A Good Death

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Nearly two hundred years ago, John Adams and Thomas Jefferson, the second and third presidents of the United States of America and long term colleagues, competitors, and correspondents, died on the same day, July 4, 1826. Both were old men, Adams was ninety and Jefferson was eighty three, and both were ill. Adams had been in comparatively robust health until just a few months before his death. Jefferson had been ill for an extended period. They had been rivals, perhaps enemies, for some time. Jefferson had defeated Adams in the 1800 presidential election. They had repaired their differences and had pursued an active correspondence with each other for many years prior to their deaths. On that final day, the fourth of July, the fiftieth anniversary of the signing of the Declaration of Independence, Adams died at his home in Quincy, Massachusetts, and Jefferson died at his home in Monticello, Virginia. Their deaths were separated by hundreds of miles and by many days travel.

The fact Adams and Jefferson died the same day has been taught to nearly all school children, but why or how they both died "that" day continues to be discussed, speculated and debated even today. Were their deaths coincidence; same day of year, same year, same significant date (July 4, Independence Day), same historic anniversary (50th anniversary

of the signing of the Declaration of Independence)? Was there divine intervention? Did they "allow" themselves to die? Laudanum was often used for pain control. It was available from the grocery store. Laudanum was carefully administered by the drop. Two to three teaspoons was a lethal dose. Both men had used it previously in their treatment. Did they "cause" themselves to die? The speculation raised by these historic deaths promote questions that are central today: disputes over withdrawing or withholding treatment, allowing one to die, the overuse of morphine, terminal sedation, physician-assisted- suicide and euthanasia. We will never know for sure what end of life decisions and choices were made by Adams and Jefferson, but one can only hope they died peacefully, with dignity and without undue suffering, "A Good Death."

A good death; a merciful ending; death with dignity; mercy killing; assisted suicide; physician- assisted- suicide; these terms and many others are commonly used in place of euthanasia. Euthanasia is defined as the deliberate killing or permitting the death of individuals who are hopelessly sick or injured with the intention of relieving their pain and suffering.

Euthanasia can be passive or active. Passive could mean the incurably ill patient refuses or withdraws from life sustaining medical

support. Passive euthanasia may also refer to cases in which a doctor prescribes pain killing drugs knowing that a permanently ill patient may choose to use them to overdose and die. Active euthanasia occurs when a person deliberately causes the death of a terminally ill individual. For instance when a person gives a dying person a lethal injection.

Euthanasia can also be voluntary or involuntary. The first is performed with the dying patient's consent and the second is performed without the patient's consent.

Advocates and critics of euthanasia have engaged in heated debates over the morality of this right of control for centuries. The central debate has always been about whether humans have the right to end a life that many believe is bestowed and only taken by God. However, Changes in social values, political institutions and modern medical technology have shifted the focus of the debate over time. Today, the mention of euthanasia or physician-assisted suicide is guaranteed to elicit a reaction from most people. Like abortion, capital punishment, and other issues related to the beginning or end of human life, end-of-life issues crop up in a variety of situations which we read about in the media or experience in everyday life. Although it is often assumed that contemporary perspectives are different

from those throughout history, it seems that the concept of euthanasia has always been the subject of debate. The difference today is that media coverage gives people and events relevant to the issue wider exposure.

During the early decades of the twentieth century, the euthanasia advocates believed that people suffering from intolerable physical and psychological pain should be allowed or helped to die for their own good. A 1937 poll showed that 46 percent of respondents favored physician-assisted suicide for terminally ill patients if the patient or their advocate requested it. However, euthanasia was still illegal and many people accused of assisting with suicide were prosecuted. Historian Ian Dowbiggin describes some of these cases.

> "The euthanasia movement received invaluable publicity from the frequent press reports of mercy-killing trials of the 1930's. These cases often featured desperate parents killing their handicapped children, or spouses putting their chronically-ill loved ones to death. Some defendants were acquitted, some given prison sentences, and others committed to mental hospitals, In most instances, there was no clear evidence that the victims had requested euthanasia formally.
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> In other instances, individuals wracked with pain begged to be put

out of their misery."

In 1938 the Euthanasia Society of America (ESA) was established in New York. Its goal was to make euthanasia legal in the United States. However, complicating the issue, its members also promoted the mass sterilization of prison inmates and the "mercy killing" of the mentally handicapped.

After World War II, news reached America of the horrific killings committed by the Nazis under the guise of euthanasia. The Nazi campaign, begun in 1934, aimed to produce a superior Aryan race by preventing the mentally handicapped from reproducing. It resulted in the forced sterilization of three to four hundred thousand people. In 1939 the sterilization program evolved into a more elaborate euthanasia program to kill the physically and mentally handicapped. From 1930 to 1945 the Nazis carried out a euthanasia campaign that killed more than two hundred thousand people, including children and the elderly. These horrific numbers are not part of the six million Jews exterminated by the Nazis during World WarII. The Nazi killings caused a decline in the promotion of euthanasia in the United States. By 1947 support for euthanasia had fallen from 46 percent in 1937 to only 37 percent.

The euthanasia campaign and the accompanying debate were renewed in the United States in the 1950s. The field of medicine was undergoing astonishing changes. Vaccines, antibiotics, medical equipment, and other inventions armed doctors with new tools to battle disease and prolong life. The newfound power of medicine to delay death led to some rethinking of religious objections. To many sick patients and their families, God was no longer the sole arbiter of death; human intervention could delay what in the past would have been immanently fatal. Doctors thus became "saviors" and "miracle workers" who could prolong life as well as help the suffering patients die.

The euthanasia movement was further strengthened by a statement made by Pope Pius XII in 1957 that made passive euthanasia acceptable to the Catholic Church. The pontiff announced that the Catholic Church condoned patient's refusal of extraordinary treatment when death was imminent and further medical treatment could only prolong agony. The church also allowed the use of painkillers that could threaten a patient's life, as long as they were not prescribed with the intention of ending life. For euthanasia proponents, the statement was a milestone. The church

had sanctioned the limited use of euthanasia. To again quote Ian Dowbiggin;

> "In a single stroke, the Pope helped to alter the terrain beneath the the entire debate over euthanasia, making a constructive dialogue possible among those concerned about medical care for the dying and ended the standoff between the Euthanasia Society of America and its opponents."

In the 1960s the debate over euthanasia gained momentum with the birth of the civil rights movement. Successes in the civil rights movement inspired students to press for other goals, to end of the Cold War, peace in Vietnam, and the abolition of the death penalty. This increased activism in the 1960s led to extended ideas that civil rights included the right to refuse medical treatment. In the early 70s I was privileged to attend an all day workshop led by Dr. Elizabeth Kubler Ross. The day was spent in small groups discussing the five stages of dying, which had been the subject of her best selling book, On Death and Dying. When the book was released in 1969, it sold more than a million copies and immediately brought national attention to the stages one experiences from an incurable illness or disease. Dr. Ross stated that "we live in a very peculiar, death-denying society," and her book was hailed as the "rediscovery of death." Before the late 60s, a terminal diagnosis often continued to focus on treatment and

cure, not necessarily on the patient's care. Doctors and caregivers were not sensitized to the emotional needs of dying people. It was the work of Kubler Ross that effectively changed the perspective of death from an approach of curing to one of caring. Her ideas and teachings regarding palliative care reflected her experiences in Europe and influenced end-of-life issues in the United States. In 1973 the American Hospital Association formulated a Patient's Bill of Rights, which included the right of the patients to be fully informed of the details of their medical treatment, as well as their right to decline treatment. This refusal of medical treatment was a form of passive euthanasia. Advocates of euthanasia viewed the Patient's Bill of Rights as a small triumph and pressed forward with their public campaign to legalize euthanasia.

In the 1970s supporters of the " Right to Die", began to use the term "Right to Die" to describe their belief that seriously ill or injured patients or their families should be allowed to discontinue life support when there is no hope of recovery. The 1976 case of Karen Ann Quinlan in New Jersey dramatically illustrated some of the issues involved in the crusade for the right to die. At the age of twenty-one, Karen fell into a coma after taking drugs and alcohol. Only a respirator and feeding tube kept her alive. Her

parents eventually concluded that she would never recover and asked the hospital to remove the respirator to allow her to die. The hospital, a large Catholic facility, refused the request, prompting a court case. In 1976 the New Jersey Supreme court finally ruled that the Quinlans had the right to have the respirator removed.

The Quinlan case was historic in that it marked the first time that a state supreme court ruled that the state has no right to force a person to remain on life-supporting devices. For supporters of euthanasia, the ruling in the Quinlan case, which established a legal precedent for passive euthanasia was a positive step toward their goal of legalizing a person's right to die.

This case was also important because it brought into focus the issue of the rights of an incompetent patient. It popularized the use of Living Wills, also known as advance directives, in which patients describe the medical treatment they would refuse if they become incompetent. Living Wills provide guidelines to families and the hospital staff about whether to withdraw life-prolonging treatment for the terminally ill. With evidence of an individual's wishes, a hospital, a doctor or a court can make decisions based on the patient"s choice. In 1976 California passed the nation's first

law sanctioning Living Wills. In the next decade, thirty six states enacted similar laws. Currently, the law has been enacted in all fifty states.

In the 1980s, advocates of euthanasia continued the debate and brought it before state voters. Their goal was to bring the matter to the American public and ask that action be taken through voter initiatives. This campaign was led by a British Journalist, Derek Humphrey. Humphrey had assisted in the suicide of his terminally ill wife in London in 1975. He later moved to California where he believed a campaign to legalize euthanasia would have its best chance of succeeding.

Humphrey and his second wife, Ann Wicket, established the Hemlock Society which in Humphrey's words, was "America's first group to fight exclusively to change the law on assisted suicide." Many states at this time considered assisted suicide to be murder or manslaughter. This made the Hemlock Society's goals very challenging. Three ballot initiatives to legalize voluntary euthanasia and physician-assisted suicide (two in California and one in Washington) were launched but all three failed. Although rejected by voters, the Hemlock Society's efforts played a major role in raising public awareness about the issue of euthanasia.

In the 1990s there was renewed focus on issues of active euthanasia and physician assisted suicide. The man most responsible for bringing these issues to the public's attention was Jack Kervorkian. a retired pathologist, best known as "Dr. Death." In the late 1980s and early 1990s, he assisted in the suicide of several people who came to him for help. On several occasions he appeared on television promoting and demonstrating a machine he had created that enabled a person to inject lethal drugs for the purpose of suicide. Due to his assistance in many suicides, Michigan suspended Kervorkian's medical license. After his suspension which denied his access to lethal prescription drugs, Kervorkian began using carbon monoxide to assist in the suicides. Making the headlines in many publications, Kervorkian claimed he had assisted 130-150 people to die. He had taped himself assisting Thomas Youk, who suffered from Lou Gehrig's Disease, in committing suicide. The tape was later broadcast on 60 Minutes, the CBS news show and became the pivotal piece of evidence that led to Kervorkian's 1998 conviction for murder by a Michigan court.

As we enter the twenty-first century, the age old debate concerning a person's right to die continues. There are convincing arguments on both sides of the debate. Increasingly, countries are relaxing or changing their

laws regarding this practice. In 2002 the Netherlands became the first country to officially legalize euthanasia with the passing of "The Termination of Life on Request and Assisted Suicide Act." For decades euthanasia had been widely accepted and practiced in the Netherlands, however, this act defined the legal requirements to be followed in such decisions. It is also worth noting, that currently, the Netherlands is considering passing a proposed "Completed Life Bill" which would allow any person seventy five or older, who decides their life is "complete," to be euthanized even if the person is otherwise healthy. Belgium (2008) and Luxembourg (2009), became the second and third countries to decriminalize assisted suicide. Passive euthanasia has also been legalized in Canada, Columbia, Germany, Switzerland, Japan, Albania, and the United States. It must be noted however, that the laws allowing or decriminalizing euthanasia are not necessarily universal in the entire countries listed. The law may only apply to certain provinces or states.

Euthanasia continues to be illegal in most of the United States, however physician-assisted-suicide is legal in Washington D.C.(2016), California (2015), Colorado (2016), Oregon (1994), Vermont (2013), Hawaii (2018), Washington (2008),Montana (2009), where its legality is disputed

and one county in New Mexico. While all states with legal physician-assisted-suicide have some differences in their respective guidelines and restrictions, they are quite similar. Some of the state guidelines are: Patient must be a resident of that state. They must be at least eighteen years of age. They must have a life expectancy of six months or less. Usually, three official requests to die must be made, two oral, fifteen days apart, and one written.

In 1998, grassroots proponents of physician-assisted-suicide in Michigan, attempted to emulate the success experienced in Oregon in 1994 and introduced Proposal B, which was modeled after the Oregon law. When put to the people, the proposal lost by a nearly three to one margin with seventy one percent of Michiganders voting against it. Currently, there is a bill in the house (HB 4461, section 18) that would allow Michigan to adopt a "Death With Dignity" law that would allow terminally ill people the right to choose a more humane way of dying. Michigan's proposed law states that terminating one's life under the law is not suicide. This bill was introduced by Democratic representatives Tom Cochran and Pam Faris, March 30, 2017, and was referred the the Committee on Health Policy. I have been unable to determine its current status.

Among American physicians, medical-aid-in-dying (MAID)/ physician-assisted-suicide (PAS), remains controversial but national data point to its increasing acceptance. A December, 2016 poll found 57 percent of doctors agreed that physician-assisted death should be available to the terminally ill. This is up from 54 percent in 2014 and 46 percent in 2010.

Perhaps this rising trend is not so surprising. What doctor would want to deny dying patients the option of ending their suffering and avoiding an agonizing, painful death? This question can be a bit encompassing. Many persons requesting physician assisted suicide are not actively experiencing extreme suffering or inadequate pain control. Data from the states of Washington and Oregon indicate that most patients choose to end their lives because they fear loss of dignity and control over their own situations. Many doctors guided by the Hippocratic Oath "do no harm to the patient," remain uneasy or conflicted by their involvement in helping to carryout their patient's last wishes.

You may recall that I shared earlier that support for euthanasia dropped severely following World War II to only 37 percent. Since that early Gallup poll the support for passive euthanasia has steadily increased. By 1973, 53 percent of Americans supported it. Since 1990, solid

majorities have expressed their support. A 2018 Gallup poll shows support for euthanasia at 72 percent. Gallup polls have shown people's views on this subject often differ based on their religious or political persuasions. Only 55 percent of weekly churchgoers support allowing a doctor to end a terminally ill patient's life upon request, whereas 87 percent of adults who rarely or never attend church say this should be allowed. About nine in ten "liberals," 89 percent, support euthanasia compared to 79 percent of "moderates" and 60 percent of "conservatives." Democrats and democratic leaners are at 81 percent support while Republicans and republican leaners are at 67 percent. Results based on gender are: Men,72 percent; women, 65 percent. Based on age: 18-29, 85 percent, 30-49,72 percent, 50-64, 67 percent, 65 and older, 65 percent.

And now, what can we do to insure our own "Good" Deaths?" Having a medical directive or living will allows one to specify choices regarding end-of-life issues and treatment. Having been given the right to make our wishes known, a 2017 survey indicated only 37 percent of American adults have advanced medical directives. People 65 or older were more likely to have completed any type of directive than those who were younger-46 percent of older people versus 32 percent of those who were younger.

Even more alarming, fewer than 50 percent of severely or terminally ill persons have an advanced directive in their medical records. Just 12 percent of patients with advanced directives received input from their physicians in its development. Sadly, between 65 and 76 percent of physicians of the patients who had advance directives, were not aware one existed.

So, what actions should we take? One: Make sure you have an up to date, signed and witnessed medical directive. Two: Talk to your family. Include each immediate family member. A clear discussion will eliminate possible discord when decisions must be made. Three: Make location(s) of your directive known to your family. Four: File and discuss your directive with your physician(s) and the local hospital.

Now-think about your adult children. Do they have directives? Do you know their choices? If they feel immortal, as young people do, say to them these two words,"Terri Schiavo." If they are unfamiliar with this young woman's tragedy, explain her fifteen years in a "persistent vegetative state." Tell of the horrible battle between her husband and her parents regarding her fate. Because there were no written wishes, opinions regarding her care differed. After years of hearings, fourteen appeals, five federal court

cases, political intervention from the Governor of Florida, Congress and President George W. Bush, as well as four denials to hear the case from the U.S. Supreme Court. FINALLY, after fifteen years, the federal court made the final choice.

Let's again consider the words of Thomas Jefferson. In a letter dated June 1, 1822, Jefferson wrote to John Adams describing the debilitation of their friend Charles Thomson, "It is at most but the life of a cabbage, surely not worth a wish. When all our faculties have left, or are leaving us, one by one, sight, hearing, memory, every avenue of pleasing sensation is closed, and althumy, debility and malaise left in their places, when the friends of our youth are all gone, and a generation is risen around us whom we know not, is death an evil?

> When one by one our ties are torn
> And friend from friend is snatched forlorn
> When man is left alone to mourn,
> Oh! then how sweet it is to die!
> When trembling limbs refuse their weight,
> And films slow gathering dim the sight,
> When clouds obscure the mental light,
> Tis nature's kindest boon to die.