Lilian Topic,

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Dear Ms Topic

Your call for submissions has just come to my attention. I hope it is not too late to offer my opinion.

I have been researching in the field of bioethics since my last year of my doctoral studies at Oxford University (1990). I have written on medical terminology, end-of-life issues, death with dignity, euthanasia and physician-assisted suicide. My teaching and research interests also include beginning-of-life, abortion, the human genome and doctor-patient relationships.

I served as a consultant to institutions, organizations and governments and was among the drafters of the Israeli Dying Patients Law, passed in 2005. I was also the Founding Director of a Medical Ethics Think Tank (1995-1998). More recently (2013), I assisted Lib-Dem MEP Chris Davies in the writing of his report Our Right To Die – Lessons for Britain from the European Experience.

Attached please find one of my articles on the subject: “Guidelines for Physician-Assisted Suicide”, Advances in Medical Ethics (forthcoming).

Thanking you for your consideration in this matter, and looking forward to hearing from you,
Sincerely,

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Guidelines for Physician-Assisted Suicide

R. Cohen-Almagor

Abstract

The article presents the Argument from Autonomy and the Respect for Others Argument and then explains who the patients who wish to die are. It emphasises the importance of comprehensive palliative care and voices objection to euthanasia, insisting on checks and balances when we wish to come to the patient’s aid. The plea is confined to physician-assisted suicide (PAS), where the last act is done by the patient, where the control lies with the patient. Detailed Guidelines for PAS are presented, arguing that we need to insist on them as human lives are at stake. Caution is a must to prevent potential abuse.

Key words: abuse, autonomy, euthanasia, palliative care, Physician-assisted Suicide (PAS), respect for others
Introduction

Most people would like to continue living. Empirical research, done time and again, shows this very clearly. I have visited more than thirty hospitals in Israel, England, Canada, USA, Australia, New Zealand, the Netherlands and Belgium. Most patients, even in the most dreadful conditions, opt to life. This is more so when patients are Catholic, Jews and Muslims.¹ This is less so in the Netherlands and Flemish-Belgium.² But the general picture is clear: We all possess a zeal for life. Therefore, whenever we are unclear about the patients’ wishes, the default position we should take is that the patients opt to life.³

Only a small minority of patients expressly wish to die. In this article, I first discuss who the patients who wish to die are. I further emphasise the importance of comprehensive palliative care and voice my objection to euthanasia, insisting on a system of checks and balances when we wish to come to the patient’s aid. The plea is confined to physician-assisted suicide, where the last act is performed by the patient.

The Argument from Autonomy

When speaking of death with dignity, the focus of attention is on the right of the patient over her body. The notion of autonomy involves the person’s ability to reflect upon beliefs and actions, and the ability to form ideas about them, so as to decide how to lead her life. The term ‘autonomy’ is derived from the Greek autos (‘self’) and nomos (‘rule,’ ‘governance,’ or ‘law’). By deciding among conflicting trends, patients consolidate their opinions more fully and review the ranking of values for themselves. Obviously, in order to be able to exercise autonomy, patients need to have a range of options to choose from, some may be of significance to the patients, others may not. Having options enables persons to sustain activities that they regard as worth pursuing. As Joseph Raz asserts, a
person who has never had any significant choice, or was not aware of it, or has never exercised choice in significant matters but simply drifted through life, is not an autonomous person. Choosing the best option or thinking correctly is not a requirement for autonomy so long as the agent exercises deliberation in assessing the alternatives. The emphasis is not on deciding the ‘best’ options or on holding ‘true’ opinions, but is on the way in which we come to make our decisions and to hold our convictions.

The liberal state is founded upon the principles of autonomy and individuality. All stems from the individual; all returns to the individual. The state is perceived as a developed instrument to help sustain our individuality within a just society. The state is far more powerful than a mere individual; it is a tool to enrich individuality, to enable people developing their innate capabilities, to facilitate progress of individuals which, in turn, will yield societal progress. Autonomous people at the end of life may expect liberal society to address their needs and concerns, provided that these needs and concerns do not harm others, are deemed justified and done in bona fide manner. The view that holds that we should always preserve life no matter what the patient wants, and that patients who opt to die are not able to comprehend their own interests in a fully rational manner, and that therefore ‘we’ know what is good for those patients better than they do is morally unjustifiable. This view is morally unjustifiable because it ignores the desires of the patients and does not acknowledge that the preservation of dignity may be valued more by some patients than the preservation of life. We must strive to reconcile the duty of keeping a person alive with her right to keep her dignity, which may also be considered as an intrinsic value. Therefore, the request for assisted dying may be justified; it has a place in the framework of liberal-democracy. Liberal democracy should not turn a blind eye to such appeals. It should not desert its patients and should attempt to accommodate their needs.
Respect for Others Argument

This argument is derived from the Kantian deontological school that 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 Immanuel Kant explains, a limit is imposed on all arbitrary use of people who are thus objects of respect. A person is, therefore, an objective end; such an end, Kant maintains, “is one for which there can be substituted no other end to which such beings should serve merely as means, for otherwise nothing at all of absolute value would be found anywhere.”

According to Kant, to respect a person is to treat her as a human being, as an autonomous being who is acting upon recognition of the moral law. The assumption is that beings are moral and Kant’s demand is that people act in accordance with the Categorical Imperative: Act only on that maxim that can be universalized and that always treat humanity, yourself and others, as an end. In formulating his Categorical Imperative, Kant recognized that each person has an inviolable dignity, which is the reason for respecting persons. The Categorical Imperative refers to the will itself, not to anything that may be achieved by the causality of the will. Morality, according to Kant, cannot be regarded as a set of rules that prescribe the means necessary for the achievement of a given end, whether the end be general happiness, human perfection, self-realization, or anything else.

Kant does not speak of the process of decision-making. In contrast, I wish to emphasize the process of reaching a decision. In this process we exercise our faculties, using concepts, categories, principles, norms, and to some degree (whether we like it or cannot help it) our emotions. We construct and deconstruct realities, converse and exchange ideas, listen to the advice of others, and share our opinions with people we appreciate. At least on
matters of importance, we strive to reach the right decision. As long as people accept the two basic principles that underlie a liberal society, respect for others and not harming others, we accord others respect when we respect their right to make decisions, because they are their decisions, regardless of our opinions of them. We simply assume that each person holds her own course of life as intrinsically valuable, at least for herself, and in most cases we respect the individual’s reasoning.\(^7\) We should give equal consideration to the interests of others and should grant equal respect to the others’ life projects so long as these do not deliberately undermine the interests of others by interfering in a disrespectful manner. As John Rawls asserts, “the public culture of a democratic society” is committed to seeking forms of social cooperation that can be pursued on a basis of mutual respect between free and equal persons.\(^8\)

Kant’s line of reasoning should be supplemented by our emphasis on the notion of concern. We not only respect people but also care for them. Kant wanted to base his reasoning on logic, attempting to exclude emotional worries, but we need to acknowledge that persons’ acts are often dictated by emotions. Human nature enables us to rationalize but it often is controlled by emotional drives. Thus it is not sufficient to speak only of respect. We should also speak of concern.\(^9\)

The notion of ‘concern’ signals the value of well-being: we ought to show equal concern for each individual’s good. Treating people with concern means treating them with empathy, viewing people as human beings who may be furious and frustrated, who are capable of smiling and crying, of careful-decision making and of impulsive reactions. ‘Concern’ does not demand giving equal weight, utilitarian fashion, to the welfare of a stranger as to the welfare of a person’s children.\(^10\) Instead, it means giving equal weight to a person’s life and autonomy.
Nothing should be done by the medical staff that might impair the patient’s dignity in keeping her alive. Some situations present grave difficulties, but physicians and nurses are said to give their foremost concern to keeping the dignity of gravely ill people. They take care of them; they clean them; they treat bodies that do not communicate with them as human beings. Physicians acknowledge that the introduction of tubes causes discomfort and may be painful to conscious patients. Any interference with the wholeness of the human body may be perceived as infringement of dignity. But as long as patients are not perceived as a means to something, and the prevailing view regarding patients is as objective ends, the attitude towards patients can be said to respect their dignity. This view perceives the patient’s existence in itself as an end. Keeping the dignity of patients requires that no other object can be substituted for such an end.

Generally speaking, the common denominator of patients who express a desire to die with dignity is the strong sense of autonomy. We are unable to control the moment we are born. We are able, to an extent, to control the moment we depart life. These patients insist on having this right. They wish to control the moment of their death. When life lost its appeal for them, they ask to die. Continuous life is perceived to them as disrespectful and agonizing. And they approach the medical profession for help because they do not wish to awaken to even more dreadful condition, in the event that their suicide attempt goes wrong and they will be required to live with the deteriorated consequences. In Oregon, research over the past few years have consistently showed that the most frequently mentioned end-of-life concerns are loss of autonomy, decreasing ability to participate in activities that made life enjoyable, and loss of dignity.¹¹

Patients who wish to die are usually inflicted with degenerative, incurable and painful diseases. They are gravely ill people who know that the death is near, and who wish
to cease fighting against it. Weighing the continuation of life against death they see more advantages in departing life than in maintaining them. In the Netherlands\textsuperscript{12} and Belgium,\textsuperscript{13} most of the people who approach physicians with requests for physician-assisted Suicide (PAS) and euthanasia are cancer patients. Cancer is a painful disease that inflicts significant suffering.\textsuperscript{14} Many patients do not wish to fight against it for too long.

For some strong-willed, suffering patients physician-assisted suicide is a solution. They would like to decide the time of their death. Only they can say: “Enough is enough. Now it is time to say good bye, because I can no longer cope with my state, and because medicine does not have a cure for me.” Physician-assisted suicide can be the solution especially for suffering cancer patients, at the last stage of their lives. It is humane to cater for these people, enabling them to die at their own bed, in the company of their loved-ones. Respecting those patients dictates honouring their request to end their life-journey.

One of the conclusions that I reached through my 20 + years of research is to advocate voluntary physician-assisted suicide and not active euthanasia. The Dutch do not pay much notice to the distinction between the two, although it is viable. Physician-assisted suicide provides control to the patients until the very last moment of their lives, prevents possible abuse, and assures that they wanted to die. In most cases, patients are able to do the final act to terminate their lives. In the rare occasions of complete paralysis or suffocation to death, when the patient is absolutely unable to activate the lethal needle, only then the doctor may do the final act of mercy.\textsuperscript{15} It is one thing to support euthanasia on general moral principles, and quite another to support it in the face of reality. Ethically speaking, one may support euthanasia. Practically speaking, I do not, and as we are talking of end-of-life, practical considerations outweigh unfounded, purely philosophical argumentation. Indeed, for a number of years I supported euthanasia, believing in the
fundamental right of patients to seek unqualified help from their physicians. But I was forced to change my views after my fieldwork to the Netherlands and Belgium, the two countries that legislated euthanasia. A fine line distinguishes between theoretical principles and health policy. The health policy in both countries is insufficient, to date, to prevent abuse. Every year, a worrying number of patients are killed without a pronounced wish to die.¹⁶ I cannot support such a system. Thus my plea is confined to physician-assisted suicide, where the final act is performed by the patient, not the physician.

Guidelines for Physician-assisted Suicide (PAS)

The right to die with dignity includes the right to live with dignity until the last minute and the right to part from life in a dignified manner. There are competent, adult patients who feel that the preferable way for them to part from life is through physician-assisted suicide. The following is a circumscribed plea for voluntary physician-assisted suicide on their behalf.

Guideline 1. Physicians are best equipped in terms of knowledge and expertise to provide aid-in-dying. It is the only profession that could come to aid patients who insist on their right to die. The medical profession is in flux. The rapid scientific and technological progress, the rise of chronic disease, the ability to keep chronic patients alive for many years, and the democratization of knowledge are all important in the shaping of medicine. The medical profession should be attentive to wishes of all patients, and strive to accommodate their wishes. In this context, the Croatian Medical Chamber’s Code of Medical Ethics and Deontology (2006) holds: “One of primary obligations upon a medical doctor who has a patient in care is to relieve that patient’s pain and suffering. That is especially important in providing treatment and care to terminally ill and dying patients”.¹⁷
Guideline 2. The physician should not suggest assisted suicide to the patient. Instead, it is the patient who should have the option to ask for such assistance. Initiation by the physician might undermine the trust between the patient and the physician, conveying to patients that the doctor is giving up on them and values their lives only to the extent of offering assistance to die. Such an offer might undermine the will to live and to explore further avenues for treatment. Many Dutch researchers and physicians do not see this issue as a significant one. Some of them consider it important to raise the issue when it seems that patients do not dare to initiate it on their own. Undoubtedly, however, all people in the Netherlands are aware of the availability of euthanasia and physician-assisted suicide. Any reluctance shown by patients in regard to this issue should be honoured and respected.

Guideline 3. The request for physician-assisted suicide of an adult, competent patient who suffers from an intractable, incurable and irreversible disease must be voluntary. The patient should state this wish repeatedly over a period of time. We must verify that the request for physician-assisted suicide does not stem from a momentary urge, an impulse, a product of passing depression. This emphasis of enduring request was one of the requirements of the abolished Northern Territory law in Australia, and is one of the requirements of the Oregon Death with Dignity Act, as well as of the Dutch and Belgian legal guidelines. It should be ascertained with a signed document that the patient is ready to die now, rather than depending solely upon directives from the past. Section 2 of the Oregon Act requires that the written request for medication to end one’s life be signed and dated by the patient and witnessed by at least two individuals who, in the presence of the
patient, attest to the best of their knowledge and belief that the patient is capable, is acting voluntarily, and is not being coerced to sign the request.\textsuperscript{23} 

Individuals may express general attitudes regarding end of life in an informal discussion made in a social setting, possibly saying that they would not want to live if they were unable to function alone and had to depend on the mercy of others. However, such hypothetical observations do not constitute reliable evidence of a patient’s current desires once an actual illness is in progress. This is especially true if the wish was stated when young and healthy. The younger people are and the further they are from serious disease, the more inclined they are to claim that in a hypothetical state of pain, degradation and hopelessness, they would prefer to end their lives. On the other hand, there is a tendency to come to terms with suffering, to compromise with physical disabilities, and to struggle to sustain life. This tendency grows as the body weakens. Many people change their minds when they confront the unattractive alternatives, preferring to remain in what others term the “cruel” world, and continue the Sisyphean struggle for their lives.

\textit{Guideline 4.} At times, the patient’s decision might be influenced by severe pain. The Oregon \textit{Death with Dignity Act} requires the attending physician to inform the patient of all feasible alternatives, including comfort care, hospice care and pain control.\textsuperscript{24}

\textit{Guideline 5.} The patient must be informed of the situation and the prognosis for recovery or escalation of the disease, with the suffering that it may involve. There must be an exchange of information between doctors and patients.\textsuperscript{25}
Guideline 6. It must be ensured that the patient’s decision is not a result of familial and environmental pressures. At times, patients may feel that they constitute a burden on their loved ones. It is the task of social workers to examine patients’ motives and to see to what extent they are affected by various external pressures (as opposed to a truly free will to die). A situation could exist in which the patient is under no such pressure, but still does not wish to be a burden on others. Obviously, we cannot say that the feelings of patients toward their loved ones are not relevant to the decision-making process.26

Guideline 7. The decision-making process should include a second opinion in order to verify the 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, either professionally or otherwise, should provide the second opinion.27 A Dutch study reveals that the nature of the relationship with the consultant in the euthanasia decision-making process was sometimes unclear. The consultant was reported to have been an unknown colleague (39%), a known colleague (21%), otherwise (25%), or not clearly specified in the report (24%). Review committees relatively often scrutinized the consultation process (41%).28 The patient’s attending physician, who supposedly knows the patient’s case better than any other expert, must be consulted, and all reasonable alternative treatments must be explored. The Oregon Death with Dignity Act requires that a consulting physician shall examine the patient and his/her relevant medical records and subsequently confirm, in writing, the attending physician’s diagnosis that “the patient is suffering from a terminal disease.” Furthermore, the consulting physician must verify that the patient is capable, is acting voluntarily, and has made an informed decision.29 The Northern Territory Rights of
Terminally Ill Act required that a physician who specialized in treating terminal illness examine the patient.30

Guideline 8. It is advisable for the identity of the consultant to be determined by a small committee of specialists who will review the requests for physician-assisted suicide. This is in order to avoid the possibility of arranging deals between doctors (“you will consult for me regarding Mr. Jones, approving my decision, and I will consult for you regarding Ms. Smith, approving your decision”).31

Guideline 9. Some time prior to the performance of physician-assisted suicide, a doctor and a psychiatrist are required to visit and examine the patient so as to verify that this is the genuine wish of a person of sound mind who is not being coerced or influenced by a third party. The conversation between the doctors and the patient should be held without the presence of family members in the room in order to avoid familial pressure. A date for the procedure is then agreed upon. The patient’s loved ones will be notified so that they can be present right until the performance of the act, making the day an intimate, family occasion.

Guideline 10. The patient can rescind at any time and in any manner. This provision was granted under the Australian Northern Territory Act32 and under the Oregon Death with Dignity Act.33 Chapter III, Article 4 of the Belgian Euthanasia Law says that patients can withdraw or adjust their euthanasia declaration at any time.34

Guideline 11. Physician-assisted suicide may be performed only by a doctor and in the presence of another doctor. The decision-making team should include at least two doctors
and a lawyer, who will examine the legal aspects involved. Insisting on this protocol would serve as a safety valve against possible abuse. Perhaps a public representative should also be present during the entire procedure, including the decision-making process and the performance of the act. This extra caution should ensure that the right to die with dignity does not become a duty. It will contribute to reporting of cases. The experiences of both the Netherlands and Belgium raise alarm light as many end-of-life cases are not been reported. In Belgium, only one out of two euthanasia cases is reported to the Federal Control and Evaluation Committee.\(^\text{35}\) The doctor performing the assisted suicide should be the one who knows the patient best, having been involved in the patient’s treatment, taken part in the consultations, and verified through the help of social workers, nurses and psychologists that PAS is the true wish of the patient.

*Guideline 12.* Physician-assisted suicide may be conducted in one of three ways, all of them discussed openly and decided upon by the physician and the patient together: (1) oral medication; (2) self-administered, lethal intravenous infusion; (3) self-administered lethal injection. Oral medication may be difficult or impossible for many patients to ingest because of nausea or other side effects of their illnesses. In the event that oral medication is provided and the dying process is lingering on for long hours, the physician is allowed to administer a lethal injection.\(^\text{36}\)

*Guideline 13.* Doctors may not demand a special fee for the performance of assisted suicide. The motive for physician-assisted suicide is humane, so there must be no financial incentive and no special payment that might cause commercialization and promotion of such procedures.
**Guideline 14.** There must be extensive documentation in the patient’s medical file, including the following: diagnosis and prognosis of the disease by the attending and the consulting physicians; attempted treatments; the patient’s reasons for seeking physician-assisted suicide; the patient’s request in writing or documented on a video recording; documentation of conversations with the patient; the physician’s offer to the patient to rescind her request; documentation of discussions with the patient’s loved ones; and a psychological report confirming the patient’s condition. This meticulous documentation is meant to prevent exploitation of any kind -- personal, medical, or institutional. Each report should be examined by a coroner following completion of the physician-assisted suicide.37

**Guideline 15.** Pharmacists should also be required to report all prescriptions for lethal medication, thus providing a further check on physicians’ reporting.38

**Guideline 16.** Doctors must not be coerced into taking actions that contradict their conscience or their understanding of their role.

**Guideline 17.** The local medical association should establish a committee, whose role will be not only to investigate the underlying facts that were reported but also to investigate whether there are “mercy” cases that were not reported and/or that did not comply with the Guidelines.

**Guideline 18.** Licensing sanctions will be taken to punish those health care professionals who violated the Guidelines, failed to consult or to file reports, engaged in involuntary
termination of life without the patient’s consent or with patients lacking proper decision-making capacity. Physicians who failed to comply with the above Guidelines will be charged and procedures to sanction them will be brought by the Disciplinary Tribunal of the Medical Association. The maximum penalty for violation of the Guidelines will be the revoking of the physician’s medical license. In the event that this penalty proves insufficient in deterring potential abusers, there will be room to consider further penalties, including heavy fines and prison sentences.

Guideline 19. An annual report should be published documenting all cases of aid-in-dying. The reports should be made available to the public. Discussions and debates about their findings should be promoted and encouraged.

Conclusion
Treating patients with respect means treating them as human beings that are capable of forming and acting on intelligent conceptions of how their lives should be lived. Respecting a person involves giving credit to the other’s ability for self-direction, acknowledging the other’s competence to exercise discretion when deciding between available options. Accordingly, each person is viewed as speaking from that person’s point of view, having perceived interests in his or her own way. We may be asked to give our opinions, or decide to express our views anyway; nevertheless, in many instances we recognize the other’s right to make choices. This notion of autonomy is crucial in our considerations. The medical profession is required to respect the wishes of certain incurably ill patients.

While most patients prefer continue living even when their health deteriorates significantly, some patients would rather die. The medical profession should not turn its
back to these patients. The medical profession should cater for the needs of all patients, not only some of them. It should be cognizant of their self-perception and their subjective view of their dignity. The thesis is that patients, as autonomous moral agents, deserve to be treated with dignity and respect until the very last day of their lives. To treat a person with dignity and respect requires an acknowledgement of her choices and life decisions. If a patient decides that her life is no longer worth living, we should respect that decision and not compel her to live. Coercion is repulsive. At the same time, a voice of caution is raised in the conducting of mercy killing, thus detailed Guidelines are required to prevent abuse. As human life is at stake, caution is simply a must.


3 See Israel Dying Patient Law, Chapter C, Section 4 (December 15, 2005).


6 The postulate, “You ought never to tell lies” is an example of the Categorical Imperative. There is no way of evading the command or the moral requirement of practical reason that it expresses, for no end is mentioned and there is therefore no end that can be given up. For further discussion, see J. Kemp, The


http://www.cancer-pain.org/treatments/treatments.html

15 R. Cohen-Almagor, *The Right to Die with Dignity: An Argument in Ethics, Medicine, and Law, and Euthanasia in the Netherlands*.


20 *Section 7, Rights of the Terminally Ill Act (1995)* (NT).


25 On this issue, see *Oregon Death with Dignity Act*, Section 3, Attending physician responsibilities. Many bill proposals to legislate PAS in the United States specify certain information that must be communicated by the physician to the patient before honouring her request. See also Chap. II, Article 3 of the Belgian Euthanasia Law.


