End-of-Life and the Good Society

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End-Of-Life And The Good Society: Affirming A Legal Right To Palliative Care – A Model For Israel

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Calling something a right is an institutional decision.

Neil K. Komesar1

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PREFACE

As western society is increasingly engaged in the debate as to whether to legalize euthanasia as a matter of public policy, it appears to have set aside what we believe ought naturally to come before such debate, i.e. a definition of the goals of end-of-life care, and the affirmation of a legal right to receive palliative care. We feel that the essential, and natural, notion that death touches every one of us, and that a right to elective death should not obscure the right to “live our death” in the comfort provided by state-of-the-art palliative care, is being neglected. We cannot help wondering about the causes of such neglect. Denial, first and foremost, comes to our mind, followed by (misplaced) economic considerations related to the cost-of-dying. We are entering an area where public policy seems to have different and contradictory voices. We ask that its standard proclamations on the dignity of the person find concrete and unequivocal application in the domain of end-of-life care. A simple proposition, apparently, yet one that requires an amount of honesty and common sense, that seems to us to be (surprisingly) lacking.

The issue of death and elective death is at the intersection of several disciplines. It is therefore impossible to fragment it into medical, legal, philosophical, ethical domains, just to name a few. As we have been attempting to navigate an endless sea of contributions from different disciplines and perspectives, and as we have been conducting field research (mainly in Israel, the prototype country which we use for this article), we have increasingly felt that our contribution should be as simple and clear as possible. And also as short and reassuring as possible, since our hope is to engage the reader not to set aside what s/he may fear to be a “morbid” piece. The main scope of this article is to confute denial, to look for the goals of end-of-life care, and to offer the reader a tentative proposal of legislation which explicitly recognizes a
legal right to receive palliative care. As we ask the reader to pause for a few moments, to think of death as part of life, we are not writing a typical legal article, but rather an advocacy one (hence our attempt to use as simple a language as possible, and to avoid jargon and heavy footnoting).

I. FACING DENIAL

The public policy discourse in the western world increasingly focuses on whether and how to legislate elective death, and euthanasia has become a household term. The terminally ill have a right to die, more and more people say with assurance. "Do Americans have a constitutional right to die?" asks Ronald Dworkin, answering in the affirmative. The legislation in Holland, the country that has recently explicitly recognized a legal right to elective death, has given legitimacy to the word "euthanasia", which is now employed with casualness, and sometimes even euphoria, if not always with precision of terminology. The right to euthanasia is discussed in an erudite, although (again) not always precise, manner by its proponents (is it a 'negative' or 'liberty' right, or is it a 'positive' right, the question arises). Slippery slope arguments are also considered, by some with force, reluctantly by others. So are economic arguments, although more sotto voce. As much as the topic is apparently faced overtly, we are left with the feeling of an aseptic mode of discourse, where the real suffering of the individual is somehow exorcized by the overt possibility of putting a clean end to it.

The human species is alone in knowing it has to die, said Voltaire, but as much as we rationally know that we all die, we don’t really believe it will happen to us. To talk about death is considered bad manners, embarrassing and, worst of all, fate provoking. Our society, increasingly capitalistic and globalized, believes itself eternal because it relentlessly reproduces itself (just as the law believes in a symbolic immortality). It must not, so it is believed, slow down to ask itself metaphysical questions, and it convinces itself that it can only proceed in a linear fashion. Not so in several non-western societies, which still adhere to the conceptions that were ours in a not too distant past, when life and death belonged to a world that accepted the cycles of the universe, where the physical nearness to the sources of life conveyed a universal pathos, and brought a reconcilement of its contradictions. It used to be a world of physicality, where smells and decay were an integral part of the cycles and seasons of life, where people died at home, surrounded by their kin.

We have always lived with dying, lived with death, died with life, and a sense of death has always been indispensable to a sense of life. Yet more than ever today the idea of death seems glaringly absurd, immoral even, in an age when we think we can conquer all. Ours is a time when a popular icon like Walt Disney “chose to have his body deep-frozen, not presumably, in what used to be called ‘the fervent expectation of the resurrection’, but in the equally fervent hope that scientists might some day discover a way of resurrecting the dead before the Day of Judgment “. ³ So death seems imaginary, while it is a fact. Dying is one of very few

events in life certain to occur, nobody has ever escaped it, yet it keeps being denied. There is a defensive belief that a full life may set aside death by not leaving it any space, so we remove it from social attention and frantically live for ourselves, rejecting historic continuity by means of exasperated subjectivism and hardened individualism.

We encourage a capitalistic refusal of physical decadence and pursue eternal youth because we have deep anxieties about our impotence and death, and we are terrified of the thought of being sucked into the world of illness and old age as we have become convinced that only illness and old age push us towards death. We refuse to admit that this narcissistic magical exorcism is a delusion, that life and death are constantly present together, universal and inseparable. No living thing begins or is completed save through death. In the cycles of the universe, in the sameness of the recurrence of seasons, there is reconciliation and universal paths as nature is living and dying (the ancient gods of much vituperated paganism were mortal, and knew how to grieve). If we indication) in reference to the western need of seeing life as a story with a “This is Your Life” book to be presented at death: “Our own urge to see life in narrative terms is clear in the creation of heroes whose lives must fit into an acceptable narrative form with alternative endings to please different factions. So Catholic propagandists rewrote the death of the great agnostic Voltaire to have him either calling out for forgiveness or eating his own excrements. Horatio Nelson, whose end occurred at the moment of greatest triumph, is actually better thanatological material than Napoleon despite all the latter’s undoubted achievements. He simply lived too long and suffered what amounts to a seedy seaside retirement in drastically reduced circumstances.”

4 Intimate association with the earth was a reality in primitive life. The earth was the mother of all living (and the earliest idea of the divine was derived from motherhood). Isis (called also Ishtar, as well as by other names) was the great mother of the earth. Subsequently the sun was associated with the earth, and was
think of life apart from death, our thought is reductive and partial. Death is always there. Death is the one thing we cannot program. Yet now we want to, and seem to believe that we will have the technological resources to do so (at what cost to the essence of our humanity, is a question asked only by few).

We are the only animals that compensate for fear by psychological tricks. We are the ones who, fearing death, buy it off by sacrificing someone else in our place, through ritual cannibalism in the past, symbolically today. *Mors tua vita mea*, as the Latin saying goes. We proclaim that we are born alone and that we die alone. Yet we are born of our kind, and unto this kind we die. Confronting the physical world, confronting birth and death, unsustained by human fellowship and community, we will become lost entities, tremble with fear, and both life and death will cease to have any meaning. Yet in our society we are usually dramatically alone before illness, and even more so in imagining and “living” our death. It is a society obsessed with planning everything — save death that cannot be planned, and therefore has to be abolished. And we can ask the question of whether our time’s emphasis on planning, of being in control, may well be one reason why euthanasia is becoming a popular notion.

And there is also the absurdity that current science and technology, in their efforts to prolong life, seem to be doing so only in order to offer the postponement of death as a solution to the human quest for immortality. There seems to be no place for humankind’s basic animal fears, their deep and indelible anxieties about impotence and death, and their fear of being overwhelmed and sucked up into void and mystery. That is why the husband through which the human existed. The human, the natural, and the divine, were blended then, and death coexisted in a simple, unembarrassed acceptance of both.
the life of man and woman has a quality of drivenness, of underlying desperation. That is why all too natural rumbling anxieties have to be buried under multi-layered armors of defense, and real man and real woman are defined by their physical courage and by their spite or indifference to danger, fear and death. That is why they are encouraged to be constant, positive optimists who actually seem never to think of death. That is why death is still a taboo, and one is asked not to “obsess” about it.

In this context, modern medicine is mostly action and cure. The language it employs is a language of warfare, where doctors battle valiantly with death, the enemy is to be conquered and those who die are losers. When there is no victory, most doctors, who are trained to triumph, feel defeated. They have not been trained to give emotional and spiritual comfort, so now they turn away from the dying person. The ones who do not, the ones who accept the challenge of the war against end-of-life suffering - if we want to continue using the war metaphor - are the palliative care doctors, still a minority group belonging to an under-recognized medical specialty. They are the ones who accept the eternal fact that death is part of us. They are the ones ready to medicate, sedate, touch and hold the dying person (we, you), for whom such compassionate concern may well be her life’s highlight.

What about the role of jurists in this debate, since this is a legal journal? Until recently, very few of them concerned themselves with the essence of death, something they considered to be a useless contemplation of human miseries, to be left to philosophers and poets. Today, death seems to be on the verge of becoming a trendy topic, but still all too much for aspects relating to “real” legal aspects, and, unfortunately, not enough as concerns fears and emotions. As much as it used to be axiomatic that legal literature deals with “real” legal, black letter issues, much has
evolved in the past few years, thanks to the influence of non-formalistic movements, such as Critical Legal Studies and Feminism. Yet the law’s basic premises still deny death (just as they deny the libido). Just as most doctors, the majority of lawyers and academicians have not been trained to deal with emotions and to face their own fear of death, which they exorcise through denial and removal.

This is a luxury that the law, in our opinion, cannot any longer afford. We had gotten used to the continuity of western civilization (and of its laws), notwithstanding cyclical rises and falls. We had gotten used to the rationality of the Enlightenment as the point of reference and the mantra of western societies’ legal systems, where the law had to be accepted as rational, or fought in the name of rationality. Rationality made the functions it defines real, and made them survive. It was a simulation of reality, that has, until now, steadfastly proclaimed its sovereignty and truth, but is starting to disintegrate as its hegemony is being questioned. Even more than by relativism, the very foundations of the law are threatened by new technologies with dynamics of their own, that produce technological realities that shift not only the distribution, but also the very basis of our social structure. We are witnessing a change of pace, a general acceleration, where the divide between man and woman, where the “order of creation” that excluded men from “producing life” may well disappear as new technologies will eventually succeed in having the whole child production process take place outside the female body, and where death increasingly assumes technological connotations. The way we are born and the way we die are changing, and with them relations of family, status, and contract, just to name a few, will also dramatically change.

But the crisis that faces the model created and spread by the west at the start of the modern era is still wider. Our feeling is that this model is not
compatible with life - and death - at its deepest, and that to still hypothesize its further diffusion in a global world is equivalent to hypothesizing the end of the biosphere, that part of the world where living things can live - and die - in their environment. It is a humanism of dominance which, whether we like it or not, has no future, unless western culture accepts to return to the culture of human rights that it had itself produced in the past, a culture, that is, which goes beyond the individual rights that today impregnate our legal systems.

We submit that the recognition of the right to end of life care as a matter of public policy belongs to such a culture of human rights.

II. LEGISLATING THE RIGHT TO END-OF-LIFE CARE

As we have stated, the public and legal debate on issues related to the final stage of life in the western world today focuses primarily on the question of euthanasia, and insufficient, if any, attention is paid to the needs and desires of those people, the majority actually, that wish to live their life to its natural end with dignity, receiving pain relief and comfort care, and in general be freed of the preoccupation that haunts them, as it haunts us all, of an end nightmarish both for them and for their families. Our concern is, that to focus the discussion almost exclusively on elective death might obscure, bypass even, the need to recognize a right to receive palliative care, a recognition, we contend, that should precede the one possibly to be granted to elective death. We contend that establishing state-of-the-art and fully accessible palliative care, the existence of which will be known to all, will lead many, if not most, terminal patients to opt to receive it, rather than consider shortening their life. What people fear the most of death, what most of us fear the most of
death, is not so much the fact that we will not be around anymore, but
rather the possibility of becoming, before dying, an intolerable burden,
for ourselves and for others. Pain (and the fear of it) remains the number
one reason for considering life as no longer worth living, and for
considering putting an end to it (the other main reasons are loss of any
possibility to relate, loss of mental faculties, depression and lack of
support). The certainty of the availability of the best possible comfort
care (and not some aleatory and chancy hope of it) will render the
dilemma moot in most cases, to the great relief not just of patients, but
also of proponents of euthanasia, the application of which would thus be
reduced to only limited and exceptional cases.\footnote{We have deliberately decided not to discuss these specific cases in this article, but they can be very generally categorized as chronic illnesses where pain relief does not suffice.}

We therefore strongly feel that explicit legislation establishing the right
to end-of-life care is of the essence, and we will present here the model
that we are bringing to the attention of the Israeli legislator. This model
presupposes a definition of the terms and goals involved. We do realize
that the word “definition” is intrinsically limitative, and may carry with it
the kind of formalistic connotations of which the current post modern
legal world is particularly wary. Furthermore, the territory of end-of-life
is of course not easily prone to definitions. Yet we believe that the current
public and legal scenario is so weighed with confusion of terms that we
should set some (admittedly subjective) points of reference lest we lose a
perspective of what our goals and priorities are. For the purpose of this
article, and of the legislative proposal it presents, euthanasia, assisted
suicide, and palliative care, are therefore to be intended as follows.
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Euthanasia is at the intersection with the notion of palliative care we are advocating in that “ending life” (euthanasia) and “allowing death” (palliative care) are not morally equivalent propositions. We share here the views of Dr. Nathan Cherny, a recognized authority worldwide in the field of cancer pain and palliative care6, whose construction of “allowing death” we find particularly relevant to our purposes. After defining euthanasia as “the deliberate termination of the life of a patient by active intervention, at the request of the patient in the setting of otherwise uncontrolled suffering”, Dr. Cherny points out that since it “always involves the active intervention of a clinician to end the patient’s life, the term ‘passive euthanasia’ is an oxymoron” and that situations commonly described as “passive euthanasia” should instead be viewed under “withholding of potentially life prolonging /death deferring treatments that do not contribute to the goals of care” and “withdrawing supportive therapies that have failed to meet the goals of care””. What this means is that these are instances of “allowing death”, where the patient or health care proxy is to be empowered to withhold or forego the treatment or therapy. It also means that “allowing death” falls within the purview of palliative care.7

Assisted suicide, that is the provision of the means and instruction to a patient to facilitate her own administering of death, is an “ending life” proposition that does not fit into the palliative care scheme we are propounding. It follows that both euthanasia and assisted suicide - justifiable, we believe, under exceptional circumstances - are not to be adopted and legislated as primary end-of-life goals.

6 Dr. Nathan I. Cherny is Director of Cancer Pain and Palliative Medicine at the Oncology Department of Schaare Zedek Medical Center, Jerusalem.
7 Based on a meeting with Dr. Nathan I. Cherny (June 10, 2001).
The primary end-of-life goal we wish to adopt is unequivocal “war on suffering” (we do not shine away here from a military metaphor, as we indeed believe that pain is to be battled and conquered) and comfort care, which we subsume under the name of palliative care. It is a level of care and attention that insures not only death under no pain, but also the maximum amount of comfort and support. It is a care that recognizes the utmost importance of the dying process in the life of the individual (and, depending upon one’s beliefs, helps shed some light and meaning to it). Palliative care is a medical specialty discipline born of the hospice movement, which, as defined by the World Health Organization, provides “…the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families”. As a medical discipline, palliative care is still in evolution, and is characterized by its ouverture to the knowledge and skills provided by different branches of medicine, e.g. oncology, psychiatry, ethics, and pharmacology.

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8 Hospice (from the Latin hospis, guest as well as host, and hospitium, lieu of hospitality) has ancient roots as lodging and shelter. Its modern version as a shelter with formalized and interdisciplinary programs of end-of-life care was started by Dame Cicely Saunders in England in the second half of the 20th century. See, among others, S. du Boulay, Cicely Saunders: Founder of the Modern Hospice Movement (1984).

9 World Health Organization (WHO), Cancer Pain Relief and Palliative Care (1990) 11-12.

10 As much as palliative care deals with the multi-faceted aspects of suffering, and therefore also with the care of pain of non-dying patients, in this article we employ the term only in relation to care in the terminal stage of life.
We have submitted that there exists a distinction between “ending life” and “allowing death”. We further submit that there is a distinction between “letting” and “prolonging” death. It is the latter that increasingly terrorizes all of us, in an era where the sentence “letting nature take its course” has been pre-empted by meaning increasingly sophisticated technological means of prolongation of life with insufficient respect for the dignity of the individual. It is where this terror meets with an all too often simplistic call for elective death that palliative care has an essential role to fulfill.

The emphasis we place in this article on the need for recognition of a legal, possibly constitutional, right to palliative care has received more than encouraging consideration from the Supreme Court of the United States. In the Quill decision of 199711, the Court, while affirming that legislatures, rather than the courts, maintain the primary role in deciding how to construe physicians’ assisted suicide, only barely stopped short of affirming a constitutional right to palliative care. This development came in the form of an unexpected but clear and strong directive that the states ensure that their laws and policies do not impose barriers on the provision of adequate palliative care, in particular for people facing death.12 One can well contend that by framing the issue in terms of relief of patient suffering, the Court intended to narrow the scope of future constitutional claims to such questions, and, while shutting the door on

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assisted suicide, it is ready to provide ample access on issues of palliative care at the terminal stage.\textsuperscript{13}

As we now turn to Israel, our prototype legislative model in this domain, we must firstly point out that the Israeli legal system does not recognize an explicit right to palliative care. The Patients’ Right Act of 1996\textsuperscript{14} provides that “anyone in need of medical treatment has a legal right to receive it according to the conditions and arrangements set by the Israeli [national] health system.”\textsuperscript{15} In the case of \textit{Yael Schaeffer},\textsuperscript{16} the Israeli Supreme Court, in interpreting the expression “human dignity” of the Basic Law: Human Dignity and Liberty of 1992,\textsuperscript{17} stated in 1997 that it is intended to mean that the reflection of God in human beings must not be debased. It also stated, that by the mere fact of life, a person concomitantly is vested with dignity. A patient’s dignity is therefore maintained if s/he does not suffer pain, receives proper medical treatment, including, when needed, special assistance, and is not humiliated and degraded.

\textsuperscript{13} But see Ronald Dworkin, “Assisted Suicide: The Philosophers’ Brief”, \textit{The New York Review of Books}, March 27, 1997, 41-47, contending that the Court, or at least a majority of its members, had not rejected his view that the “liberty” of its abortion opinions meant that there is a “constitutional right to die”. Also, see Ronald Dworkin, “Assisted Suicide: What the Court Really Said”, \textit{The New York Review Of Books}, September 25, 1997, 40-44, contending that in the suicide cases decided by the Court [among them \textit{Quill}] where it refused to recognize a right to assisted suicide, a majority of the justices were actually careful not to bar the constitutional debate on assisted suicide for the future.

\textsuperscript{14} Published in \textit{Sefer Ha-Chukkim} of 5756 (1996), 327.

\textsuperscript{15} \textit{Ibid}., section 3.

\textsuperscript{16} \textit{Yael Schaffaer v. The State of Israel} (1988), P.D. 48 (1) 87.

\textsuperscript{17} Published in \textit{Sefer Ha-Chukkim} (1992), 150.
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From the above statements of the Israeli Supreme Court, we submit, one can read that the right to receive palliative care is inseparable from the right to live with dignity. Moreover, the preamble to the Declaration of the Rights of Patients of the national union of physicians and nurses in Israel (Histadrut Ha’Refuit be’Israel) of 1995, states that “the objective of physicians is to maintain the physical and emotional health of a human being and to ease his suffering while maintaining his human value and dignity, with no distinction based upon age, sex, ethnic origin, religion, nationality, social or economic status, political ideology or any other consideration, in peace as in wartime”. Section 10 of the said Declaration further states that “[d]uring a terminal disease, the patient’s independence and will must be respected when he can express them. The physician must assist him, ease his physical and mental suffering, ensure quality of end-of-life, and maintain the dignity of the dying person”.

All the above shows a remarkable amount of thought, accompanied by a rare dose of common sense. We contend, however, that it only represents the first step towards the unequivocal recognition of the legal right to end-of-life care that we are propounding, and that it is imperative to move to explicit recognition of such a right.

The existence of a formal right represents the only practical way to force an operative duty, not just on the part of the medical establishment but also, and possibly more importantly, on the part of the executive branch, e.g. the Ministry of Health. Such a duty would include media campaigns to increase awareness on the part of the public, mandatory palliative care instruction for the medical establishment, and, last but certainly not least, cutting red tape (one of today’s major obstacles). It would also mean, and this is the crux of the issue, that adequate financial resources would have to be allocated by the executive branch. An estimation of the relevant costs is outside the scope of this article. We would only stress here that
there is much unjustified apprehension about such costs. Given the character of palliative care, which excludes recourse to highly costly technological modes of prolonging life, such care may actually be the cheapest (short of recourse to extensive and undoubtedly cost-effective “mercy” killing - a slippery slope possibility of which we have a duty of honesty to be aware).

In such context, as we have repeatedly stated, explicit legislation is of the essence. The formulation we are proposing is as follows: “Every person has the right to live with dignity life in its entirety, and to receive throughout it proper medical treatment, including easing physical and mental suffering, ensuring quality of life, receiving assistance, and being treated with respect”. As much as we believe the recognition of the right should ideally be at the constitutional level, where both the start and end of life deserve to be equally recognized and protected, we are also advancing proposals for alternative modes of legislation (one should point out that Israel does not yet have a formal written constitution). The “constitutional” option is to include the right in the Israeli proposed Basic Law: Social Rights. The second option is to amend the Patients’ Rights Act to include the formulation suggested above (an option that might be easier to implement both politically and practically). The third alternative is to include the right to end-of-life care within a law on euthanasia that is tentatively being considered at a ministerial committee level. Our model is therefore three-fold, an aspect that we believe might

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18 Basic Laws represent the formulation in stages of a Constitution for Israel.
19 The Euthanasia Committee, set up by the Ministry of Health in 2000 and headed by Prof. Abraham Steinberg, is divided into ethical, medical, religious, legal sub-committees. The first author of this article is an observer in the legal sub-committee.
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present some comparative interest for other countries that are in the process of defining end-of-life legislation.

The language of our formulation is simple and essential, where the emphasis is on life in its entirety, i.e. a life not electively terminated, and the insurance of a right to the various components of palliative care. As the situation currently stands in Israel, there is no such explicit statutory right, so palliative care is in a sort of limbo. Explicit legislation would ground it firmly in the consciousness of the public and medical establishment alike, and ensure that everybody enjoy a “positive” right to end-of-life care, thereby forcing the executive to allocate the resources necessary.

III. CONCLUSION

The debate on death is nothing new, but until recently it was mostly confined to academic-philosophical-theological discussions, and for most jurists it did not appear to be an immediate concern. The picture has changed dramatically, as the debate on euthanasia has increasingly gained momentum, with legislation already adopted or being considered in different legal systems. The purpose of this article is to call attention to the fact that there has not been a parallel increase of attention as concerns palliative care, and to advocate that a philosophy of palliative care be developed and properly legislated before a philosophy of euthanasia is considered.

In this context, we have presented a model of legislation for Israel, which we hope might be of interest for other legal systems. We have contended that the American Supreme Court appears inclined to recognize a
constitutional right to palliative care. As for Europe, most European countries have constitutions that recognize the rights of the individual in a social context, which should greatly facilitate the task of the legislator. As we have been wondering on the vagaries of the law and the public alike, that seem more prone to accept notions of elective death than to integrate state-of-the-art palliative care, we have suggested that one explanation might lie in how society denies the natural process of dying.

As western health care systems are currently in transition and present common issues of pressure, coming from demand, aging, social change, and increasing costs, technological progress reinforces the belief that all can or will be cured, and not enough attention and resources are allocated to the relatively non-costly care for the relief of suffering. Only if we accept not just to know but also to believe that death is an inescapable part of life, and that palliative care is an integral part of the end-of-life equation, we will not run the risk of all too casually adopting euthanasia as a short cut from the more demanding proposition that we must care for the dying, because the process of dying is the natural corollary of the process of living.