

MEDICAL AID IN DYING – THE RIGHT TO DIE WITH DIGNITY

Richard S. Gilbert – Interfaith Impact of New York State – 2016 - A Background Paper
(IINYS has not taken an official position, but presents this background paper for your information)

There is a Jewish story from the last century in which a tourist from the United States visited the famous Polish rabbi Hafez Hayyim. He was astonished to see that the rabbi's home was only a simple room filled with books. The only furniture was a table and a bench.

"Rabbi, where is your furniture?" asked the tourist.

"Where is yours?" replied Hafez.

"Mine? But I'm only a visitor here."

"So am I," said the rabbi.

What then do you wish to be doing when you are found by death? I, for my part, would wish to be found doing something which belongs to a man, beneficent, suitable to the general interest, noble. But if I cannot be found doing things so great, I would be found doing at least that which I cannot be hindered from doing, that which is permitted me to do: correcting myself, laboring at tranquility of mind, rendering to the relations of life their due. Epictetus

A BRIEF HISTORY OF AID IN DYING

The words of the stoic Epictetus properly frame the question concerning the right to die with dignity. History is replete with dramatic scenarios of human death. There was Socrates drinking the hemlock in the company of good friends. It was the custom on the island of Cos, the birth place of Hippocrates, where very old people who were ready to die might gather annually as if for a banquet, and leave the world by drinking together a fatal potion. The elderly Eskimo who, when feeling a drain on scant family resources, chooses to meet his/her maker on a barren ice flow. Native Americans had a similar ritual with a remote hilltop replacing the barren ice flow.

All people are sentenced to die; the only really important questions about death are when and how and who will make the decision. The when is a matter over which there is some limited control. "How?" is a question for which human beings might like to have some choices in answering. Clergy are familiar with a common scene when visiting the old and terminally ill – often they hear a pleading - "I want to die; I am ready; make them let me die." The who is important as we are sometimes unable to make decisions for ourselves at life's end, and even if we have the ability to do so the government may not let us. Everyone wants a dignified death.

There are many poignant, dramatic, not to say controversial, examples of death which are important historical markers in contemporary discussion of euthanasia.

Dr. Arthur E. Morgan, former President of Antioch College and first chairman of the Tennessee Valley Authority, wrote the following account of the last few months of his wife of sixty years. She was "blind and unable to hear well enough to understand and unable to speak so that she can be understood. I have few ways of communicating with her. I think she is now just enduring existence. The other day when I was there at meal time, I found her trying to refuse food, but with the nurses prying her mouth open with a spoon to force her to eat. When I took the matter up with the directress of the nursing home, she said it was a rule to keep everyone alive as long as possible. I protested forced feedings and told her that Mrs. Morgan should be allowed to die if she wished. She said, "Should we not allow God to decide that?"

Karen Quinlan existed for many months in a respirator with no hope for recovery. Despite the pleadings of her parents, the approval of her priest, one judge refused to permit the respirator to be removed, declaring such a decision was a medical one, thereby supporting her doctors who did not want to terminate treatment.

Subsequently, that determination was overruled and her father was declared her legal guardian, paving the way for cessation of treatment and ultimately, after many months, her death.

In Rochester, New York, two incidents bear upon the issue. Dr. John Krai (76) was charged with murder when he injected life-ending drugs in one of his patients, Frederick C. Wagner. A nurse in the nursing home where this was done observed the procedure and informed authorities who charged Krai. The deceased, a long-time patient and friend of Dr. Krai, was suffering from Alzheimer's disease and in a deteriorating condition. The District Attorney termed Dr. Krai's action "mercy killing." Wagner's family voiced support for the physician's actions. Mr. Wagner had evidently wanted to die and trusted Dr. Krai to aid his dying. Before the case played out, Dr. Krai committed suicide in his garage.

In the second instance, Dr. Timothy Quill's article in the *New England Journal of Medicine* plunged the community into a debate on what was then, but no longer accurately is termed, physician-assisted suicide. Dr. Quill, a well-known physician at the University of Rochester's Strong Memorial Hospital, wanted to confront the public with the hard issue of terminal suffering. In his article for the *Journal* he described his treatment of a patient whom he referred to only as Diane. In very personal terms he told how this woman of 45, a long-time patient, refused treatment for leukemia which had a one-in-four chance of success. Together they examined the alternatives available to her and discussed them with her family. She had been previously treated for alcoholism, depression and vaginal cancer.

Diane determined she would rather take her own life than submit to what might prove to be not only a painful, but futile treatment. Dr. Quill and her family both urged her to consider treatment, but she was adamant. They respected her wishes; Dr. Quill provided her barbiturates with instructions on how to use them for sleeplessness, and how to use them to take her life.

She spent the next weeks saying goodbye to her friends, her doctor and her family. Then she asked her husband and college-age son to give her some privacy, took the fatal dosage and died peacefully on her living-room couch. Editorial pages were filled with letters, both praising his courage and condemning him for "playing God." A Christian anti-abortion group called for his arrest and boycotted Genesee Hospital, where he then practiced medicine. The case against him was ultimately dismissed by the Grand Jury and he continues to practice medicine, and until recently, as head of palliative care at the University of Rochester Medical Center. (He has written several books of medical aid-in-dying, including *Caring for Patients at the End of Life: Facing an Uncertain Future Together* (2001), *A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life* (1996) and *Death and Dignity: Making Choices and Taking Charge* (1993)). Quill challenged the New York law on constitutional grounds (*Vacco v. Quill*), but the U.S. Supreme Court rejected his case in 1997 on grounds it could not find a federal constitutional right for aid-in-dying. However, it invited the states to grapple with the issue, while leaving the door open to a future challenge, as there had been no open practice of again what was then called physician assisted suicide in the US, and so the court had some legitimate concerns.

The case of Dr. Quill differs markedly from that of Janet Adkins. Janet, a 54-year-old wife and mother, a member of the Portland Unitarian Church, was diagnosed with Alzheimer's. She was horrified at the prospect of diminished faculties, and resolved to end her life before the symptoms became more serious. She died by her own hand through use of the so-called "suicide machine" of Dr. Jack Kevorkian, whom she had never met until the day before she died. Kevorkian was a controversial advocate of active euthanasia. He assisted, directly and indirectly, in a number of physician aid-in-dying situations and finally was imprisoned for doing so. His practice differed dramatically from that of Dr. Quill in that the latter had an ongoing relationship with his patients while Kevorkian did not, and his methods were obviously far different.

The case of Brittany Maynard has riveted popular attention of the right-to-die movement and public policy. Ms. Maynard, an attractive young mother of 29, lived in California and was diagnosed with terminal brain

cancer. At the time there was no medical aid-in-dying protection in the state. She moved to Oregon so she could choose to end her life under that state's law. When videos of her case were posted on YouTube, she became the face of the movement. She died peacefully in November of 2014 after taking prescribed barbiturates at her home in Portland.

The issue is resurfacing in New York State. A 1994 report of Gov. Mario Cuomo's Task Force on Life and the Law recommended against "physician-assisted-suicide" in 1994, "largely out of a concern over the undue pressure that such a law might put on the poor and uninsured in a fragmented health-care system that wasn't doing enough to treat pain and depression." (*New York Daily News*, February 17, 2015).

However, as the author of that article Bill Hammond points out, there is now "better awareness of depression, improved pain treatment and wider availability of hospice care." It should also be noted that states which have approved medical-aid-in dying, Oregon 18 years ago, have not seen any of the dire predictions of opponents materialize in any way. Nonetheless, groups have organized to oppose the legislation introduced in the New York State Legislature in 2015: Not Dead Yet and the Patient Rights Action Fund are representatives from the disability rights community. However, another disability rights group, the Disability Rights Legal Center, supports medical and in dying and has taken the matter to court (see below).

Clearly, the issue has been a controversial one for decades though the medical aid-in-dying movement has made some policy gains. The Supreme Court of Canada ruled unanimously that individuals have a right to medical aid-in dying by striking down a century-old provision of their constitution banning the practice. A court in Montana has protected the practice, and a decision is pending in the and New Mexico Supreme Court. Washington and Oregon have laws pursuant to ballot initiatives and Vermont, and most recently California, have enacted physician aid-in-dying legislation. The California End of Life Option Act stipulates that physicians can prescribe a life-ending dose of drugs (presumably barbiturates) after patients go through a three-part procedure: they must be physically capable of taking the medication themselves; two doctors must approve it; they must present two oral requests (15 days apart) to an attending physician, as well as one written request, which has to be signed in front of two witnesses who declare the patient *compos mentis*.

Legislation is pending in numerous states. It is anticipated that several similar bills will be introduced in the 2016 legislative session.

WHAT ARE THE MORAL ISSUES?

Terminology: While "physician-assisted-suicide" is the term most often used by the media and in public discourse, the preferred term is "medical aid-in-dying" or just "aid in dying." The former term is emotionally laden, while the latter is more objective. Suicides are committed by those who can continue to live but choose not to do so; are done in isolation, often impulsively and violently, and are tragic. Medical aid-in-dying is the opposite: persons have terminal illnesses and want to live; decisions are made voluntarily in consultation with physician and family; dying is done in a supportive community in which the person is surrounded by love.

One: Will we control our technology or be controlled by it? The issues are many and complex. We are facing what some have called "the tyranny of technology;" that is, persons who previously would have died natural deaths now can have their lives prolonged by medical technology. This is a mixed blessing - it provides hope and life for many, but also condemns others to enduring meaningless existence by making them "artifact humans." "In plain truth," one doctor said, "the effect of medical technology has outstripped the quality of the professional conscience which guides it."

Can we do responsibly everything we can do technically? Ought we to do everything we are technically capable of doing? We come then to the moral question of euthanasia - the deliberate withholding of therapeutic medicines and procedures, or, in rare cases, the administration of lethal drugs. The former is passive, the latter is active, or negative and positive euthanasia - one letting the patient die without using extraordinary means; the other actively intervening to accelerate the dying process.

People of the Western tradition have become so confident in their capacity to control nature there seems to be abroad a "desperate defiance of death." People have been shielded from death as it has been moved from home to hospital. The result is often a kind of "medicated survival." Intervention seems to be the default mode of American medical practice instead of intelligent use of medical technology to relieve suffering.

We ought not be victims to what has been called the "tyranny of technology" – to use every available tool when that often means to prolong suffering.

Two: Reverence for Life: Certainly, a central moral injunction of the Jewish, Christian, humanist and other religious traditions is "thou shalt not kill" which affirms the sanctity of life. Yet it is strange to hear moralists condemn euthanasia with this argument and yet also affirm a "just war" position which justifies taking hundreds of thousands of lives.

The late Charles Francis Potter, Unitarian minister and founder of the Euthanasia Society of America, wrote: "It seems that if the killing is done wholesale and in anger and bitter hate, the Ten Commandments can be set aside, but when come to an individual case, and the killing is done in mercy, to release a sufferer from intolerable agony, then the Ten Commandments are suddenly in force again. Perhaps the time has come to forget Moses and listen to the words of Jesus, 'Blessed are the merciful.'"

The concept of reverence for life draws the distinction between the sanctity of biological life and the quality of human life. The legal and medical definitions of life are important and necessary, but tend to stress biological existence more than human meaning. The so-called "right to life" does not refer so much to biological existence as to the quality of human living. Life is more qualitative than quantitative. There is no inherent virtue in longevity and no inherent meaning in what the Roman Catholic tradition calls "the mystical beauty of pain." Life has to do with the capacity to feel human emotions, to know what is happening around us, to relate to nature and our companions and to create something out of our lives that has not been before. Sometimes the greatest reverence for life is to end human suffering and the anguish of those who love the dying.

This can be more graphically put: "The process of dying may be likened to opening a Chinese puzzle in which each of three boxes is enclosed in a larger one. During dying, each outer box is removed in turn, revealing another box, smaller but far more basic to the biological viability of the human organism. Outermost is the most obvious box which represents man's social life. It is made up of human behavior and interpersonal relationships. Being outermost, it is - also most vulnerable to attack and destruction by disease, usually early in its course. After a social death, the diseased person retreats from the world at large into an ever narrowing circle of people. Inside the outer box and intimately related to it is the box symbolizing man's intellectual life, the single feature of his being that best sets him apart from beast. Vital to the intellectual life are consciousness and rational interaction with the environment. Once the dying process has claimed the middle box of the mind, though, there remains just the innermost box of biological life, life that is not uniquely human because it shares its features with all protoplasm." We believe it is a mistake to focus primarily on the inner one.

"The body should be the temple of the soul and not its prison."

Three: Self-determination/Freedom: We affirm human self-determination - the basic right of a person to choose his or her own destiny except as it compromises the destinies of others. In current medical practice

and care, this value is often negated. Doctors are frequently asked by patients to let them die or cause them to die; some doctors do quietly acquiesce; many others will not both for fear of the law and by virtue of their own medical ethics which urges the preservation of life.

Yet who is to decide for another human being that they are to be condemned to endless suffering, or to painless but drugged existence, or that their family may be plunged into emotionally and financial ruin? If our moral imperative is not just to live but to live well, not just life, but the good life, who will presume to deny the patient of their wishes? That is reserved to each person in consultation with their medical provider and their family. That any religious group opposes medical-aid-in-dying does not give them the right to deny that freedom to those of a different religious faith who support it.

There are those who take matters into their own hands when medical providers will not cooperate in their dying. There is the dramatic story of the "suicide pact" of Professor and Mrs. Henry Van Dusen which illustrates the ultimate self-determination of persons. Van Dusen, a leading liberal theologian and leader in the Euthanasia Society, and his wife made a solemn commitment that when they determined life was not worth living, together they would end their lives. Their children were fully informed of this. Dr. Van Dusen had a stroke rendering communication and mobility virtually impossible and his wife had crippling arthritis. One evening they retired to their bedroom, as per agreement, and took lethal drugs. Mrs. Van Dusen died; Henry Van Dusen vomited the pills, but died several days later of heart failure.

In the letter they left behind, they wrote: " it is difficult to die. We feel that this way we are taking will become more and more usual and acceptable as the years pass. Of course, the thought of our children and our grandchildren makes us sad, but we still feel that this is the best way and the right way to go. We are both increasingly unwell and who would want to die in a nursing home? We are not afraid to die."

There is already a legal right to refuse treatment. Diane Rehm, notable National Public Radio talk show host, has shared the story of her husband's death. He was terminally ill with Parkinson's disease and was in misery, as was his wife. He begged to have medical aid in dying, but it was refused. Instead, he took matters into his own hands and starved himself to death. Ms. Rehm's account of those two weeks of unnecessary suffering has propelled her into being an advocate for the medical aid in dying movement. Dr. Timothy Quill cites the case of one patient whose bones were breaking from advanced cancer, and consciously stopped eating and drinking. "It took him about ten days to die. You have to be disciplined to do it," said Dr. Quill.

Fortunately, the Affordable Care Act through administrative means will provide reimbursement for doctor-patient conversations about end of life decisions. This decision is in the wake of the inaccurate talk of "death panels" which developed during debate on the ACA. Studies indicate that 80% of Americans say they want such conversation, while only 7% of seriously ill patients ever do.

We affirm the freedom of an individual to die in dignity with medical aid-in-dying legislation an option.

Four: The Meaning and Quality of Life: Roman Catholic teaching stresses the spiritual meaning of suffering while dying, "that the suffering of illness and dying is an opportunity for finding oneness with Christ. Suffering can be an instrument of redemption when we seek in faith to join our suffering to that of Jesus on the cross at Calvary." Euthanasia is considered a grave sin for both the patient and the doctor. "Catholics are not morally bound to prolong the dying process by using every medical treatment available. Allowing natural death to occur is not the same as killing. Some treatments may be considered "extraordinary" (as opposed to ordinary) and are not morally obligatory because the burdens and consequences are out of proportion to the beneficial results anticipated for a particular patient. These are considered morally optional treatments." In Catholic doctrine pain relievers can be administered even if they hasten death if the intent is to reduce pain, not hasten life. Timothy Cardinal Dolan of New York says

“If people want to talk about death with dignity (there are) magnificent services like hospice.... Assisted suicides devalue life.”

However, as the Albany *Times Union* writes in an editorial endorsement of right-to-die legislation: “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 die peacefully, with dignity, on their own terms.”

Various religious bodies have different views on what constitutes the meaning of life and how quality of life relates to simply longevity. See the Unitarian Universalist position at <http://www.uua.org/statements/right-die-dignity>.

We affirm that it is the quality of life, not the mere prolongation of biological life, that is decisive.

Four: Justice and Medical Triage: There is the question of justice, posed in this instance by the term, "medical triage." The cost of keeping a human being alive by extraordinary means is astronomical. Estimates of the total cost of all such measures to the whole society runs into the billions, though one cannot judge a person's worth in monetary terms. More personally put, "Assuming the average length of a patient's stay in the hospital is two weeks, a bed occupied by an unconscious patient for a year could have been used by 26 other patients, whose admission had been correspondingly delayed; prolonging the life of one may have resulted in loss of life to 26."

Medics in the First World War could not treat all the wounded. They had to leave those who were certain to die, to ignore those whose wounds were minor and would recover in any event, and treat those who could be saved. While it is sad that our society does not provide life-long care that can be afforded by all, it is nonetheless true that there are hard choices to be made. Medicare spends 28% of its budget on patients' last six months of life, and it has been estimated that up to 30% of these expenses have no meaningful impact – except, in many cases, to prolong and increase suffering.” (*The Christian Century*, August 5, 2015)

We affirm health care as a universal right of all people. However, we also affirm that individuals may choose medical aid-in-dying for justice reasons as well as for other reasons stated.

Five: The wedge or "slippery slope" moral argument. That is the fear that if we practice euthanasia, the moral climate will be so polluted no one will be safe. The logical outcome of this argument is that we will become another Nazi Germany practicing genocide. But to raise up the specter of Nazi Germany is ludicrous. The genocide practiced by Hitler was not based on the self-determination of the victims or their next of kin; it was a merciless extermination of people; dangerous to, or felt not fit for, the state.

We advocate medical aid in dying, supported by law which would maximize self-determination, the participation of the patient in determining his or her own fate. It would allow voluntary euthanasia both in its active and passive modes; in case of incompetence, a team of doctors, family and other specialists would be empowered to make decisions; it would free doctors from fear of prosecution; it would not coerce them to act against their conscience; it would establish safeguards; it would be a last resort; the burden of proof would be on ending life. That is not a slippery slope; quite the contrary. Euthanasia - the good death - might well turn our attention to the central imperative - expanding and enriching the quality of life.

Of course decisions would be difficult. There are no moral slide rules for calculating action. As people of faith we have affirmed the right to live in dignity, though our actions have not matched our affirmations. We understand death to be a part of the life process. We understand that sometimes it is friend not enemy.

We will affirm the right to die with dignity, the last right of a human being.

CURRENT SITUATION IN NEW YORK STATE

While this paper focuses on New York State, it should be noted that there has been movement at the federal level as well. Sen. Mark Warner (D-VA) and Johnny Isakson (R-GA) introduced the Care Planning Act of 2015, legislation which was designed to give people with serious illness the freedom to make more informed choices about their care, and the power to have those choices honored. Their bi-partisan legislation would further efforts to strengthen end-of-life care by developing quality measures, promoting public and provider education, addressing the decision-making for people with serious illness throughout the process, and including adherence and portability measures to ensure that patients' choices are honored.

In New York there are two major groups seeking medical aid-in-dying legislations: End of Life Choices New York www.endoflifechoicesnys.org and Compassion & Choices. www.compassionandchoices.org.

Compassion & Choice is backing legislation introduced in February 2015 by State Senator Diane Savino with co-sponsor Brad Hoylman (S.3685 the New York End of Life Options Act) and also sponsored by Assemblywoman Linda Rosenthal, (A.2129A) which would permit doctors to prescribe lethal drugs to terminally ill patients.

End of Life Choices New York began supporting legislative efforts for medical aid-in-dying in New York in 2015 with the introduction of A. 5261B and S. 5814 (sponsored by Assemblywoman Amy Paulin and Senator John Bonacic. These bills have majority bi-partisan support.

The bill likely to be introduced in 2017 is the Medical Aid in Dying Act – go to www.compassionandchoices.org.

There is currently a law suit (*Myers v. Schneiderman*) brought by three patients, four doctors, a nurse, the Disability Rights Legal Center and End of Life Choices New York challenging New York's current law under which a doctor can be prosecuted under the manslaughter statute for providing a fatal dose of medication which "intentionally causes or aids another person to commit suicide." The plaintiffs contend that doctors are already allowed to help terminally ill patients die in some circumstances as when they remove life support. They further argue that when they are forbidden to hasten death for other terminally ill patients it violates the due process and equal protection clauses of the State Constitution. It is not intended, for example, to help a love-sick teenager commit suicide, but to enable doctors to prescribe medicines to a mental competent, terminally ill patient, which the patient would have to self administer to achieve a peaceful death. One of the plaintiffs, Sara Myers, has ALS (Lou Gehrig's Disease), uses a wheelchair, her arms are paralyzed, her breathing and talking compromised and though she can still swallow, she has to be fed. She is not yet ready to ask for help in dying. "the line in the sand is constantly moving. Knowing you have a choice means you don't have to use it." The dismissal of the lawsuit is on appeal.

Q & A: Some Issues

Q: Will this legislation put pressure on vulnerable people – the aged, the several handicapped and the mentally incompetent to choose medical-aid-in-dying?

A: Studies in Oregon, for example, have shown that this is not the case. A higher percentage of people not in the vulnerable category choose this option. The profile for those who choose aid-in-dying is highly educated and economically secure. Aid-in-dying is rarely used – about one in three hundred deaths occur in this manner where the practice is legal and about one third of patients who obtain the medications do not take them. There is no evidence of disproportionate impact on vulnerable populations nor any evidence of coercion or abuse. About 90% of those who used medical aid-in-dying in Oregon are receiving hospice care; almost all have health insurance and most are college educated. Go to www.jmedethics.com "Legal

physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in “vulnerable” groups”

Q: Won't such legislation compromise the religious freedom of those who find medical-aid-in dying a sin?

A: No. The legislation proposed is purely voluntary. Everyone will be able to exercise their freedom of religion to make choices in accordance with it.

Q: How can I make my wishes for end of life care known?

A: Every citizen of New York State is encouraged to discuss end of life care with their doctor and their family. A wide range of options, including hospice, stopping or refusing treatment, pain and symptom management and palliative sedation, voluntarily stopping eating and drinking are available, but not yet medical-aid-in dying. People are encouraged to discuss this issues with their families, their medical providers and their religious advisors. For further information, go to www.compassionandchoices.org/information. For counseling go to End of Choices New York with clinical director Judith Schwartz, a PhD prepared nurse at 212-252-2015 or Judy@endoflifechoicesny.org. New York State offers MOLST (Medical Orders for Life-Sustaining Treatment). Go to MOLST New York.

A summary of positions taken by various religious groups can be found on the Interfaith Impact website www.interfaithimpactnys.org.

A power point program developed by Dr. Timothy Quill will soon be available at www.interfaithimpactnys.org.