Legal Euthanasia Is Necessary But Not Enough

An Introduction to Eutélia

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We have taken death out of the hands of 'God'.
New laws should no longer be derived from concepts or precedents predating the Middle Ages. Rather, they must be adopted or adapted with knowledge and consideration of modern biological, physiological, psychological, philosophical and sociological concepts and the complexity of the issues concerning death and dying.

The fear of dying, which lies behind many of our anxieties and phobias, often seizes us amid the course of great bliss or even in moments of ecstasy. Hence, our happiness may depend in no small measure on how we come to terms with our mortality. Do we regard death as a divine punishment that we should fear? Or do we see it as the redemption that spares us the humiliations of a deteriorating body?

I mention redemption because I am not addressing the suffering caused by the impatient and cruel kind of death that threatens to take us long before our journey's natural end. That death we must oppose with all our might, using all the resources that medical science and a compassionate society can provide. Eutélia is concerned primarily with the other kind of death, the one that patiently awaits us at the end of our journey. This death we must learn to accept, for even if we should win a couple of bouts against it, we will gain little more than a respite before the final defeat, often at the price of excruciating pain and the humiliation of a body that has lost control over all physiological functions.

In my book on the emblematic aspects of life from conception to death, which has been published in Europe in several languages, I introduced the term *eutélia*, meaning "good end." By this I refer to a comprehensive approach dealing with the practical, theoretical, medical, psychological, and socio-economic considerations that can create the conditions necessary to extend our inalienable right to the pursuit of happiness until our last breath. We cannot talk about dying with dignity if we deny ourselves or our fellow humans this fundamental right or if government places limits on our autonomy precisely at a moment when we are no longer able to stand up to defend it.

This broad approach to dying and death is in sharp contrast to the very narrow scope of the well-known word euthanasia, which liter-

ally means good death, but which, since its introduction by David Hume in the eighteenth century, has led to much abuse and controversy, as well as unresolved debates about the means and goals of "bringing about a gentle and easy death." Eutélia goes beyond addressing the ethics and the practice of euthanasia, "passive" or active, that have dominated public discourse to include many interlacing approaches that can enrich the last mile of life's journey. It aims to accept and befriend the merciful death that spares us total loss of the dignity for which we have striven all our lives.

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A gentle death in old age is not to be feared, but rather valued as a gift bestowed on those who have earned their right to peaceful repose. However, our youth-centered societies fail to acknowledge the mercies of this blessing and continue to do a disservice to the elderly by refusing to consider death from the perspective of the dying. There are, of course, many practical questions that I must address in my advocacy of the concept of eutélia and its institutions. But first I would like to sketch a broad foundation for the basis of future discussions that can help us reach the goal of dying with dignity. As modern medicine extends lives, overburdened health services will either collapse or have to curtail the services they offer younger generations. Such a dramatic outcome can be avoided if we, the elderly, become less selfish in our expectations and discover the joy of lovingly passing on our greatest treasure, our place under the sun, to those we leave behind. But in exchange, the younger generation that take their fundamental right of self-determination for granted with respect to all midlife decisions, must accept their elders' right to self-determination with respect to all end-of-life decisions.

Many misconceptions concerning end-of-life issues must be dispelled, but first we must raise two fundamental questions: Do we have a moral obligation to suffer the pain and humiliation of terminal illness even when a life worth living is no longer an option? And if not, does society have a moral obligation to heed our cries for help when we can no longer endure the agony of dying? Eutélia's answer to the first question is a definite, well-arguable no and to the second, a resounding yes. The unavailability of such help may not only fill our medically extended final days or months with the fear of unbearable suffering, but it may also cast a long shadow over much of our lives as we witness the seemingly endless agonies of relatives and friends waiting in vain for death, often attached to ever-more sophisticated life-sustaining equipment. All this, even after they have been brought back to life from the easy death of cardiac arrest or have been cured of pneumonia, which once was regarded as the best friend to the moribund elderly.

Those who support the right to ask for and obtain help in order to die with dignity when an acceptable quality of life is no longer possible refer primarily to the right of self-determination. Opponents, whose view is often influenced by religious considerations, refer to the sanctity of life, a principle that is derived from the Judeo-Christian teaching that God created us in His (or more precisely His and Her) image. "Let *us* make man in *our* image, after *our* likeness," we read in the first book of Moses. This use of the plural form, together with the conclusion of Genesis "So God created man in his own image, in the image of God created he him; male and female created he them." indicate the dual nature of God in the first chapter of the Bible. This may represent a transition from polytheism to monotheism that finally had no other option

but to assign the roles of Prometheus and Zeus, as well as those of Ares and Thanatos, to one God, bestowing on Him/Her the taking away of our progenitors and the giving of our progeny.

Western civilization is built on the premise that God the Creator decides whether we are to have an easy exit or a long, painful, and humiliating decline before we are allowed to die. This ancient position of our churches disregards the fact that before resting on the seventh day our Creator endowed us with a keen mind, dexterous hands, free will, and all the other attributes that allow us to help one another as social beings in all endeavors of life. For if death is part of life, we must eventually accept that we were intended to help those who wish to die before they are stripped of the last remnant of their dignity: their autonomy, their self-determination, their right to tell us when and how they wish to depart.

It is time to admit that medical science long ago took death out of God's hands. We now replace diseased or worn-out organs, restart stopped hearts, and prolong the agony of dying. With our increasingly sophisticated technologies, we bring people back to life (and keep them alive, even if only in a vegetative state) after God has shown mercy by stopping their hearts. Yet we are deaf to the pleas of those who, overburdened with years, want to die in peace. Even if we hear their pleas for help, we lack the courage to break with long-outdated traditions and laws that date back to times when we did not have the means to keep even the brain-dead alive.

Who should decide?

The exponential development of biomedical science and technology enables us to keep an ever-increasing number of bodies biologically "alive," artificially maintaining them in vegetative states that do not resemble human life, often not even in appearance. If this trend continues, in a few decades we may need to provide for the care and storage of millions of functionless bodies worldwide at any given time. Even as we maintain "living" bodies far beyond their natural capacity to sustain human life, doctors must ultimately take it on themselves to decide when those people should be allowed – or helped – to die. So the question of exercising passive or active euthanasia is becoming less and less a question of whether we morally can make such decisions and more and more a question of who decides, and when. Eutélia maintains that any end-of-life decision – palliative care until the end, whether in a hospice or at home, "passive" or active euthanasia and its means – must be an expression of self-determination directed either by the patient or by the patient's appointed proxy. But no "living will," advance health care directive, or any other piece of paper will allow us to anticipate all eventualities. Only a person with whom, over time, we have shared our concerns and wishes can do that. But who should that person be?

Many examples demonstrate that relatives frequently do not even agree on what last rites the deceased should or wished to have. Friends can interpret a living will differently, if one exists. Some people may have a best friend or a close relative who may appear to be the logical choice as an official health care proxy but, when called on, may not be able to handle the emotional burden of making a life-or-death decision. And even if they do make that decision, they may be tormented for years by doubts or guilt regarding the outcome. We need to have trained professionals to be available as proxies and discuss our living wills with us from time to time, amending them as our choices change, if they do. Thus, knowing the way we think about end-of-life issues, they would be able to act according to our concepts and beliefs even with regard to unanticipated eventualities. Such a specialist could, for example, act through and be licensed by an Institute of Eutélia. Such an organization is essential as a means of representing and protecting those who wish to maintain their right to self-determination, even with regard to the question of last rites, to the last minute of life.

Although euthanasia means "good death," what it represents in public consciousness today is simply the shutting off of a respirator, the ad-

ministering of an overdose of a "painkiller," or a lethal injection as the ultimate *coup de grace*. We have the audacity to call such cases "good deaths" even when no one is present to hold the hand of the dying person. In contrast, most veterinarians have the compassion to ask the master of a dog to hold it in his arms while he administers the fatal injection. But as long as human euthanasia remains illegal, it has to be enacted secretly, too often under undignified circumstances and far too often only when caregivers can no longer endure witnessing the sufferings of a terminally ill patient.

Although I went into this in some detail in my book, I confess that after the Terri Schiavo case, I welcomed the rush to prepare living wills, which had become a right in most Western countries. Only on reflection did I realize that under the present circumstances living wills can be detrimental to the cause of eutélia, which is to enrich rather than to impoverish the last stage of life and certainly not arbitrarily or capriciously to shorten that stage. Specifically, if you give a do-not-resuscitate order, instructing doctors not to restart your heart after cardiac arrest, you may deprive yourself of the most rewarding years of your life since, as is commonly observed many people appreciate life more after a near-death experience than they did before and begin living richer, more caring, and gratifying lives.

Eutélia discourages the inclusion of do-not-resuscitate orders in living wills until a more enlightened time when one will be able to request that one's heart be restarted, but with a caveat something like the following: "As soon after resuscitation as it is determined that I have suffered brain damage that will leave my body in a persistent vegetative state or that has caused defects inconsistent with human autonomy, I want all life-sustaining procedures to be stopped immediately. If death does not ensue within 24 hours, it is to be brought about by active intervention under the supervision of my proxy, whom I also authorize to execute all my wishes concerning farewell rites." As long as one cannot stipulate this in the absence of legal "euthanasia," one probably should not even mention resuscitation in living wills unless private arrangements can be made with a doctor who would respect such a caveat and find a way to execute it.

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Eutélia calls for comprehensive laws crafted with appropriate attention to the complexity of the biological, sociological, and psychological considerations involved in end-of-life decisions. The statutes must allow for and provide assistance in many ways of making a final exit, recognizing that we are different in many ways, having different religious or secular creeds and different concepts of life after death. We have different ailments and different pain thresholds. Discontinuing treatment may lead to rapid death in someone with congestive heart failure, but only intensify the pain of metastatic bone cancer. Some people can tolerate this pain stoically, while others may be driven nearly insane by it.

For several decades, Western societies have acknowledged our right to palliative care and most countries provide at least some financing for it. In the United States, governmental and commercial insurers finance both at-home and in-house hospice care. Even the uninsured can benefit from such care through the support of private foundations. Hospice care already provides help for more than a third of the people dying in the United States each year. Eutelia must fully support this service and its expansion as an important alternative that we can choose

in exercising our right of self-determination. It must also stand up against laws that forbid the use of some of the most effective painkillers. In this country, codeine and morphine are routinely used, but the law prohibits the use of some other opiates such us the much more effective diacethylmorphine, because of its bad press under its more common name, heroin. True, it is more habit forming than morphine, but in terminal cases this should not prevent its use in doses that do not hasten death or cause severe adverse side effects for those whose pain can no longer be controlled by morphine or some other morphine derivatives.

I believe that if we are terminally ill and must face the possibility of increasing agonies and humiliations, the knowledge that euthanasia is legally available to us if we need it will help us cope much more peacefully and patiently with pain and suffering, making it possible for us to bear our sufferings longer and with less anxiety.

Fortunately, in some states lawmakers have begun to realize that they have no right to forbid the medical use of some of nature's most effective drugs, such as marijuana. For it is not always pain that torments the dying the most, and cannabis is one of the most effective treatments for nausea, for example, which is a frequent and in some cases devastating side effect of several essential drugs. If there were a demand, pharmacology could also come up with effective drugs to ease the anxieties of the dying. Indeed, such drugs are already used to alleviate patients' acute anxieties before surgery. Some of these agents surely could be modified to allow their use for longer times.

I see the need for an Institute of Eutélia not only to provide direct assistance for those who must prepare to leave this world, but also to represent in legislative bodies the needs of those nearing the end or preparing for it. If we want to establish our right to a dignified death, we must not only guarantee terminally ill individuals the right to self-determination, but must also establish an organization to defend this right. I regard this as being an important function of an institution that is devoted to end-of-life issues.

New laws should no longer be derived from concepts or precedents predating the Middle Ages. Rather, they must be adopted or adapted with knowledge and consideration of modern biological, physiological, psychological, philosophical and sociological concepts and the complexity of the issues concerning death and dying. Enactment of these laws should be preceded by public discussions to bring about a new appreciation of the last phase of life and to overcome the hypocritical and bureaucratic half measures that have passed as "legalized euthanasia" in some European countries. Those measures do little more than to introduce bureaucratic measures that are obviously avoided by most busy doctors to maintain the status quo ante of helping covertly people to die.

Under the concept of eutélia, I do not promote the legalization of euthanasia in order to encourage everyone to "shuffle off this mortal coil" with a lethal elixir or injection. To the contrary, I believe that if we are terminally ill and must face the possibility of increasing agonies and humiliations, the knowledge that euthanasia is legally available to us if we need it will help us cope much more peacefully and patiently with pain and suffering, making it possible for us to bear our sufferings longer and with less anxiety. This can bring comfort, particularly to those who would like to have their lives end naturally but do not wish to be kept in a coma for years, hooked up to more and more contraptions, and who do not regard "terminal sedation" as natural. Such sedation is increasingly being used to make the maintenance of bodies less troublesome.

Rather than have relatives debate in court about when a body in an artificially maintained vegetative state should be allowed to die, we need a well-trained and experienced proxy to say when enough is enough. And when such a decision is finally made, is it not barbaric to let the body slowly dehydrate until the circulation fails, or even worse, maintain hydration but terminate artificial nutrition, allowing the body to deteriorate even more slowly by consuming itself? Society would be up in arms if someone did this to a horse. The knowledge that this terrible fate may befall us even within the walls of a hospital can only increase our dread of dying, or even just going in for surgery.

Since my book on eutélia appeared in Europe, two objections have repeatedly been raised. Many people – and not only in the legal professions – are concerned that by advocating legalized euthanasia eutélia would open the way to the killing of elderly patients who are a burden on their relatives or who may leave behind a substantial inheritance (or both). I came to recognize the need for establishing institutions with licensed professionals and strict rules precisely because this would provide the best safety measures to prevent such abuses. Illegal euthanasia, on the other hand, is obviously uncontrollable. It would also be next to impossible to control legal euthanasia if we were to put it in the hands of hospital staffs that daily administer hundreds of doses of potentially lethal painkillers.

Physicians, on the other hand, object to the legalization of euthanasia on the assumption that they would have to implement it. This is not the case. Indeed, the concept of eutélia rules this out, maintaining that the physician's role, which is to heal, ends when health can no longer be restored or maintained to an extent that life would be worth living. At that point, the physician, bound by the Hippocratic oath, should be able turn the patient over to someone with a very different avocation and training, just as an internist turns a patient over to a surgeon when medical treatment no longer works. This is consistent with the Hippocratic oath, which in some of the many versions we have inherited states: "I will not cut for [bile]stone, even for patients in whom the disease is manifest; I will leave this operation to be performed by practitioners, specialists in this art." Eutélia maintains that when only death can save the terminally ill from further suffering and indignity, the physician must turn the patient over to a specialist in the art of helping people to die.

Most of the physicians with whom I have spoken in detail on the subject clearly object to eutélia because of its emphasis on patients' right to self-determination, while most doctors still regard life-and-death decisions as their prerogative. Clearly, preparing people for their last voyage and helping them across the threshold requires skills that could hardly be acquired within the context of an already overburdened medical school curriculum. And even if we trained them for it, we cannot realistically expect busy medical practitioners to help guide their patients to a dignified end.

Just as we have already established the professions of midwifery and obstetrics to help the fetus out of the womb, we need well-trained, dedicated, and empathetic specialists to help us, when our time comes, to step out of life. Instead, we are surrounded in our final days and hours by health-care professionals who have sworn to keep us in this life. We could refer to the specialists skilled in the art of helping us out of life as thanatologists. But because eutélia assigns them a broader role in preparing people for *and* helping them across the threshold if need be, I would rather call them by a friendlier name: Christophers, after the saint who, according to legend, carried many people, including the little Jesus, across a river of terrifying eddies.

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