out the request for aid in dying and the medication prescribed.
- Because aid in dying hastens the death of a dying patient, it is accurate and appropriate for the death certificate to list the cause of death as the patient's underlying terminal illness or condition. Death resulting from the withdrawal of life-sustaining treatment or the refusal of food and hydration also hastens death, and are not listed as the cause of death. In addition, it is important for public health and other purposes that the patient's actual illness be listed as the cause of death. The fact that aid in dying was involved will be maintained in the medical record and in the Health Department's records and statistics.

Objection: The Conscience Clause is Ineffective

- A "physician, nurse, pharmacist, other health care provider or other person" is under no duty to participate in the provision of medication to a patient under Paulin/Savino. They can also refuse to engage in discussions about end of life options and their risks and benefits.
- Private health care facilities are explicitly exempt from participating in aid in dying if doing so violates a formally adopted facility policy expressly based on religious beliefs or sincerely held moral convictions.
- The two preceding provisions follow the model common in New York's Public Health Law.
- In addition, Paulin/Savino explicitly allows a health care facility to prohibit its staff from participating in aid in dying, and allows the facility to sanction them if they violate those rules if the facility previously notified the staff of the prohibition.

PALLIATIVE SEDATION:
AID IN DYING WITHOUT THE SAFEGUARDS

- “Palliative sedation” is a legitimate end of life option—but not the only option. Unlike aid in dying, it requires that patients suffer intractable pain, and it lacks the safeguards required in aid in dying.

- Palliative sedation, which was originally called “terminal sedation,” is the continuous administration of medication, to the point of coma, to relieve severe, intractable pain that cannot be controlled while the patient is conscious.

- Palliative sedation is an option used when nothing else works to control a patients suffering, usually from pain. As such, its use requires that the patient suffer before it is utilized.

- Once the patient is unconscious, all life support is sometimes withdrawn or withheld.

- Palliative sedation takes days to weeks to produce death. As such, it is a less humane way than aid in dying to help a dying patient manage their dying process.

- Palliative sedation is not a “natural” death, as some would suggest. It involves the administration of powerful sedatives, and often the withholding or withdrawal of food and hydration.

- Even though palliative sedation can lead to death, it is practiced in Catholic health care institutions, and supported by leading Catholics. A paper on the United States Conference of Catholic Bishops website, written by the Secretariat for Pro-Life Activities for the National Conference of Catholic Bishops, Richard Doerflinger, said:

  > “In competent medical hands, sedation for imminently dying patients is a humane, appropriate and medically established approach to what is often called "intractable suffering."

- Palliative sedation is done to commence the dying process when all hope is lost – just like aid in dying—but without any of the safeguards. Palliative sedation has none of the protections that aid in dying does. There is no written patient consent, no required statutory determination that a patient has capacity, no mandatory reporting of related actions in the patient’s medical record, and no reporting to the Department of Health when it occurs. It can also be requested by a health care agent or surrogate for those who lack capacity. It’s therefore ironic that some opponents of aid in dying consider palliative sedation a better alternative.

OREGON'S DEATH WITH DIGNITY ACT (ODDA): MAJOR FINDINGS

- Enacted in 1994, the ODDA was delayed by court challenges and an unsuccessful repeal initiative. It finally took effect in 1998. It is quite similar to the bill in NY.
- From 1998-2017, 1,967 people have had prescriptions written, and 1,270 have died using aid in dying medications.
- Over the past 20 years, only 0.20% of all deaths in Oregon are a result of aid in dying.
- Annually, the proportion of patients who ingested the medication they received ranged from 47.7% to 82%. The remainder of patients died from their disease progression, having never used the drugs.
- Approximately 90% of aid in dying patients were enrolled in hospice at the time of their death.
- Over 98% of aid in dying patients had health insurance.
- Cancer patients made up 77% of all aid in dying patients, with neurologic disorders second at 14%.
- The median duration, from first request to death, was 52 days.
- The most frequently cited motivation for aid in dying was a loss of autonomy (87%), a decreased ability to participate in activities that make life enjoyable (88%), a loss of dignity (67%), and the loss of bodily function (37%). Inadequate pain control (21%) and financial concerns (5.6%) were the least frequently cited reasons.
- Approximately 5% of Oregon physicians have received formal requests for aid in dying.
- A survey of hospice participation in aid in dying revealed that 16% participated fully, 32% moderately, 27% in a limited fashion, and 25% not at all.
- Approximately 90% of aid in dying patients died at home. In 20 years, only 4 of 1,270 deaths occurred in a hospital.
- Unconsciousness and death occur rapidly: unconsciousness occurred in a median of 5 minutes, and death in a median of approximately 30 minutes.
- Studies indicate that the families of aid in dying patients are, on average, more prepared for the death, and more accepting of it.
- The very small number of aid in dying cases, and the stability in the number of cases each year, has alleviated concerns that the law would lead to coercion and other pressures on patients to use aid in dying.
- Researchers found no evidence of heightened risk resulting from aid in dying for the elderly, women, the uninsured, people with little education, the poor, the physically disabled or chronically ill, minors, people with psychiatric disorders, or racial or ethnic minorities.

THE OREGON DEATH WITH DIGNITY ACT ANNUAL REPORT: WHAT THE DATA DOES--AND DOES NOT--REVEAL

The Oregon Public Health Division (OPHD), by law, issues a report on the Oregon Death with Dignity Act annually. The 2017 report, their 20th, was released in February of 2018. In past years, some New York advocates have made thoroughly unsubstantiated claims related to these reports designed to foment fear rather than provide facts. To avoid any confusion that may be generated by these statements, to follow are the actual findings of their reports.

Misleading Claim #1: The majority of those requesting lethal drugs are vulnerable, isolated elderly people with functional impairments and low incomes.

What the OPHD Report Says:

- The Oregon reports contain no data on patient income or assets, and makes no income or asset claims. Any statement about Oregon aid in dying patient income is pure conjecture unsupported by facts.
- Data in the 2017 report that is suggestive of economic condition includes: 99% of patients have insurance, 90% died at home, and approximately 69% have attended college or have graduated from college (49% with a bachelor's degree).
- Research studies of Oregon aid in dying patients have consistently reported that they are predominately white and middle class. In support of these previous findings, the 2017 OPHD report found that 94% of patients were white.
- The 2017 report contains no data on family structure, other than reporting that 43.4% of patients are widowed or divorced, a not surprising fact given that the median age of patients is 74. The lack of a spouse does not mean a patient is isolated, and the report makes no claims with regard to patient isolation. However, it does state that 90% of patients died at home, which would argue against claims of isolation.
- Patients most certainly were elderly, as one would expect when discussing death, with 80.5% age 65 or older.

Misleading Claim #2: The Oregon data shows that unaddressed disability-related concerns underlie assisted suicide requests.

What the OPHD Report Says:

- The report contains no data on patient disability, and makes no claims with regard to possible discrimination against the disabled under the law. In fact, the word "disabled" is not used anywhere in the report.
- The report does find that 100% had one of several terminal illnesses, as required by law, including 77% with cancer, and 14% with neurological diseases, and 6% with heart disease.
- On a related note, in February 2016 the Executive Director of Disability Rights Oregon, the advocacy and patient protection organization that provides legal services to people with disabilities in Oregon, stated that after so many years of the law being in effect their organization "has still not received a complaint of exploitation or coercion of an individual with disabilities in the use of Oregon's Death with Dignity Act."

Misleading Claim #3: The Oregon data reveal a higher number of reported assisted suicide deaths than ever before.

What the OPHD Report Says:

- Because so few people in Oregon have used their aid in dying law it's easy to make alarmist claims, as even modest actual numeric increases in the use of the law will look significant when represented as percentages or multiples.
- In fact, over the 20 years that the Oregon law has been in effect, only 1,967 patients have registered for aid in dying, and only 1,270 have actually used it. That means that aid in dying patients represent only .20% of all Oregon deaths during that 20 year period. Conversely, over 99% of all Oregon deaths from 1998-2017 did NOT result from aid in dying. Clearly the Oregon law is working as intended: it is an important option for those that want it, but it is very far from becoming the widespread practice that opponents claimed it would become.

Misleading Claim #4: The top three end-of-life concerns cited by Oregon patients requesting suicide pills had nothing to do with physical pain and suffering. These concerns were: decreasing ability to participate in enjoyable activities, loss of autonomy, and loss of dignity.

What the OPHD Report Says:

- Those three conditions have consistently been the most significant reasons why patients request aid in dying over the entire 20 years of the Oregon law, and they are just as valid as concerns related to pain. Patients facing the end of their lives have every right to choose aid in dying when confronted with the potential for being hooked up to machines or otherwise placed in circumstances or institutions that they don't want to enter. These concerns are reflected in the fact that in 2017, 90% of Oregon aid in dying patients die at home, and 90% are enrolled in hospice at the time of their death.
- 21% of Oregon aid in dying patients did mention concerns about inadequate pain control, so that issue does exist for some patients.

It's important to learn all the facts about the Oregon Death with Dignity Act, as their 20 years of experience is the best evidence that aid in dying laws are effective at helping dying patients maintain control while guarding against abuse. The entire OPHD report, *"Oregon Death With Dignity Act: 2017 Data Summary,"* can be found here:

http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

THE DISABLED:
OREGON'S EXPERIENCE

Some advocates for people with disabilities have been vociferous opponents of aid in dying legislation.

Their concerns, while sincere, are unfounded:

- Being disabled is not a qualifying condition for aid in dying. Under the proposed law, only patients with capacity who have a terminal illness can utilize aid in dying. Being disabled is obviously NOT a terminal illness.

- Some advocates for people with disabilities claim that because society views the disabled as a "burden," an aid in dying law will lead to the premature, forced death of the disabled. Because only a patient may request and carry out aid in dying—and then only having cleared numerous safeguards—it is difficult to understand how this could happen.

- Some advocates for people with disabilities raise many theoretical problems with the law; frightening outcomes that might happen if aid in dying were legal in New York.

  Fortunately, we don't have to rely on theory. Oregon has 20 years of practical, real-life experience with a law that is the model for the New York legislation. In those 20 years, absolutely none of the hypothetical fears of advocates for people with disabilities have proven true. Indisputable evidence of this fact can be found on the next page in a letter from the Executive Director of Disability Rights Oregon (DRO), the organization in Oregon charged with defending the rights of the disabled. As this letter confirms, <u>DRO has never had a case filed claiming exploitation or coercion under the Oregon aid in dying law.</u>

DISABILITY RIGHTS OREGON

FEB 16 2016

February 10, 2016

Roland L. Halpern, MNM
Cultivation Manager
Compassion & Choices
4155 E Jewell Avenue
Denver, CO 80222

Dear Roland:

Thank you for your letter of January 22 asking if anything has occurred that would change my former position on the matter.

The answer is no. DRO has still not received a complaint of exploitation or coercion of an individual with disabilities in the use of Oregon's Death with Dignity Act.

Thanks for you inquiry.

Sincerely,

Bob Joondeph
Executive Director

610 SW Broadway, Suite 200 / Portland, OR 9720
Voice: 503-243-2081 or 1-800-452-1694 / Fax: 503-243-1738 / **www.droregon.o**

AID IN DYING REPORTS REPORTS
FROM OTHER STATES

Recently other states have issued reports on their aid in dying laws. To follow are brief summaries of those reports.

Colorado

Their 2017 report concluded the following:

- 69 eligible patients received prescriptions
- Their median age was 75; 78% were over 65 years of age
- 83% had cancer, ALS, or heart disease
- 71% had some college or a college degree
- 96% were white
- 93% were enrolled in hospice at the time of death
- 56 of those patients are deceased, but their data does not indicate whether those patients used the medications prescribed
- The med

Vermont

Their 2017 report concluded the following:

- From May 2013 thru June 2017, 52 patients were approved for aid in dying
- 48 of those patients have since died
- 29 of the 48 took the prescribed medication, or 60%
- 83% had cancer, while 14% had ALS

California

Their June-December 2016 report concluded the following:

- 191 individuals received aid in dying prescriptions
- 111 of them, or 58%, used the medication
- Of those 111, 87% were over 60 years old, 96% had health insurance, 84% were in hospice care, 90% were white, and 71% had attended or graduated from college
- Aid in dying deaths accounted for .061% of all 183,265 California deaths during this six month period

PERSPECTIVES

ON AID IN DYING

Medical aid in dying should be a compassionate option

By Janet Duprey, Commentary
Published 3:54 pm, Wednesday, December 21, 2016

In the 10 years since I was elected to the state Assembly, I've voted on hundreds if not thousands of bills to come to the floor of the "People's Chamber." I've fought for improving the lives of my constituents in the North Country, advocated for the rights of the disabled, fought against tax hikes and excessive job-killing regulations, and helped make marriage equality a reality in New York.

To be sure, every vote requires thoughtful deliberation and reflection. But every once in a while, a piece of legislation lands on your desk that makes you pause and reflect on your own life experiences. One such bill is the Medical Aid in Dying Act.

Medical aid in dying would allow a terminally ill, mentally capable adult the option to self-administer medication — when and if they choose — to bring about a peaceful and humane death, should their end-of-life suffering become too great to bear. The language is very clear; only a terminally ill, mentally capable adult can qualify to receive aid-in-dying medication.

Oregon has had their own version of this law for almost 20 years, the Death with Dignity law. Fewer than 1,000 people have utilized the medication, but there are countless more who have enjoyed an increased peace of mind knowing there was another option if their suffering became unbearable. In Oregon, access to hospice actually increased, and overall end-of-life health care improved, because patients were able to have more open conversations with their families and doctors after Death with Dignity became law. California and Colorado both recently legalized medical aid in dying, joining four other states that currently have it on the books.

When the bill made it to the Assembly Health Committee earlier this year, I decided to share a very personal story about my family's painful history with end-of-life options. I knew the bill wouldn't get to the floor for a full debate before my retirement, so I wanted my colleagues to know my support of the bill is based on what two people I love very much went through. My mom and dad.

My father died in 1995 from mesothelioma. He was an old-school "tough guy," but at the end he experienced excruciating pain, even with the tremendous care he was given in hospice. Even the morphine he was prescribed wasn't touching the pain. As too many of us know, watching a loved one suffer is too much to bear.

Five years later, my mother died after a series of strokes. She lost the ability to swallow, and the only thing that was keeping her alive was a feeding tube. My mom had lost her will to live.

We spent a lot of time talking about what she could do. After a lot of time, and a lot of tears, my mom asked me if I would support her decision to remove her feeding tube.

I told her I would support her, and the next day she had it removed. My daughter and I sat helplessly and watched my mom starve for an agonizing 11 days. When the end finally came, my daughter and I were there, holding her hand. 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.

I'm a Catholic, and like millions of other Catholics in New York, I feel we should give people the option to make a choice. People should have the right to choose their own destiny.

Even though I'm retiring at the end of the year, I fully expect to remain a positive voice for change that I think is long overdue in the state I love. I will continue to speak out in favor of medical aid in dying, and other important issues should they need a little push at the Capitol. After several decades in public service, it's something I think I'm bound to do.

To this day I still miss my parents, and I am not going to presume that they would have chosen to ask for medical aid in dying at the end. But I am certain that they should have had the ability to choose their own destiny.

Assembly Member Janet L. Duprey, R-I Peru, represents the 115th Assembly District.

The New York Times

On Assisted Suicide, Going Beyond ‘Do No Harm’

The Opinion Pages | OP-ED CONTRIBUTOR

By DR. HAIDER JAVED WARRAICH   NOV. 4, 2016

DURHAM, N.C. — Out of nowhere, a patient I recently met in my clinic told me, “If my heart stops, doctor, just let me go.”

“Why?” I asked him.

Without hesitating, he replied, “Because there are worse states than death.”

Advances in medical therapies, in addition to their immense benefits, have changed death to *dying* — from an instantaneous event to a long, drawn-out process. Death is preceded by years of disability, countless procedures and powerful medications. Only one in five patients is able to die at home. These days many patients fear what it takes to live more than death itself.

That may explain why this year, behind the noise of the presidential campaign, the right-to-die movement has made several big legislative advances. In June, California became the fifth and largest state to put an assisted suicide law into effect; this week the District of Columbia Council passed a similar law. And on Tuesday voters in Colorado will decide whether to allow physician-assisted suicide in their state as well.

Yet even as assisted suicide has generated broader support, the group most vehemently opposed to it hasn’t budged: doctors.

That resistance is traditionally couched in doctors’ adherence to our understanding of the Hippocratic oath. But it’s becoming harder for us to know what is meant by “do no harm.” With the amount of respirators and other apparatus at our disposal, it is almost impossible for most patients to die unless doctors’ or patients’ families end life support. The withdrawal of treatment, therefore, is now perhaps the most common way critically ill patients die in the hospital.

While “withdrawal” implies a passive act, terminating artificial support feels decidedly active. Unlike assisted suicide, which requires patients to be screened for depression, patients can ask for treatment withdrawal even if they have major depression or are suicidal. Furthermore, withdrawal decisions are usually made for patients who are so sick that they frequently have no voice in the matter.

Some doctors skirt the question of assisted suicide through opiate prescriptions, which are almost universally prescribed for patients nearing death. Even though these medications can slow down breathing to the point of stoppage, doctors and nurses are very comfortable giving them, knowing that they might hasten a “natural” death.

In extreme cases, when even morphine isn’t enough, patients are given anesthesia to ease their deaths. The last time I administered what is called terminal sedation, another accepted strategy, was in the case of a patient with abdominal cancer whose intestines were perforated and for whom surgery was not an option. The patient, who had been writhing uncontrollably in pain, was finally comfortable. Yet terminal sedation, necessary as it was, felt closer to active euthanasia than assisted suicide would have.

While the way people die has changed, the arguments made against assisted suicide have not. We are warned of a slippery slope, implying that legalization of assisted suicide would eventually lead to eugenic sterilization reminiscent of Nazi Germany. But no such drift has been observed in any of the countries where it has been legalized.

We are cautioned that legalization would put vulnerable populations like the uninsured and the disabled at risk; however, years of data from Oregon demonstrate that the vast majority of patients who opt for it are white, affluent and highly educated.

We are also told that assisted suicide laws will allow doctors and nurses to avoid providing high-quality palliative care to patients, but the data suggests the opposite: A strong argument for legalization is that it sensitizes doctors about ensuring the comfort of patients with terminal illnesses; if suicide is an option, they'll do what they can to preclude it.

And, again, we are counseled that physicians should do no harm. But medical harm is already one of the leading causes of death — and in any case, isn't preventing patients from dying on their terms its own form of medical harm?

With the right safeguards in place, assisted suicide can help give terminally ill patients a semblance of control over their lives as disease, disability and the medical machine tries to wrest it away from them. In Oregon, of the exceedingly few patients who have requested a lethal prescription — 1,545 in 18 years — about 35 percent never uses it; for them, it is merely a means to self-affirmation, a reassuring option.

Instead of using our energies to obfuscate and obstruct how patients might want to end their lives when faced with life-limiting disease, we physicians need to reassess how we can help patients achieve their goals when the end is near. We need to be able to offer an option for those who desire assisted suicide, so that they can openly take control of their death.

Instead of seeking guidance from ancient edicts, we need to re-evaluate just what patients face in modern times. Even if it is a course we personally wouldn't recommend, we should consider allowing it for patients suffering from debilitating disease. How we die has changed tremendously over the past few decades — and so must we.

Dr. Haider Javed Warraich, a fellow in cardiovascular medicine at Duke University Medical Center, is the author of the forthcoming book "Modern Death: How Medicine Changed the End of Life."

NOTE:
In email correspondence regarding this article on Nov. 29, 2016, Dr. Warraich stated: "I do not like to use the term assisted suicide to represent assisted death and have made it clear that patients who seek this choice are not suicidal; I used this term in this particular piece primarily because I wanted to address a skeptical audience (physicians), and wanted them to be comfortable with the principle of aid in dying, regardless of what it is called."

Hospice Care Isn't Enough for all the Dying

CEO of Oregon hospice group says she changed her mind about right-to-die law

BY ANN JACKSON - Special to The Sacremento Bee - December 9, 2015

People who opposed laws in California, Oregon, Washington, Montana and Vermont authorizing medical aid in dying for terminally ill adults often claim there are better alternatives to relieve suffering.

I was one of them. In fact, I served as chief executive officer and chief spokesperson of the Oregon Hospice Association before and after the implementation in 1998 of the nation's first medical aid-in-dying law. I voted against the referendum because I believed it was unnecessary if terminally ill Oregonians had access to high-quality hospice and palliative care.

However, I came to realize that it was arrogant of me to believe that hospice and palliative care professionals could meet all the needs of the dying.

Oregon is consistently rated among the best states for providing hospice and palliative care. Yet, even with the best care, some patients still suffer intolerably and want the option to take prescription medication to die painlessly, peacefully and quickly in their sleep.

Other medical professionals also are realizing that terminally ill adults should have access to a full range of end-of-life options. In May, the California Medical Association dropped its 28-year-long opposition to medical aid in dying, acknowledging that "despite the remarkable medical breakthroughs we've made and the world-class hospice or palliative care we can provide, it isn't always enough."

Many opponents claim that palliative sedation (sedating the patient into coma and withholding nutrition and fluids until death occurs in days or weeks) effectively eases the suffering of patients when other means fail to do so. However, it is an unacceptable option for most terminally ill adults whose primary concerns are losing autonomy, quality of life and their dignity.

Today, I am convinced that medical aid in dying can be, and is, practiced responsibly in Oregon. That explains why Oregon's law is the model for subsequent laws or legislation in 30 states and the District of Columbia, including California's law that takes effect next year.

Until I retired from the Oregon Hospice Association in 2008, I met with front-line hospice workers regularly to discuss their experiences. Whether they supported or opposed medical aid in dying, they unanimously agreed that conversations about death and dying improved significantly after the law's implementation. It literally put the topic on the table.

Evidence shows that these conversations are far more likely to reassure a dying person rather than to direct them toward making a request for medical aid in dying. The vast majority of people who raise the possibility of medical aid in dying with their doctor will not go on to make a formal request. When a physician can respond openly, the likelihood of successfully addressing fears or reasons behind the request is much greater than when patients are deterred by the law from expressing their concerns and wishes.

While some health care professionals expressed fierce opposition to medical aid in dying prior to the law changing in Oregon, since then, those voices have softened, in the face of indisputable evidence, and no representative medical organization has called for the law to be repealed.

Ann Jackson is former CEO of the Oregon Hospice Association and co-wrote the chapter about hospice and palliative care in "The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals." She can be contacted at Jackson@ann-jackson.com.

The Buffalo News.com

Opinion

Another Voice / Medical ethics

Another Voice: Patient autonomy demands respect at the end of life

Published: May 18, 2016

By Michael Mezzadri

I write this article in response to the Another Voice column in which the author condemns physician-assisted suicide because it has “never been an ethical part of medicine.”

I ask the author two questions: According to whose ethics? And, are we serious about patient autonomy? As an associate professor in philosophy, I would expect the author to see that he is interested in imposing a particular set of narrow ethical principles on the physician-patient relationship, principles that may not be shared within the confines of this sacrosanct relationship, and that limit both patient autonomy and the physician’s duty to minimize suffering.

The set of ethical principles the author espouses puts “life at all costs” on a pedestal, but does not offer solutions to serious questions. It’s an easy way out, one where there are no shades of gray, an un-nuanced philosophy applied to situations that demand nuance.

In terminal illness where pain can be intractable, suffering immeasurable, is the author willing to say that patients under these circumstances must continue to live contrary to their wishes if they are indeed voiced?

By doing so, we make a conscious choice to not only impose and prolong suffering, but to say that their values are secondary.

Having autonomy removed at the end of life is precisely what those approaching end of life fear. Perhaps when patients at the end of life voice fear of losing autonomy and dignity we should take them seriously. Perhaps we should respect them enough to not say “you must continue to live despite your suffering. I know what is best, and it is life.”

Is prolonging life for the sake of life itself a worthy goal? For the healthy and young, it may seem so, yet when we approach death in sickness, values may change, opinions may shift. The response should not be to restrict options for competent patients at the end of life, to impose upon them a particular hierarchy of ethics, but to say, “I take your autonomy seriously.”

Some may not wish to prolong their life; the suffering may be too great. Who are we to say otherwise? We can pretend we are “protecting” people by doing so, but these people do not need protection, they need to have their autonomy respected and their fears of having this autonomy removed ameliorated.

The “aid in dying” movement simply wishes to remove the medical paternalism associated with end-of-life options, to respect the autonomy of the terminally ill, and to remove the pretentious notion that terminally ill patients need protection from the consequences of competently made decisions.

Michael Mezzadri is a student at the University at Buffalo Jacobs School of Medicine and Biomedical Sciences.

THE BUFFALO NEWS

New York needs to decriminalize physician aid in dying

By Robert A. Milch, M.D.
May 22, 2016

I have been privileged to practice medicine in Buffalo for nearly four decades, 35 of those years in hospice and palliative care. I have had the "bad news" discussions with innumerable patients and families, sat vigils at bedsides and "rescued" patients in crises of pain and faith.

More importantly, I have listened to my patients, now in the thousands, heard of their hopes and fears and loves, their goals and values and hates, as they faced the trials of progressive illnesses I was incapable of altering, not for all my effort or earnestness. From this experience, I have become a firm believer in the professional and ethical legitimacy of physician aid-in-dying and the need to decriminalize it as a stigmatized aspect of medical care.

In truth, this is not about me save as a clinical player in the human drama of every patient with terminal illness and the overarching, overriding ethical commandment of competent patient autonomy in medical decision-making. Debate over labeling is distracting and unhelpful if our focus is on the definition of physician assisted suicide rather than the suffering of the patient. Please, do not quote me the Hippocratic Oath, now in one of 42 adaptations and revisions, except to refer to its spirit rather than its letter. Instead, stay with me at the bedside.

I find it more helpful to consider suffering from a clinician's view rather than from the theoretical Kabuki dance of legalistic cataloging. Suffering is that which exists when what we are enduring serves no meaningful or helpful purpose in our lives, is inconsistent with our values and what we would want to avoid. It is what I have sworn to alleviate to the best of my ability knowing that the enemy isn't death, but inhumanity.

In that context, the practice of which we speak is for a patient with whom I have a supportive, professional relationship over time; a patient thought by two physicians to have a life expectancy of less than six months; a patient with full decision-making capacity; a patient free of coercion in decision making; a patient who wishes to avoid a burdensome final days or weeks in the throes of soon-to-be fatal illness; one who is legitimately given a prescription for medication, to be taken at a time and place and circumstances of his/her desire, or not at all. Understand, the intent here is to provide release from his/her suffering, real and anticipated, achievable by no other means acceptable to the patient.

I see this as no different in practice than my acquiescence to remove my patient from a ventilator at his/her request, knowing that death is likely shortly to ensue; no different from ordering discontinuation of dialysis at the patient's demand, fully aware of the consequences of that decision; no different from assuring my patient with Lou Gehrig's disease that he will never need to be tethered to the ventilator he dreads to be relieved of his inability to breathe. And, I believe, my patients are reassured knowing I will not abandon them or their families in accompanying them through this most difficult part of their care, as they desire it. I cannot, will not, tell them what they must endure. Nor should anyone else.

I am reassured that the decades of documented experience in Oregon and the other states that have decriminalized physician aid in dying, with the same safeguards as the proposed New York State legislation, have shown that the fears of abuse are overblown or not substantiated by a single case in decades of practice. The "slippery slope" of abuse has proved to be more of theoretic concern than real, an unhelpful distraction from the realities or needs of care. In short, the sky is not falling. Further, no legislation or proponent of physician aid in dying has advocated mandatory endorsement of or participation in the practice – the entirety is optional and participation is voluntary, both by patient and practitioner.

The endorsement of the pending New York legislation to decriminalize physician aid in dying is ethically consistent with the tenets of modern medical practice. It gives deserved ethical primacy to patient autonomy while shining the light of regulated, monitored, evidence-based, patient-centered practice onto a secretive practice that has lurked in the shadows far too long.

For those who oppose its practice, so be it; you need not subscribe or submit. For those patients and caregivers who would avail themselves of the option should need be, we must impress on our legislators the imperative of passage of the enabling legislation.

That done, we need to encourage all our fellow citizens, by survey more than 75 percent of us, to pursue with our caregivers our desires regarding this and all aspects of our end-of-life care.

Robert A. Milch, M.D., is a physician in Western New York.

EDITORIAL SUPPORT
FOR AID IN DYING LEGISLATION
ACROSS NEW YORK STATE

The New York Times

Aid in Dying Movement Advances

By THE EDITORIAL BOARD OCTOBER 10, 2016

New York, Colorado and the District of Columbia may soon join the handful of states where doctors are allowed to help terminally ill patients die by prescribing a lethal dose of painkillers.

A proposal to allow physician-assisted dying will be on the ballot in Colorado next month. In the District of Columbia, the District Council's Health and Human Services Committee last week approved a physician-assisted dying bill that the full council could vote on before the end of the year. New York lawmakers, meanwhile, are hopeful that support in the Legislature for aid-in-dying bills will soon overcome opposition from religious leaders and some medical groups.

Victories in the three jurisdictions would galvanize a movement that seeks to give terminally ill Americans a dignified alternative to the dismal choices they face in most of the country. In states where assisted dying is banned, some terminal patients manage to get a lethal dose of drugs from medical professionals under the table, which exposes the health care workers to prosecution. Others are advised to starve themselves to death.

Doctors are allowed to help terminally ill patients die in Oregon, Washington, Vermont, California and Montana under strict guidelines. Two physicians must concur that the patient is likely to die within six months. Doctors must ensure that patients making the request are of sound mind and that they are not being coerced. In four of the states that allow it, a request for a lethal dose of painkillers must be reiterated 15 days after it was originally made in order for the drugs to be prescribed.

Some medical groups, including the Medical Society of the State of New York, oppose physician-assisted dying. "Although relief of suffering has always been a fundamental duty in medical practice, relief of suffering through shortening of life has not," the group says in its position statement. "Moreover, the social and societal implications of such a fundamental change cannot be fully contemplated."

In fact, terminal patients in excruciating pain and their relatives contemplate those implications every day around the country. There is no compelling reason to deprive them of physician-assisted dying as one option alongside high-quality, innovative palliative care.

A New York assemblywoman, Amy Paulin, agreed last year to introduce an aid-in-dying bill after meeting with a constituent and a lobbyist who made a persuasive case. Within months, the issue became personal as her sister, who lived in Georgia, was told she would soon die from ovarian cancer. "The pain was unbelievable," Ms. Paulin said, describing her sister's final days. "She would be crying in agony."

If her sister had lived in a state where requesting a lethal dose of medicine was legal, Ms. Paulin said, she may have been spared days of misery. Relatives could have gathered to say goodbye before she took the pills.

"It would have been a much better ending to losing your sister," she said. "We could have all been there. We could have held her hand."

The New York Times

Offering a Choice to the Terminally Ill

BY THE EDITORIAL BOARD
MARCH 14, 2015

Last year, the radio host Diane Rehm watched in agony as her husband, John, starved to death over the course of 10 days.

Severely crippled by Parkinson's disease, his only option for ending the suffering was to stop eating and drinking. Physicians in most states, including Maryland, where he lived, are barred from helping terminally ill patients who want to die in a dignified way.

"He was a brilliant man, just brilliant," Ms. Rehm said in an interview. "For him to go out that way, not being able to do anything for himself, was an insufferable indignity."

Ms. Rehm, whose current affairs talk show at WAMU is distributed by NPR, the public radio network, has brought a strong and poignant voice to a debate gaining attention in state legislatures around the country.

Currently, only Oregon, Washington, Vermont, New Mexico and Montana allow health care providers, under strict guidelines, to hasten the death of terminally ill patients who wish to spare themselves and their loved ones from the final, crippling stages of deteriorating health. Lawmakers in 15 other states and the District of Columbia have introduced so-called aid in dying bills in recent months to make such a humane option available to millions of Americans at a time when the nation's population of older adults is growing.

The impetus for many of the bills was the widely publicized story of Brittany Maynard, a 29-year-old woman from California who moved to Oregon, after learning in the spring of 2014 that she had incurable brain cancer, so she could die on her own terms. The nonprofit organization Compassion & Choices, which has worked closely with Ms. Maynard's relatives and with Ms. Rehm, has played a leading role in getting state lawmakers to introduce bills.

The right-to-die movement has strong opponents, including the Catholic Church, which opposes any form of suicide. Meanwhile, some medical professionals argue that the practice is at odds with their mission as healers and worry that it could be abused. Unfortunately, many Americans associate the issue with Dr. Jack Kevorkian, a notorious advocate of assisted suicide who was convicted in 1999 of murder and who aided dozens of patients, many of whom were not terminally ill, in ending their lives.

As local lawmakers around the country debate the bills, they should consider how successfully and responsibly the law has been carried out in Oregon. The state's Death With Dignity Act, which went into effect in 1997, gives doctors the right to prescribe a lethal dose of medication to patients who are terminally ill and who have been advised of their alternatives, such as hospice care. The law provides layers of safeguards to ensure proper diagnosis of the disease, determine a patient's competency to make the decision, and protect against coercion. Last year, 105 patients in Oregon, a record high, died after receiving a lethal dose of medication.

Health care providers in states where assisted suicide is illegal face wrenching choices when dying patients ask them for help. In one case, prosecutors in Pennsylvania perversely charged Barbara Mancini, a nurse, with assisting a suicide for handing a bottle of morphine in February 2013 to her 93-year-old father, who was in hospice care. A judge dismissed the case the following year.

Some doctors caught in these painful situations end up handing patients lethal doses of painkillers with a wink and a nod, right-to-die activists say. But these unregulated practices put patients and doctors on dangerous terrain. "Making a secret process transparent makes it safer," Barbara Coombs Lee, the president of Compassion & Choices, said in an interview. Ms. Rehm said she and her husband had long agreed they would help each other die if either was in growing distress from a terminal illness. Her inability to help him die humanely is a situation no spouse should have to face.

"There was no question but that I would support him and honor whatever choice he would make," she said. "As painful as it was, it was his wish."

THE BUFFALO NEWS

Editorial: New York should consider joining states that allow doctors to help terminally ill patients die

SATURDAY MAY 16, 2015

It is time to have a serious conversation about death and dying. We need to discuss allowing the terminally ill and mentally fit to be able to fulfill their final wish to leave the good Earth with dignity.

The group End of Life Choices New York is pushing for that conversation and has, along with the national nonprofit disability rights advocacy group, Disability Rights Legal Center, recently filed a lawsuit in State Supreme Court to clarify the ability of mentally competent, terminally ill New York patients "to obtain aid in dying from their physician if they find their dying process unbearable."

There has been plenty of pushback. Religious groups and others incorrectly perceive hastening of death in these specific situations to be "assisted suicide." It is not.

End of Life Choices New York describes "aid in dying" as "the practice of a physician prescribing medication to a terminally ill, mentally competent patient who may choose to ingest it to end suffering they find unbearable, and achieve a peaceful death."

The idea is that patients, who have met a series of requirements ensuring they are not being coerced and are mentally capable of such a decision and are within a few months of dying, must themselves ingest the medication. Some correctly wonder how this is worse than a decision to discontinue life-sustaining treatment such as a ventilator or feeding tube.

Aid in dying is permitted by statute in Oregon, Washington and Vermont. Montana and New Mexico permit the practice by court decision. Montana has a lower court decision on appeal. All these states or courts recognize "aid in dying," and not "assisted suicide."

The distinction is critical. The language goes directly to the heart of the discussion for someone who is of sound mind but whose body has failed him and there is no hope for an extended life. To fully understand the calculation that goes into such a decision, listen to the stories of people like Sara Myers, who with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, merely wants the right to choose, with the medicine on hand. So do many others in similarly hopeless situations.

Findings have shown that about one-third of people who get the medicine in states where the right is given never take it. Denying a terminally ill, mentally competent patient this choice can cause undue emotional suffering for the patient. Dr. Marcia Angell wrote an article for the Washington Post that was published in The News last November about her dying husband, a distinguished physician in his own right, and his request to choose the process of his demise. Diagnosed with metastatic cancer, he had a good idea of what the end would look like. He died at home in Massachusetts, with hospice care, his wife wrote, "but not in the way he wanted."

Brittany Maynard brought a national spotlight to the subject when the 29-year-old who had incurable brain cancer moved from California to Oregon, the jurisdiction with the longest history of allowing aid in dying, so that she could have her wishes legally met.

The end is inevitable, but for some it comes as the result of an excruciating and cruel illness. Why not allow those capable of making a sound decision a choice? It won't be an easy discussion, but it is an important one that is well worth having

TIMES UNION
THE INFORMATION SOURCE SINCE 1856 FOR THE CAPITAL REGION

Suffering's silent treatment

BY TU EDITORIAL BOARD ON JULY 5, 2015

We're all going to die, some of us peacefully in our sleep, some of us not so gently. For some of us, death will be the climax of prolonged suffering.

Many people, and some states, have decided it does not have to be that way – that competent, terminally ill individuals in pain should have the choice to end their life on their own terms, with the aid of lethal drugs prescribed by a physician.

Legislation was introduced this past session to make that a right in New York.

But the bills died in committee.

This issue demands a public debate, not legislative silence.

We realize this is not an easy discussion. It conjures frightening prospects – of greedy heirs pressuring patients to stop running down their inheritance on medical bills; of a devaluation of the lives of the elderly, sick, or disabled; of a societal message that suicide is an easy answer to any suffering; or a slippery slope toward involuntary euthanasia.

Yet as some states – Oregon, Vermont and Washington – have shown, it's possible to write well-crafted laws that take into account these serious concerns. They can require that the person be terminally ill, with six months or less to live; suffering, in the judgement of one or more physicians; competent and able to make an informed decision; and able to administer the medication – typically, a lethal dose of barbiturates – by themselves. A second physician can be required to review the case, and the request could also require disinterested witnesses – not the physician, family members, or staff of the health care facility the person is in. Among the physicians' responsibilities would be to insure that, in their best judgement, the patient is not being coerced.

Oregon's law has been in place since 1997, and to date, studies have found no evidence of abuse or coercion.

Though New York lawmakers may prefer to dodge this issue by burying bills in committee, it isn't going away.

Besides the states that have already passed thoughtful aid-in-dying laws, 20 other states are looking at the issue legislatively. And in two states so far – Montana and New Mexico – advocates have successfully pressed the issue in court (although the latter has appealed the ruling).

The fact is, we already allow people to make the choice to end their lives, and in far less pleasant ways. People can refuse life-prolonging treatment. They can stop eating and taking fluids. They can write an advance directive not to be resuscitated or to have extraordinary measures taken to keep them alive should they fall into a coma, become brain dead, or otherwise become unable to voice that wish.

Many opponents of aid-in-dying legislation support those clearly life-ending acts.

We recognize that some people and religions view suicide as a sin, and suffering as a path to an affirmation of faith.

They're entitled to that view. But such spiritual beliefs are far from universal. They should not be used to hinder intelligent, compassionate laws that respect the right of suffering people, should they choose, to choose to die peacefully, with dignity, on their own terms.

SERVING THE HUDSON VALLEY AND THE CATSKILLS

TIMES HERALD-RECORD

Editorial: Keep talks going about aid-in-dying

May 12, 2016

When state Sen. John Bonacic of Mount Hope introduced a bill that would legalize physician-assisted suicide in the state, he said he wanted to ensure that New Yorkers had a thorough conversation about the issue.

The support of a conservative Republican was important because many of his Senate colleagues have said that they do not share his opinion on this issue and many opponents outside the Legislature dismiss the idea out of hand.

This week, sponsors of the bill in the Assembly announced that they have settled on a unified measure with the Senate, allowing that important conversation to go on. And for those who are either already in favor of the idea or open to discussing it and raising specific concerns, the conversation is important.

As explained by Amy Paulin, a Democrat from Westchester who is the lead sponsor in the Assembly, the combined bill includes several clarifying details. It would require two doctors, one who is treating the person and another for a second opinion, to approve the prescription of the drug. The person making the request would have to be diagnosed with a terminal illness with death expected within six months. And there are additional safeguards to verify that the person has the mental capacity to make such a request.

Similar legislation has been approved in five states — California, Montana, Oregon, Vermont and Washington. Although the laws vary, most have similar details and sponsors said much of the language in the proposed New York law is based on the original one in Oregon, which has been in effect for almost two decades. Proponents have noted that there have been no reports of abuses in that time in Oregon.

The conversation, for those willing to engage in it, really is “all about how a terminally ill person lives their final days,'' according to Corinne Carey, New York director for Compassion & Choices. The bill’s supporters also point out that terminally ill patients who are on various forms of life support, whether than means a feeding tube, ventilator or medication, already have the right in New York to end that care and end their lives if that is their wish. They stress that the bill now being proposed would extend that right to those who also are terminally ill but are not on any medication or device that they can discontinue. They are, in fact, condemned to suffer with no legal recourse.

None of this makes for an easy conversation. But it seems apparent that many New Yorkers have already had this talk and they have reached the conclusion that the rights embodied in this legislation should become part of state law.

As Bonacic and the Assembly sponsor said when they started the conversation, “New Yorkers strongly support empowering terminally-ill, mentally competent patients to control their own death. A 2015 poll found that 77 percent of all New Yorkers support aid in dying, including 75 percent of Catholics, 72 percent of Republicans, 67 percent of self-identified Conservatives and 78 percent of New Yorkers upstate.”

At this point the conversation needs to concern the details of the legislation, not the need for it.

Newsday

Right to die is tricky

January 27, 2016 Anne Michaud, Interactive Editor, Newsday Opinion.

Youssef Cohen is an associate professor of political science at New York University. He is 68 years old, and has a deadly form of cancer: mesothelioma.

He has been combating the cancer for nearly four years, with chemotherapy, surgery and radiation. Recently, he enrolled in a trial of a new therapy at Memorial Sloan Kettering Cancer Center. Cohen hasn’t given up on life, but he has one request: the option, when hope is exhausted, to choose a death without agony.

“I don’t think I’m afraid of dying; I’ve accepted that,” Cohen said in an interview. “But I have a lot of fear. I wake up in the night, and the fear is the fear of dying in agony unnecessarily.”

Cohen works to control his fear with humor and laughter, but he dreads no longer being able to swallow, to breathe or to numb the pain. He is speaking out in support of New York State passing a death-with-dignity bill, which is the law in four states. The state laws allow a terminally ill adult who is mentally sound to request life-ending medication that can be self-administered.

“If I had that choice, I would be less afraid,” Cohen says.

Listening to this brave, hopeful man who has lived on three continents and written three books, I want him to have that choice. He was raised in a Jewish home but isn’t particularly religious. I was raised in a Catholic home and am not particularly religious. I don’t know what I would do in his situation.

The Medical Society of the State of New York, the Catholic Church and the disability rights group Not Dead Yet oppose physician assistance in dying. They argue that it promotes suicide for people considered no longer useful or a burden to society. They say there are sufficient medicines to ease suffering at the end of life.

However, physician help in dying is gaining traction with the public. In September, a poll by Eagle Point Strategies found that 77 percent of New York voters said they support access to assisted suicide. Two advocacy organizations — End of Life Choices New York and Compassion & Choices — are lobbying in Albany and gathering grass roots support. Oregon has had an assisted suicide law for 18 years, and California passed a similar law in October.

California acted after the high-profile advocacy of 29-year-old Brittany Maynard, who moved from California to Oregon to access medical aid in dying after a terminal diagnosis of brain cancer. Maynard decided to end her own life on Nov. 1, 2014. Her case, youth, and courage gave a new face to the aid-in-dying debate, and her online video explaining her decision held the interest of audiences around the world. Oregon’s law gave her the option of autonomy and self-determination to the end.

Dr. David S. Pratt is an Albany-area palliative care specialist whose position on aid in dying has changed over his 15 years of practice in pulmonary medicine. Some patients if his intensive care unit were on ventilators, weren’t strong enough to live without them and hadn’t made provisions to prohibit their use. The patients had arrived at the emergency room blue and breathless, he said, and “in some sense, they were stuck.”

Another two of Pratt’s patients ended their lives violently, with devastating effect on their families. These cases persuaded Pratt that there are insufficient compassionate tools for patients who wish to stop suffering.

Cohen has watched friends decline, including one with pancreatic cancer who didn’t want aid in dying. “That’s OK with me, it was his choice,” he said. “But I wouldn’t choose it.”

We must add options for people like Cohen.

Right to die is right

Scarsdale Inquirer Editorial

April 29, 2016

People are different. That where we're going to start and that's where we'll end.

Democratic Assemblywoman Amy Paulin, a Scarsdale resident, is the current face of a bill in the state legislature called the Patient Self-Determination Act, more commonly referred to as right to die. If it becomes law, a terminally ill patient mentally capable of making health care decisions – with two doctors in agreement he or she has six months or fewer to live – can ask a doctor to prescribe a lethal does of medication the patient would self-administer at any time thereafter.

This is a good idea, and the Legislature and Gov. Andrew Cuomo should make sure it becomes New York law.

Now maybe you don't agree with me. Maybe you realize doctors are human and, like the rest of us, make mistakes, even when it comes to terminal diagnoses.

Maybe you think passage of this bill will lead to less research and development of rare forms of cancer and the diseases for which advocates are already fighting to receive money and attention.

Perhaps you think the already greedy, callous, corrupt insurance industry will be greedier, more callous and more corrupt if those companies know certain terminally ill patients have the option to end their lives with some degree of dignity and a lesser degree of suffering.

It's possible you're a disabled person or love someone who is. Under those circumstances, maybe you're against the bill because, even though it doesn't apply to the disabled, you feel it diminishes them by the suggestion there are people with an irreversible condition for which a medically facilitated death is a palatable option.

Maybe you realize this bill, if it becomes law, will likely be most available to those who already have the best health insurance plans at their disposal. You may wonder if the economically disadvantaged – already often scrambling for affordable, effective health care – will be able to avail themselves of the bill's provisions.

You might be someone who says wait, let's do something to fix the hospice system in this state and around the country, and you might be correct in that belief, but patients choose to end their terminal illness every day by taking themselves off ventilators, medication and even food to hasten their eventual release from suffering and it's perfectly legal. I might say it's better and more humane to take medication prescribed by a doctor for the express purpose of ending a terminally ill person's suffering than that person starving to death in a race against his or her disease. You might disagree.

You might be worried this bill, if made law, would bring undue attention to the already far too many suicides we endure as driven by any of a host of pre-existing circumstances.

Maybe you're a devotee of any of a number of religions that say suicide – if that's how you choose to view voluntarily ending an ending life – is morally wrong, sinful even.

Or, maybe you're more aligned with terrestrial law, which bars suicide, the act of which is usually driven by depression and is often achieved through violence.

Maybe one of the above is your reason for wanting to keep the Patient Self-Determination Act from becoming the law of New York State. If that's the case, you're absolutely right; every one of these reasons is a sufficient one for why you should never and would never avail yourself of the provisions of the bill.

But not one of them, nor any other, is an affirmative argument for why I, or anyone else, can't and shouldn't take advantage of right to die should it become a legal option.

Your ability to govern – or even opine on – what should happen inside a person's body is limited to your molecular structure and ends where it meets the air around you.

I would never presume to tell you how you must die, and I know with absolute certitude I'm not smart enough to determine whether something like right to die legislation is suitable for any other person. But when my time comes I do know I want that choice; I want to be able to have a hand in the method and manner in which I cease to be, and I don't think there's a thing wrong with that.

But you might, and so you should be free to make another decision. For you. And no one else.

When it comes to something as universal as death, it's essential we have as many options available to us as possible.

Because people are different. That's how we started, and that's how we all will end.

- J

The Daily Star

Oneonta, New York

In Our Opinion: Doctor-assisted suicide bill must be passed

October 20, 2016

Imagine waking up each morning only to face yet another day ... and night of unremitting, intense pain, mitigated only occasionally by powerful drugs that knock you out or put you into a fitful stupor.

There is no chance for a cure or improvement in your condition, which may require you to have tubes emanating from various parts of your face and body hooked up to a contraption in a hospital or nursing facility.

Your family and friends can only watch helplessly as you deteriorate. They share your suffering and have this image of you ingrained in their minds when you would much prefer they remember you from when you were robust and your mind was alert.

Day after day, night after night, you are living in a hell worse than anything Dante ever imagined.

You consider death to be a part of life, and you pray for it every lucid moment of every day. You want to be able to say goodbye to your loved ones and pass from this world with dignity under the supervision of a doctor.

But if you live here in New York state, you don’t have that choice.

You must continue to suffer.

That’s because unlike five other states, New York has yet to pass a “death with dignity” statute.

A national Gallup poll last year showed 70 percent of respondents believe doctors ought to be allowed to assist in the death of patients suffering from incurable illnesses if they or their families request getting a lethal dose of drugs.

Obviously, the vast majority of Americans desire that choice, so why can’t New Yorkers have it?

For starters, the Legislature would have to amend a section of the state criminal code that makes it a criminal offense for doctors to assist in the death of a patient.

“Overwhelmingly, the public is in favor of this, and now it’s just a matter of getting the Legislature to see that is the case,” said Laurie Leonard, director of the End of Life Choices New York, an advocacy group.

But standing in the way are a coalition of advocates for the disabled and elderly and the New York Catholic Conference, representing Catholic bishops. The Church is still a powerful force in state politics.

We respect and understand the religious aspects of opposition to the legislation, but the concept of a separation of church and state is a foundation of American government.

If Catholics or members of any other religious group do not want to employ the “death with dignity” option, no one would be forcing them to do so. But citizens of other faiths, those with no religion and even other Catholics should not be required to endure physical and mental torment because of an interpretation of Scripture.

There are well-meaning, legitimate concerns regarding doctor-assisted suicide, including whether elderly people will be pressured by heirs who don’t want their inheritances drained by long hospital stays.

But the author of a bill that advanced this year before being stymied, Assemblywoman Amy Paulin, D-Scarsdale, said the measure has built-in safeguards to prevent abuse.

The legislation requires that before a patient can hasten his or her death, approval is needed from two doctors, as well as a diagnosis that the person has fewer than six months to live.

“This,” Paulin said, “is about a personal choice.”

Yes, it is.

It is important that each person in New York state have that choice. We recommend that you contact your state representatives in the Assembly and Senate, along with Gov. Andrew Cuomo, and tell them that.

BIBLIOGRAPHY

1. Aid in Dying: History & Background for Students, Activists and Professionals. Compassion & Choices, Denver, CO.
2. Battin, Margaret, et al. “Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning impact on patients in “vulnerable” groups.” *Journal of Medical Ethics*, 33: 591-597.
3. Battin, Margaret. “Terminal Sedation: Pulling the Sheet Over Our Eyes.” *Hastings Center Report*, September-October 2208, pp 27-30.
4. Coombs Lee, Barbara. “Oregon’s experience with aid in dying: findings from the death with dignity laboratory.” *Annals of the New York Academy of Sciences*, July 2014, pp 1-7.
5. Coombs Lee, Barbara; Aid in Dying: Law & Experience. Compassion & Choices, 2012.
6. Death with Dignity Act Annual Reports; Oregon Health Authority. Available online at: https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx.
7. Emanuel EJ et al. “Attitudes and practices of U.S. oncologists regarding euthanasia and physician-assisted suicide.” *Annals of Internal Medicine.* 2000;133 527- 532
8. Emanuel EJ et al. “Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public.” *Lancet.* 1996;347 1805- 1810
9. Emanuel, EJ, et al. “Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers,” *Journal of the American Medical Association* 284 (2000): 2460-8.
10. Ganzini, L, et al. “Mental health outcomes of family member of Oregonians who request physician aid in dying.” *Journal of Pain and Symptom Management*. Sept 2009
11. Ganzini, L, et al. “Experiences of Oregon Nurses and Social Workers with Hospice Patients Who Requested Assistance with Suicide.” *New England Journal of Medicine*, August 22, 2002, pp 582-588.
12. Ganzini, L. “Oregonians' Reasons for Requesting Physician Aid in Dying.” *Archives of Internal Medicine.* 2009; 169(5): pp 489-492.
13. Ganzini, L, et al. “Physicians’ Experiences with the Oregon Death with Dignity Act.” *New England Journal of Medicine*, 2000, pp 557-563.
14. Ganzini & Dobcha. “Clarifying Distinctions between contemplating and completing physician-assisted suicide.” *Journal of Clinical Ethics*, Summer 2004.
15. Lee, MA, et al. “Legalizing assisted suicide—views of physicians in Oregon.” *New England Journal of Medicine* 1996;334 310- 315
16. Logger, ET et al. “Implementing a Death with Dignity Program at a Comprehensive Cancer Center.” *New England Journal of Medicine* April 11 2013; 368. pp 1417-1424.
17. Meier, Diane E., et al. “Characteristics of Patients Requesting and Receiving Physician-Assisted Death.” *Archives of Internal Medicine*, 2003; 163 (13), pp 1537-1542.
18. Meier, Diane E., et al. “A national survey of physician-assisted suicide and euthanasia in the United States.” *New England Journal of Medicine.* 1998;338 1193- 1201
19. Smith, KA. et al. “Quality of Death and Dying in Patients who Request Physician-Assisted Death.” *Journal of Palliative Medicine*, Vol. 14, # 1, 2011; pp 445-450.
20. Tolle, Susan W. et al., “Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide,” *Journal of Clinical Ethics*, Summer 2004.

21. General Accounting Office; End of Life Care: Key Components Provided by Programs in Four States. Report to Honorable Ron Wyden, U.S. Senate. GAO-08-66; December 2007.