My journey in the field of medical ethics has started in 1991. The major result of this journey is a book entitled: The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law, which was published in 2001 (Rutgers University Press). The journey began when I participated in a seminar conducted by Ronald Dworkin on “Abortion, Dementia, and Euthanasia” at Oxford University, England. At the time, he was writing Life’s Dominion, a book that was published in 1993 (Knopf). This was the most fascinating seminar I had ever attended. My research there took an unexpected twist and influenced my life and career in many ways, as I still commit some 30 percent of my research time to death, dying, and end of life issues.

I decided to title my book The Right to Die with Dignity. Dignity has many meanings. To have dignity means to look at oneself with self-respect, with some degree of satisfaction. Some of us, not all of us, would like to be able to determine the time of our death. We are born with no idea that we are about to come into this world and, in turn, some of us would like to decide the time in which we depart from this world. This is the argument that some people offer – that individuals should be allowed, whenever it is possible, to choose the time of their death.

Another issue I would like to discuss is the way that people die. Nowadays, many people die in hospitals, but that is not true in all countries throughout the world. In the Netherlands, many people die at home. This begs the question of whether we should die with the help of medical professionals or whether we should die with the help of our loved ones. It is a question of whether we can maintain our autonomy and self-respect at the end of life, without humiliation and without losing our honor and dignity.

We face a dilemma. Suppose there is a person who suffers great pain and wants to die. Those who believe life is intrinsically valuable object to taking life and to taking any action on the person’s desire because the end of life is something granted only to nature, and is not a decision that is incumbent on human beings. However, this objection ignores the autonomy of the agent’s concerns, because she might say: “I would like to die. I would rather die in these circumstances because I don’t feel that I am adding anything just by surviving.” Can life be intrinsically valuable independent of the interests of the individual? Does the state have the right to impose its will over the will of the individual? This is the dilemma we face.

I would like to introduce another notion that accompanies the notion of dignity— the notion of respect. The objections to the sanctity of life moral that speaks about a higher being or nature as the only agent entitled to take life is accompanied by a respect-for-others’ argument, derived from Immanuel Kant and the Kantian theological school which accords all people equal respect. Respect for a person means conceiving of the other as an end rather than as a means to something. As Kant explains, persons are not merely subjective ends whose existence has an effect on our actions, but such beings are objective ends; they exist as ends in themselves. An objective end, Kant maintains, is one for which there can be substituted no other end, for otherwise nothing of absolute value would be found anywhere.

We should give equal consideration to the interest of others and grant equal respect to a person’s life.

* Keynote presentation given by Raphael Cohen-Almagor, D.Phil., during “The Right to Die with Dignity: An Argument in Ethics and Law” lecture held during a symposium presented by the Health Law Project, Program on Law and Government, at American University Washington College of Law on January 30, 2008. Professor Cohen-Almagor is the Chair in Politics at the University of Hull in England and is currently a Fellow at the Woodrow Wilson International Center for Scholars in Washington, DC. He would like to thank Professor Corrine Parver for inviting him to speak on this important societal topic.
objects so long as they do not deliberately undermine the interests of others by interfering in a disrespectful manner. The popular culture of a democratic society is committed to seeking the influence of social cooperation that can be discerned on the basis of mutual respect between free and equal individuals. This line of reasoning should be supplemented by our emphasis on the notion of concern, which is seen as the value of well-being. We ought to show equal concern for each individual’s good, to acknowledge that human beings are not only rational creations but irrational, emotional creatures. Treating people with concern means treating them with empathy – viewing people as human beings who may be furious and frustrated while, at the same time, are capable of smiling and crying, of careful decision-making, and of impulsive reactions. Concern means giving equal weight to a person’s life and autonomy. This is a combination of mind, body, and communication between the agent and those around her bed.

In opposition to those who speak about the sanctity of life, there is another school of thought that emphasizes quality of life. Quality of life in many respects has positive connotations, for example in rehabilitation, in cosmetic treatments, in psychiatry, and in psychology. However, when discussing end-of-life issues, ethicists who support euthanasia and physician-assisted suicide (PAS), often refer to quality of life in a negative sense rather than in a positive sense; they do not seek to improve the patient’s life, but rather to end it because the individual’s quality of life is so poor. Quality of life considerations feature in end-of-life discussions, both in scholarly settings and in hospitals corridors.

I am a political scientist. I do not believe in pure philosophizing and being aloof from reality. Thus, after learning and studying what has been done in end-of-life care in the democratic world, I carried out fieldwork in hospitals and research centers. I should say that my conclusions are confined to the democratic world. I am not concerned with all countries around the world, not because I don’t think that what I am saying is inappropriate or irrelevant to the entire world, but simply because I am realistic. If a country is not founded on the notions of equality, liberty, pursuit of happiness, individuality, and autonomy, then it would be futile for me to speak about these values. I can speak endlessly, but it would not strike any chord.

An Examination of Various Countries’ End of Life Laws

In 1996, the Australian Northern Territory, comprised of mainly native Australian-indigenous people, enacted a law that allowed PAS in that province. For six months, this law was in operation, evoking a lot of criticism and debate in Australia at large. After six months, the national Senate of Australia decided to strike down and annul the law. During that period of time, a few people were put to death with PAS. For a short period of time, however, Australia’s law created an important precedent.

As background, euthanasia, according to the Dutch definition, is the deliberate ending of life by taking action, usually by injection, to the veins of the patient, in order to kill him or her. PAS gives the control to the patient rather than the doctor. The doctor prescribes a certain lethal medication that can be put into yogurt or pudding, and the patient can ingest the yogurt with the lethal medication and kill herself. The major difference between the two is that, with euthanasia the doctor is in control, but with PAS, the patient is in control.

In England, there is no law allowing either PAS or euthanasia. There had been a few precedents with people in persistent unawareness, people with conditions similar to that experienced by Terry Schiavo. Most recently in the United Kingdom, there was the case of Diane Pretty, a woman in her fifties who suffered from ALS (Lou Gehrig’s Disease), a degenerative disease which spreads from the limbs up, and eventually suffocates the patient. Unfortunately, this terrible illness is deadly and untreatable. Diane Pretty attempted to change the country’s laws so that she could end her own life with the help of a doctor, and her case went all the way to the House of Lords (Queen on the application of Dianne Pretty v. Director of Public Prosecutions and Secretary of State for the Home Department UKHL 61 (29 November 2001)) and later to the European Court of Human Rights, where it was ultimately unsuccessful. The European Court of Human Rights ruled that England could decide on these matters. At present, the position in England is that neither PAS nor euthanasia is permissible.

Most if not all 50 states in the United States had, at some point or another, initiatives to legislate end-of-life laws, either PAS or some sort of end-of-life mechanisms. All such laws, with the exception of one, have failed. There may be some further attempts in Maine, Vermont, and California, but only Oregon to date has enacted PAS legislation. Every year, Oregon publishes a very detailed report about the previous year. Since the legislation was enacted in 1997, the situation has been more than satisfactory. Oregon can serve as a model for other nations.

Canada does not have any laws on PAS or euthanasia. The most important precedent in the country took place in 1993, when Sue Rodriguez, another ALS patient
In 1994, I was invited to The Hastings Center in upstate New York, which is a great place for people interested in medical ethics. The Hastings Center is a relatively small institute with vast resources on medical ethics. For six weeks I read many journals and books about Dutch euthanasia. I was puzzled before I started; I was even more puzzled when I ended this seven-week-long research excursion.

The data about the Netherlands is quite clear. Since euthanasia is such an important issue, the country’s government decided to appoint a committee of top researchers in the fields of medicine, sociology, statistics, and research methodology to study all aspects of euthanasia. The committee gathered qualified physicians who interviewed practitioners of euthanasia. The lengthy questionnaire was comprised of 250 questions. In 1990, the Netherlands published the first extensive report. I commend the country’s government for taking this initiative. The data was clear, but the interpretations contradictory. As an academic, you learn that life is not black and white, but full of shades of gray and pink. In contrast, the interpretations of this report were disparately varied; some said the report and its findings show that the Netherlands was on the right track, presenting a model that more nations should follow, whereas others said the Netherlands served as a model to explain why euthanasia should never be permitted, advising other countries not to follow suit because the Dutch system was risky. As a researcher, I was baffled. Thus, in order to resolve this issue, I had to visit the Netherlands. At this point, my book was nearly finished, and its thrust was in favor of euthanasia.

I went to the Netherlands in 1999. Before arriving, I got in touch with the major figures in the Dutch euthanasia policy and practice. I contacted the person who wrote the law, the people who were part of that prestigious committee, the person in charge of medical ethics in the Dutch Ministry of Justice, the people who were heading the medical ethics departments in the Netherlands, scholars who wrote about euthanasia, and practitioners who practiced euthanasia. In total, I contacted 30 highly distinguished people who were very familiar with the topic, far more familiar than I was, as at that time I had been working on these issues for a mere eight years. Only one person, Dr. Chabot, explicitly declined my request for interview. He did, however, answer some questions in writing.

I went to the Netherlands as a supporter of euthanasia. After extensive research about death and euthanasia, however, I could no longer endorse euthanasia. Morally speaking, I can think of individual cases in which a person may ask and should receive euthanasia.
However, there is a fine line between ethics and policy, and when you are thinking as a policymaker, you must be very careful because peoples’ lives are affected by the practice of your policy decisions. In the Netherlands, I heard of abuse — lots of abuse — and, as a result, I had to change my view about the practice of euthanasia. At the same time, I do support PAS.

I have visited the Netherlands five times for follow-ups. My findings are included in many articles and in a book, *Euthanasia in the Netherlands*, published in 2004 (Springer-Kluwer), in which I gave a voice to the issues, and detailing all that I found in the Netherlands. Here, I will present the data that troubled me the most.

Both the Netherlands and Belgium have accepted the Dutch definition, namely: euthanasia is the taking of someone’s life by another upon her request. It follows, then, that euthanasia does not apply to incompetent people. If you are incompetent, if you cannot voice an opinion, if you are a minor, or if you are in a state of unawareness, euthanasia is inapplicable. It should not be practiced according to the Dutch medical guidelines, which were later translated into law. With regard to incompetent people, there is a different definition for termination of life. Stopping treatment conceived as “futile” is not euthanasia, and the term should not be used in these cases. What is sometimes termed indirect euthanasia, or the use of analgesics with the possible effect of shortening life, is also clearly distinguished from euthanasia. Euthanasia refers to using an injection in order to provide mercy killing; this principle must be very clear.

The Dutch attracted international criticism because of this practice. The Dutch government took it upon itself to issue comprehensive reports. As said earlier, the first euthanasia report was published in 1990; the following reports were published in 1995, 2001, with the last one in 2005.

The most worrying data in all the Dutch euthanasia reports from 1990 until the present is that, consistent within the Dutch culture for twenty years or so, 0.4 percent of deaths were the result of the use of lethal drugs, not at the explicit request of the patient. This means that lethal drugs were injected to patient although the patient did not clearly state: “I want to die.” This statement is now a prerequisite of the Dutch law and guidelines. The patient must sustain her wish to die, and express her desire to die over a period of time to provide evidence of her wishes. However in 0.4 percent of the cases, this did not happen. All published reports indicate that, every year, between 900 and 1,000 patients were put to death without clear volition to die.

According to the survey published in 2007, when life was ended without the explicit request of the patients, there had been previous discussions of the act or previous permission of the patient to perform the act in 60 percent of the patients, as compared with 26.5 percent in 2001. In 2005, the ending of life was not discussed with patients because they were unconscious (10.4 percent), or incompetent owing to young age (14.4 percent), or because of other factors (15.3 percent). Of all cases of the ending of life in 2005 without an explicit request by the patient, 80.9 percent had been discussed with relatives. That means that there was no evidence in writing, discussions with family substituted the need to discuss this important issue with the patient whose life was at stake, and unconscious patients were put to death although the law stipulates euthanasia is only for competent patients. In this context, one should further note that not all families are harmonious, especially when the patient is very ill and the possibility exists that there may be some ulterior motives.

One way to address this abuse is to advocate for PAS for all patients who are able to swallow the medication. In the Netherlands, however, there is a tradition in which the doctors administer the lethal drugs, and these doctors like to have control over the process. In both the Netherlands and Belgium, you find very few cases of PAS. What I suggest to both countries is to put this issue on public agenda, and speak to the public and the physicians about the findings and fear of abuse, and suggest PAS as a substitute for euthanasia. One thing that became clear to me when I spoke with doctors and physicians in both countries was that General Practitioners (GPs) have significant influence over their patients. In every case where the physician preferred euthanasia, his patients requested euthanasia. I met one doctor who did not like euthanasia, preferring PAS. Suddenly all his patients preferred PAS. The influence of doctors over their patients cannot be underestimated. We need to speak with doctors, to persuade them that the main consideration is not control: the issue is abuse, and this issue is far more important than having control over the process.

The last examination of euthanasia in the Netherlands shows that the number of cases has dropped. In 2005, 1.7 percent of all deaths in the Netherlands were the result of euthanasia, more than one-third less than the 3,500 cases in 2001. Only 113 cases were through PAS. Requests for euthanasia are most frequently from cancer patients, because cancer apparently is the most painful disease on earth. Furthermore, consistently since the 1990’s, most acts of euthanasia have been carried out by GPs. A worrying development is the rise in number of terminal sedation (or terminal palliation) cases. Further research should be conducted in this sphere to verify that end-of-life decisions are carefully reached, serving the best interests of the patients.

In September 2004, the first major study into the effects of Belgium’s new legislation permitting euthanasia found that approximately twenty terminally ill people per month asked doctors to help them die. This is not a large number. The study found that 259 acts of legal euthanasia were carried out in Belgium up until the end of 2003, about 17 registered cases each month. About 60 percent of euthanasia cases occurred in hospitals; this is in contrast to the Netherlands, where the act is performed by GPs in patients’ homes. In both countries, the vast majority of people asking to be euthanized were suffering from terminal cancers.

My research in the Netherlands in 1999 revealed that the agenda of euthanasia had been pushed, while the issue of palliative medication had been largely ignored. Palliative medication had been underdeveloped in the Netherlands for many years. Palliative care is very expensive. If you want to opt for palliative care, you must invest a lot of resources, and up until that time, the Dutch government decided it did not want to invest those resources. The quickest way to die is through euthanasia, where there is no need for palliation. Indeed, until 2000, palliative care was underdeveloped in both Belgium and the Netherlands. In 2000, the Dutch government decided to develop palliative care, and at present, it is far more developed than it used to be when I started my research there. Research on palliative care
should continue, and comparisons should be drawn to see the extent to which palliation is being developed in these two countries as compared with other European countries.

In both countries, physicians are not obliged to carry out euthanasia. However, the culture in both countries is such that, if a physician is not willing to perform euthanasia, then her position might be undermined. A physician will find it difficult to advance to any higher rank in which she would be overseeing decisions if she opposes euthanasia. Euthanasia is part and parcel of the state, and a physician must be able to give full advice on all end-of-life-issues. Doctors are required to inform their patients that they do not provide euthanasia before starting to treat them so that the patients can decide if they want to work with the physician. Unsurprisingly, the majority of GPs in the Netherlands support euthanasia – it is part of the culture.

As a result of the euthanasia law, a Dutch physician is required to devote energies to explain everything to the patient and her loved ones, consult with specialists, and communicate with people with relevant concerns. There is scope to consider an improved physician-patient communication model. In the United States, Jack Kevorkian presents an example of a bad model for end-of-life issues. Jack Kevorkian helped 130 patients to die between 1990 and 1999. Some of those patients were healthy. They thought they were sick, but a coroner’s examination found nothing medically wrong with them. Dr. Kevorkian was a retired pathologist who was accustomed to dealing with corpses, not with living people. For him, the issue of their illness was secondary — the main consideration was autonomy, that they wanted to die. The individuals sent Dr. Kevorkian their medical files and he agreed to provide the service without ever getting to know them professionally. In his book, *Prescription Medicide* (Prometheus Books, 1991), Dr. Kevorkian wrote that he knew his very first patient, Janet Atkins, for a short while before he assisted in her suicide.

In my view, Dr. Kevorkian presented a rogue model of an overenthusiastic, self-promoter, media-crazed physician. There were no control mechanisms over his practice; he simply believed he recognized the need and entered into the legal lacuna with shocking insensitivity. As I noted earlier when I spoke about the issue of dignity, concern, and respect, some people want to determine the time of their death; 130 such people simply hired Dr. Kevorkian to help them do just that. I think Dr. Kevorkian’s overzealousness is the wrong model to pursue.

One troubling issue is that, for many years, the Dutch believed that the issue of administering death was a personal and private issue, an issue between patients and their GP. Therefore, even though the Dutch Medical Association demanded and prescribed that the doctors must report euthanasia when it was performed, most of these physicians failed to report because they argued it was a breach of privacy and a breach of trust between them and their patients. In 1990, only 18 percent of doctors reported having performed euthanasia. After the law was passed legitimizing euthanasia, approximately 80 percent of doctors filed reports. While there has been a significant improvement in reporting, the goal is to reach 100 percent, where all doctors report participating in euthanasia cases.

Another issue that is highly troubling is the issue of consultation. The Dutch law prescribes that a physician must consult with an independent colleague who is an expert on the patient’s disease before performing euthanasia. My fieldwork revealed that most of the time the doctors consulted a colleague in the same office, and thus, the consulting physicians were not independent nor were they necessarily experts of the disease under consideration. Moreover, my research revealed that sometimes consultations were devised over the phone. This is in breach of the Dutch guidelines because the role of consulting is said to be twofold. One aspect of consultation involves verifying the patient’s medical situation, and the Dutch stipulate you cannot do this by looking at the files alone. Indeed, many of the doctors whom I met in the Netherlands, the United States, the United Kingdom, Canada, and Israel say it is necessary to do a physical examination to reach an accurate decision. The second important role of the consultant is to verify that euthanasia is the independent, autonomous wish of the patient. If it is only the physician who discusses the patient’s condition with the consultant, then could the consultant know what the patient wants? I hope that such a bad practice of phone consultation is no longer in existence. I am told that Dutch physicians no longer conduct consultations over the phone.

The Dutch believed that the practice of doctors agreeing to serve as euthanasia consultants for each others’ patients was not the best way. Consequently, they created a special committee of experts called Support and Consultation of Euthanasia in the Netherlands (SCEN) that began in Amsterdam and later spread throughout the country. At present, I am told most consultations about euthanasia are done with SCEN doctors. An expert who the GP is said not to know comes and examines the patient. Belgium has adopted a similar consultation mechanism. I applaud
this development, as it is far better than independent deals between not-so-independent doctors.

I previously mentioned the Oregon model and indicated it was a good model to follow for end-of-life issues. When the state first authorized the practice in 1994, the worry was that once the system was in place, the practice would spread and there would be many, many cases of PAS. However, there was not a huge increase in the number of people asking for PAS; more or less, there are the same number of people requesting PAS -- about 30 each year (341 in ten years, 1997-2007). The highest number of PAS cases was in 2007, when 49 Oregonians ended their lives by taking a lethal drug dose. Secondly, the other concern was that PAS would be disproportionately applied to kill the poor, the uneducated, the neglected, the deserted, those who could not take care of themselves, and the underprivileged. This has not happened. Most of the people asking for and accepting this service are well-educated middle class people, and it seems there is no abuse of the system. Therefore, I think this model is a good path for others to follow. That being said, Oregon should continue to have close annual scrutiny of the practice and keep an alert eye against potential abuse.

Guidelines for End-of-Life Issues
I have devised a set of guidelines to improve the current system. I would like to advance the issue of PAS, because I recognize that individuals should have the power to decide end-of-life issues, and because I oppose euthanasia. I developed these guidelines by studying what has been done in Oregon, the Netherlands, Belgium, Switzerland, and the Northern Territory of Australia. Let me conclude with the following recommendations and suggestions:

• The physician should not suggest PAS to the patient. Instead, it is the patient who should have the option to ask for such assistance. What I discovered in my independent field research in the Netherlands is that, many times, the patients did not ask for euthanasia. It was the doctor, a trusted GP whom the patient had known for many years, sometimes 30 or 40 years, who offered death to the patient with cancer. This practice may compromise the issue of voluntariness; it is difficult for many patients to contest the advice of a loyal GP. The GP may present the patient the range of available options without manipulation, and with due respect for patient’s life and wishes.

• The request for PAS should be voluntary and come from a competent adult, 18 years-of-age or older, who suffers from an intractable, incurable, irreversible disease. The decision should be made by the patient, and not by the family or as a result of family pressures. Some families can make the decision to end life because they feel overwhelmed by the individual’s illness – it is troublesome and very demanding to have a cancer patient in the home. It is also very sad, and many people cannot cope with the fact that their loved one is suddenly dying. For these reasons, the PAS decision has to be reached without any pressures. The patient should state this wish repeatedly over a period of time. This recommendation is similar to the one invoked in laws and guidelines in Oregon, the Netherlands, Belgium, and Australia.

• It is the task of social workers to examine to what extent the patient is affected by external pressures. The decision-making process shall include a second opinion in order to verify the medical diagnosis and minimize the chances of misdiagnosis, as well as to allow the discovery of other medical options. A specialist who is not dependent on the first doctor should provide the second opinion. A committee like the Netherlands’ SCEN can be a good system. It is advisable for the identity of the consultant to be determined by a committee of specialists who will review the request for PAS.

• At times the patient’s decision might be influenced by severe pain, and therefore, the role of palliative care can be, and is, crucial. Palliative care is required in both Belgium and Oregon.

• The patient must be informed of her situation, the prognosis for recovery or escalation of her disease, and the degree of suffering that may be involved. There must be an exchange of information between doctors and patients. The laws in Belgium and Oregon contain these guidelines.
• Sometime prior to the performance of PAS, a doctor and a psychiatrist shall be required to visit and examine the patient to verify that this is the genuine wish of a person of sound mind, and that the individual is not depressed or being coerced or influenced by a third party. The conversation between all doctors and the patient should be held without the presence of family members in order to avoid familial pressures.

• The patient must be able to rescind her decision to pursue PAS at any time and in any manner, as it is the case in Australia and Oregon. In Belgium, the patient can withdraw her declaration at anytime.

• PAS may be performed only by a doctor in the presence of another doctor. I am very much opposed to family members administering assisted suicide (or euthanasia), as I think it can lead to abuse. The decision-making team should include at least two doctors and a lawyer who will examine the legal aspects involved and ensure there is protocol in place which will prevent against possible abuse. Perhaps a public representative should also be present during the entire procedure, including the decision-making process and the performance of PAS.

• PAS may be conducted in one of three ways, all of which should be discussed openly and decided upon by the physician and the patient: (1) Oral medication; (2) Self-administered, lethal intravenous infusion; or (3) Self-administered lethal injection. In this context, I should note that some medication may be difficult or impossible for patients to ingest because of nausea or other side-effects of the illness. The only exception in which the physician would be allowed to administer the lethal injection would occur in the event that medications have been provided and the patient’s dying process has been lingering on for long hours. I would only allow euthanasia after the failing of PAS, or if the patient cannot physically administer the medications to herself.

• Doctors may not demand a special fee for the performance of PAS. There must be no financial incentive to perform or assist with the procedure since the motive for PAS is humane. There should be no special payment that might cause commercialization or promotion of such procedures.

• There must be extensive documentation in the patient’s medical file, including: (1) the disease diagnosis and prognosis by the attending and the consulting physicians; (2) attempted treatments; (3) the patient’s reasons for seeking PAS; (4) the patient’s request in writing or documented on a video recording; (5) documentation of conversations with the patient; (6) the physician’s offer to the patient to rescind her request; (7) documentation of discussions with her beloved people; and (8) a psychological report confirming the patient’s condition.

• The drugs required to end one’s life are known. Since there are 900 to 1,000 patients in the Netherlands who are killed every year without clear volition, pharmacists should be required to file a report every time lethal medications are sold to act as a control mechanism. Then it would be possible to track down the medication to the doctor, and keep track of how many times PAS was performed.