A Dozen Caveats Concerning the Discussion of Euthanasia in the Netherlands

As the discussion of voluntary active euthanasia heats up in the United States, increasing attention is being given to its practice in the Netherlands. There, euthanasia (and with it, physician-assisted suicide) is more and more openly discussed and practiced; it is performed with the knowledge of the legal authorities; physicians who follow the guidelines are protected from prosecution; and, as a result of broad public discussions of the issue in the media, euthanasia is familiar to virtually all Dutch residents as an option in end-of-life medical care.

In the United States, those who think euthanasia should be legalized often cite the Netherlands as a model of conscientious practice; those who think it should not be legalized, on the other hand, often claim that Dutch practice already involves abuse and will inevitably lead to more. For the most part, these generalizations invite misunderstanding, and they often reflect only the antecedent biases of those who make them. I would like to offer a few caveats for those about to become embroiled in the discussion of euthanasia, as the United States debates whether it, too, will permit this practice—caveats offered in the hope of contributing to better mutual understanding rather than greater polarization over this extremely volatile issue.

1. Legal claims are misleading, either way. Many American observers of the Dutch practice of euthanasia are tempted to claim that euthanasia is legal in Holland; others insist that it is not. Both are right—but only partly so. Killing at the request of the person killed as well as assistance in suicide remain crimes under the Dutch penal code, punishable by imprisonment; however, several lower court decisions, supported by a Supreme Court decision and reflected in the policies of the regional attorneys-general, and further promulgated by the Royal Dutch Medical Association, have held that when euthanasia meets a certain set of guidelines it may be...
defended under a plea of *force majeure* and so is reasonably sure of not being subjected to prosecution. In February 1993, these provisions were accepted by the Second Chamber of the Dutch Parliament, and, if accepted in the fall of 1993 by the First Chamber as well, will be enacted into law. While euthanasia will still remain technically illegal by statute, the physician who conscientiously meets the guidelines in practicing it can be sure he or she will not be prosecuted. These guidelines, sometimes called "rules of due care," are not to be understood as rules in a legal sense and are not themselves incorporated into any statute or regulation (this may explain why they are so variously stated), but rather as a set of "points for consideration," the questions the physician must answer to the Ministry of Justice as it decides whether he or she has met the guidelines, and hence whether a given case of euthanasia is to be prosecuted. Nevertheless, these guidelines have come to define the Dutch consensus on when euthanasia is permitted. They are as follows; I’ve roughly divided them into two groups:

**Substantive Guidelines**

(a) Euthanasia must be voluntary; the patient’s request must be seriously considered and enduring.

(b) The patient must have adequate information about his or her medical condition, the prognosis, and alternative methods of treatment.

(c) The patient’s suffering must be intolerable, in the patient’s view, and irreversible (though it is not required that the patient be terminally ill).

(d) It must be the case that there are no reasonable alternatives for relieving the patient’s suffering that are acceptable to the patient.

**Procedural Guidelines**

(e) Euthanasia may be performed only by a physician (though a nurse may assist the physician).

(f) The physician must consult with a second physician whose judgment can be expected to be independent.

(g) The physician must exercise due care in reviewing and verifying the patient’s condition as well as in performing the euthanasia procedure itself.

(h) The relatives must be informed unless the patient does not wish this.

(i) There should be a written record of the case.

(j) The case may not be reported as a natural death.

Is euthanasia legal or illegal? It is a violation of the statute but is *gedoogd or "tolerated"* if it meets these guidelines, and will not be prosecuted. Yet it is not excused in advance, and the plea of *force majeure*, although often compelling in single cases, does not easily serve as a basis for policy. Until 1990, it was required that any case of euthanasia be reported to the police and investigated after the fact, further prosecution being set aside if the case met the guidelines; in fact, comparatively few cases were reported, and physicians complained that they—and patients’ families—were being treated as criminal suspects even when they had met all the guidelines. Policy changes in 1990 avoided the step of initial reporting to and investigation by the police; instead, the physician provides a written account of the case to the medical examiner, who then forwards it to the public prosecutor. If the
criteria are satisfied, a certificate of "no objection to burial or cremation" is issued and there is no further investigation. These policy changes, however, have not altered the delicate legal status of euthanasia in the Netherlands—prohibited by law, but tolerated under guidelines developed in the courts, and now recognized though not stated in the law—a delicate balance often misunderstood by outside commentators. This delicate legal status has been seen by many observers as a deterrent to abuse; it is also seen by some as accounting for a great deal of the underreporting. In any case, it is clear why the legal status of euthanasia in the Netherlands is so frequently misinterpreted by American commentators: its delicate balance between legality and illegality—the Dutch posture of "tolerance"—would be difficult to replicate in the American legal system.

2. Exaggerations are frequent. It is also sometimes supposed that euthanasia is a routine, frequent, everyday practice in the Netherlands, a commonplace that happens all the time. On the contrary, euthanasia is comparatively rare. There are about 2,300 cases of euthanasia per year; these represent just 1.8 percent of the total annual mortality, which in 1990, was 128,786 deaths in a population of about 15 million. In addition, there are about 400 cases of physician-assisted suicide, just 0.3 percent of the total annual mortality. Although a substantial proportion of patients, about 25,000 a year, seek their doctors' reassurance of assistance if their suffering becomes unbearable, only 9,000 explicit requests for euthanasia are made annually, and of these, fewer than one third are honored. Thus, the contention sometimes heard that there is widespread euthanasia on demand is seriously exaggerated. The actual frequency of euthanasia is about 1 in 25 deaths that occur at home, about 1 in 75 in hospital deaths, and about 1 in 800 for deaths in nursing homes.[4]

3. The institutional circumstances of euthanasia in the Netherlands are easily misunderstood. Although many American observers of Dutch euthanasia risk misinterpreting many features of this practice, a particularly frequent error arises from failing to appreciate differences between health-care delivery systems and other social institutions in the Netherlands and those in the United States. In the United States virtually all physician care is provided in a professional or institutional setting: an office, clinic, care facility, or hospital. By contrast, most primary care in the Netherlands is provided in the patient's home or in the physician's home office by the huisarts, the general practitioner or family physician. The family physician, who typically serves a practice of about 2,300 people and is salaried on a capitation basis rather than paid on a fee-for-service basis, typically lives in the neighborhood and makes frequent house calls when a patient is ill. This provides not only closer, more personal contact between physician and patient but also an unparalleled opportunity for the physician to observe features of the patient's domestic circumstances, including any family support or pressures that might be relevant in a request for euthanasia.

Furthermore, all Dutch have a personal physician; this is a basic feature of how primary care is provided within the Netherlands' national health system. While euthanasia is sometimes performed in hospitals (about 700 of the 2,300 cases), usually when the family physician has been unable to control the patient's pain and it has been necessary to readmit the patient to the hospital, or when the patient has had extensive hospital care and feels most "at home" there, and while most hospitals
now have protocols for doing so, the large majority of cases take place in the patient's home, typically after hospitalization and treatment have proved ineffective in arresting a terminal condition and the patient has come home to die. In these settings, euthanasia is most often performed by the physician who has been the long-term primary care provider for the family, and it is performed in the presence of the patient's family and others whom the patient may request, such as the visiting nurse or the pastor, but outside public view. Yet the (non)institutional circumstances of euthanasia in the Netherlands are not easy for Americans to understand: whereas dying at home is not unusual in the Netherlands (about 40 percent of Dutch deaths occur at home, and 48 percent of cancer deaths), in the United States as many as 85 percent of deaths occur in a hospital or other health-care institution, where attendance by a long-term family physician is far less frequently the case.

4. **Euthanasia isn't routine or anonymous.** Especially in the United States, euthanasia is often understood on the "It's Over, Debbie" model, derived from the notorious account in a 1988 issue of the *Journal of the American Medical Association*, which described a sleepy resident giving a lethal dose in the middle of the night to a young woman dying of ovarian cancer—a patient he'd never seen before, whose chart he had not actually examined, with whose unidentified companion sitting by the bed he had no communication, for whom he made no attempt to provide other treatment or better pain control, and with whom he exchanged only the briefest of words.

"Let's get this over with," Debbie said, in the midst of her pain. The resident ordered a syringe of morphine sulfate drawn and—telling Debbie only that he would give her something to "let her rest" and that she should say goodbye—killed her. In fact, "It's Over, Debbie" is a virtual compendium of all that is not tolerated in Holland. Euthanasia is typically performed by the patient's personal physician, not a stranger; it is performed within the context of an extended period of consultation and care. Not only is it usually performed at home with the patient's family present, but the physician remains with the patient or in an adjoining room throughout the process. The physician takes no fee for performing euthanasia. Nor will Dutch physicians perform euthanasia for patients from other countries, with whom they have had no prior contact. Fears sometimes voiced in the United States concerning the commercialization of euthanasia or the development of a death trade, practiced for profit by greedy physicians, have no place in Holland. Euthanasia remains a rare event, generally presupposing a long-term relationship between physician and patient, and it involves an often substantial commitment of time with no financial reward.

5. **There isn't enough hard data about the practice of euthanasia in the Netherlands.** Until the appearance of two large empirical studies in 1991–1992, very little hard data had been available about the practice of euthanasia in the Netherlands, even though the practice had become open, vigorously discussed, and legally tolerated. Despite the policy that cases of euthanasia were to be reported to the Ministry of Justice by physicians who performed them, in 1986 only 84 cases were reported (now estimated to have been 3 percent of the total), and by 1990 only 454 (about 17 percent). This generated an extensive amount of conjecture about the unreported cases, variously estimated to range in frequency between 2,000 and 20,000, and
invited the accusation that these cases were unreported because Dutch physicians had something to hide.

Two major empirical studies of the actual practice of euthanasia in the Netherlands were published in 1991–1992: the government-sponsored study popularly known as the Remmelink Commission report (named after Professor J. Remmelink, attorney general of the Dutch Supreme Court, who chaired the committee to which it was presented)\(^6\) and a dissertation presented at the Free University in Amsterdam by Gerrit van der Wal.\(^7\) Although the Remmelink Commission study involved a much more complex design, covered a wider range of physicians (including specialists and nursing home physicians), and received a great deal more attention than the van der Wal study of family-practice physicians only, the two studies were similar in many respects. Although their range was different, both sought to discover what Dutch physicians actually do and do not do as their patients approach death; both attempted to assess the frequency of euthanasia in the Netherlands; both attempted to assemble information about the characteristics of patients, the nature of their requests for euthanasia, and the nature of the physician’s response; and both were alert to the possibility of abuse. Both studies involved surveys of physicians under the strictest guarantees of confidentiality, and both achieved high response rates. The Remmelink study included extensive direct interviews with a large sample of physicians; the van der Wal study examined police reports. Both studies were well designed, and both quite informative.

Furthermore, the two studies agreed in many of their results. Although based on extrapolations from different survey populations, they came very close in their estimates of the overall frequency of euthanasia in the Netherlands. According to the Remmelink report, of the approximately 2,300 cases of euthanasia a year, about 1,550 are performed by general practitioners, 730 by specialist physicians, and about 20 by nursing home physicians. In addition, there are another 400 cases of physician-assisted suicide. Van der Wal found a combined total of about 2,000 euthanasia and assisted-suicide cases per year in general practice alone. These studies thus revised the previously accepted best estimate of 6,000 cases a year (not to mention the extreme estimate of 20,000 cases a year) dramatically downward. Both studies agreed that euthanasia was far more frequent than assisted suicide. Both found that only a minority of requests for euthanasia are honored. Both studies examined the reasons why patients request euthanasia, and both found that pain is very seldom (about 5 percent in both studies) the sole reason, though pain is often (46 percent) one reason among others. Both found that the diagnosis in the majority of cases is cancer and that the average age of euthanasia patients is in the sixties. The Remmelink study found that euthanasia is slightly less common among men than women (48 percent males, though there was no significant difference) while assisted suicide is more common for men than women (61 percent males), and van der Wal found that euthanasia is about equal for both sexes. Both studies found that the estimated life expectancy for patients receiving euthanasia is usually a week or two, though in a small fraction of cases it is longer than six months and in another small fraction it is less than a day. And both also revealed the existence of cases that do not strictly fit the guidelines.

As extensive as the contributions of these two studies to the discussion of
euthanasia in Holland have been, however, there still is not enough hard data. To be sure, some further information has become available: for example, the researchers who prepared the report to the Remmelink Commission have recently published a more intensive study of the findings in about a thousand cases that involve active termination but without explicit, current request from the patient; this took the form of three representative case scenarios. But there is not yet a broad collection of what one might call phenomenological data: interior narrations by patients themselves of their experiences as they decide to request euthanasia—perhaps available from personal journals, dictations to family members, direct interviews, diaries, and the like—that might shed further light on the nature of such choices, though there have been a few documentaries and real-life interviews (for instance, on television) between physicians and patients. A participant-observer study of euthanasia is now in progress, as well as a small, anecdotal study involving interviews of family members concerning their grieving processes following the euthanasia of a loved one. But there are neither hard nor soft comprehensive data on the perceptions of family members, nurses, clergy, or others who might have played an observer’s role, nor on the perceptions of patients themselves. In short, there is still a great deal more to be learned about the practice of euthanasia in Holland. The two studies now available should be understood as crucial first contributions of empirical information rather than as the last word.

6. Terminological differences operate to confuse the issue. By and large, Dutch proponents of euthanasia use the term to refer only to what in the United States would be called voluntary active euthanasia. The term active euthanasia is considered essentially redundant and the term passive euthanasia meaningless. The Remmelink study examined not only euthanasia and assisted suicide, but also drew distinctions between withdrawal and withholding of treatment (approximately 17.5 percent of deaths) and the use of opiates while “taking into account the probability of hastening death” (another 17.5 percent of deaths). The latter phrase was chosen deliberately to cover such actions as the heavy use of morphine to control pain, even though this might depress respiration and thus bring about death, which are understood under the principle of double effect. However, the Dutch also employ the term levensbeëindigend handelen (“life-terminating acts”) to refer to practices that result in the death of the patient but cannot be considered voluntary active euthanasia; this term is sometimes used broadly to encompass all withholding or withdrawing treatment, including, for instance, that in severely defective newborns, permanent coma patients, and psychogeriatric patients (all of these are situations in which withholding or withdrawing treatment is also frequent in the United States), and it is sometimes used (as in the Remmelink study) to refer to direct termination. The Remmelink researchers defined a category of practices they more narrowly called “life-terminating acts without explicit request” or LAWER; this category includes the 1,000 cases (0.8 percent of the total annual mortality) of actively caused deaths where there was no current, explicit request. Since these cases do not fit the criteria for euthanasia, they are not labeled by that term. Thus, the claim that there is no nonvoluntary active euthanasia in Holland may seem to be merely analytically true.

On the other hand, it is clear that claims by some of the more vocal opponents of euthanasia also rest on terminological confusion. For instance, Dutch cardiologist
Richard Fenigsen's assertion that involuntary euthanasia outside the guidelines is widespread rests on his confounding what in the United States would be called active and passive euthanasia: Fenigsen, like many others of the opposition, does not always distinguish between causing death and withholding or withdrawing treatment, that is, what we call "allowing to die." In the United States, withholding or withdrawal of treatment, including respiratory support, antibiotics, chemotherapy, cardiopulmonary resuscitation, and artificial nutrition and hydration, tends to be regarded as morally acceptable in certain circumstances, even when these decisions are not actually made by the patient but by second parties, perhaps following the patient's antecedent wish (a view reflected in many of the cases from Quinlan to Cruzan), whereas, on the other hand, the direct causing of death, even at the current, explicit request of the patient, is regarded as problematic in the extreme. In the Netherlands, the view tends to be the other way around. One suspects that much of the opposition in Holland to active voluntary euthanasia has actually been opposition to passive nonvoluntary euthanasia, a practice much more accepted in the United States than in the Netherlands. It is often said in the United States that the Dutch are stepping out onto the slippery slope in permitting active euthanasia; the Dutch, in contrast, think it is we who are already on the slippery slope, given our readiness to "allow to die" in ways that are not voluntary on the part of the patient. As the Dutch now begin more open discussion of decision-making concerning incompetent patients, they are entering a territory already heavily discussed in the United States in the cases from Quinlan to Cruzan; as Americans begin to debate the issues in first-party choices of euthanasia or assisted suicide, we are entering territory already well familiar to the Dutch.

7. The Dutch don't want to defend everything. The Dutch are sometimes accused of being self-serving or, alternatively, of being self-deceived in their efforts to defend the practice of euthanasia. To be sure, not all Dutch accept the practice. There is a vocal group of about a thousand physicians adamantly opposed to it, and there is some opposition among the public and within specific political parties (in particular, the Christian Democratic Party, which has for years controlled the Netherlands' coalition government) and religious groups (especially the Catholic church). Yet the practice is supported by a majority of the Dutch populace (rising from 40 percent in 1966 to 78 percent in 1992) as well as a majority of Dutch physicians. Of physicians interviewed for the Remmelink study, 54 percent said they had practiced euthanasia at the explicit and persistent request of the patient or had assisted in suicide at least once (62 percent of the general practitioners, 44 percent of specialists, and 12 percent of nursing home physicians), and only 4 percent said they would neither perform euthanasia nor refer a patient to a physician who would. In the words of the Remmelink Commission's comment on the report, "a large majority of physicians in the Netherlands see euthanasia as an accepted element of medical practice under certain circumstances." But this is not to say that the Dutch seek to whitewash the practice. They are disturbed by reports of cases that do not fit the guidelines and are not explained by other moral considerations, although these may be quite infrequent. Of the approximately 1,000 cases of active termination in which there was no explicit, current request—the LAWER cases—36 percent of patients were competent, the physician
knew the patient for an extended period (on average, 2.4 years for a specialist physician, or 7.2 years for a huisarts or general practitioner), and in 84 percent life was shortened somewhere between a few hours and a week. Because there was no current, explicit request, these cases are sometimes described in the United States as cold-blooded murder, yet most are explained by other moral considerations. Of these 1,000 cases, according to the Remmelink researchers in both the initial and supplementary reports, about 600 did involve some form of antecedent discussion of euthanasia with the patient. These ranged from a rather vague earlier expression of a wish for euthanasia, as in comments like “If I cannot be saved anymore, you must give me something,” or “Doctor, please don’t let me suffer for too long,” to much more extensive discussions, yet still short of an explicit request. (Thus, these cases are best understood in a way that approximates them to advance-directive cases in other situations.) In all other cases, discussion with the patient was no longer possible. In almost all of the remaining 400 cases, there was neither an antecedent nor current request from the patient, but at the time of euthanasia—“possibly with a few exceptions”—the patient was very close to death, incapable of communication, and suffering grievously. For the most part, this occurred when the patient underwent unexpectedly rapid deterioration in the final stages of a terminal illness. (These cases are best understood as cases of mercy killing, with emphasis on the motivation of mercy.) In these cases, the report to the Remmelink Commission continued, “the decision to hasten death was then nearly always taken after consultation with the family, nurses, or one or more colleagues.” Most Dutch also defend these cases, though as critics point out, the danger here is that the determination of what counts as intolerable suffering in these cases is essentially up to the doctor.

Direct termination of life is also performed in a handful of pediatric cases, about ten a year, usually involving newborns with extremely severe deficits who are not in the ICU and from whom, therefore, life-prolonging treatment cannot be withdrawn. These cases are regarded as difficult and controversial. Equally controversial—and as rare or rarer—are cases concerning patients in permanent coma or persistent vegetative state; patients whose suffering, though intolerable and incurable, is mental rather than physical; and patients who have made explicit requests for euthanasia by means of advance directives, but after becoming incompetent no longer appear to be suffering.

The Remmelink study also provided some suggestion, though no clear evidence, that there may be a small fraction of cases in which there is no apparent choice by the patient and in which a merciful end of suffering for a patient in extremis is not the issue. These cases do disturb the Dutch: they are regarded as highly problematic, and it is clearly intended that if they occur, they should be stopped. In the Remmelink study, interviews with physicians revealed only two instances, both from the early 1980s, in which a fully competent patient was euthanized without explicit consent; in both, the patient was suffering severely. In the Remmelink study interview, the physician in one of these cases indicated that under present-day circumstances, with increased openness about these issues, he probably would have initiated more extensive consultations. There is no evidence of any patient being put to death against his or her expressed or implied wish.

The Dutch also distinguish between procedural and substantive or material fail-
ures to meet the guidelines, regarding the latter as much more problematic than the former. They note that failure to meet the procedural requirements of the guidelines is not uncommon; for instance, according to van der Wal, only 75 percent of family doctors asked another doctor for a second opinion, slightly fewer than half (48 percent) had kept written records, and 74 percent has issued a false death certificate, stating that the death was due to natural causes. Only around a quarter had reported performing euthanasia to the Ministry of Justice, and as van der Wal pointed out, “cases that reveal shortcomings are hardly ever reported to the Public Prosecutor.” 17 Procedural failures do not particularly trouble the Dutch, but they are alert to cases in which euthanasia was performed against the wishes of the patient or for ulterior reasons. Neither study yielded concrete information about any such cases, although neither study denied that such cases (“a few exceptions”) might occur.

To understand how the Dutch defend their practice of euthanasia, given the possibility of such cases, a domestic analogy may be helpful. We, like the Dutch, recognize and defend the practice of marriage: it is enshrined in our law, our religions, and our cultural norms. Among other things, we understand this practice to be quintessentially voluntary: in order to marry, the parties involved must each choose freely to do so, and their signatures on the marriage license serve to attest to this fact. But we also recognize that some marriages are not voluntary: shotgun weddings, for example, in which the groom has been threatened by the father of the pregnant bride or in which the bride sees no alternative to marrying the man who has impregnated her. Yet although we recognize that physically or socially coerced marriages do occur from time to time, we continue to defend the institution of marriage, claiming that coerced marriages aren’t really central to the practice we otherwise respect. The Dutch attitude toward euthanasia is a bit like this, though coerced marriages are no doubt a good deal more frequent than problematic cases of euthanasia: it is the practice that is defended, not each single case that occurs within or around it. On the contrary, the Dutch seek to control these few problematic cases on the fringes—that is part of the point of bringing the practice out into the open. The Dutch government has recently indicated its intention that physicians performing LAWER will as a rule be prosecuted (though this does not guarantee that all prosecutions will result in conviction), presumably as a way of asserting more thorough control over this practice and eliminating the risk of abuse.

8. There are no “indications” for euthanasia. In the Netherlands, euthanasia is understood by definition to mean voluntary euthanasia, and nonvoluntary practices, such as the thousand cases of “life-terminating acts without explicit request,” are not grouped under this term. Nor are the two additional categories of practices, mentioned earlier, which were treated as distinct “medical decisions concerning the end of life” in the Remmelink and van der Wal reports (as they are also in the United States): doses of opiates intended to relieve pain but which, foreseeably, may shorten life; and discontinuations or withholdings of treatment, even when death is likely to be the outcome. But although patient choice is a necessary condition for euthanasia, it is not a sufficient condition; the patient who requests euthanasia is not thereby guaranteed it and does not oblige a physician to perform it. Indeed, according to both empirical studies, the majority of requests for euthanasia (60–67 percent) are turned down.
This situation, however, has led some observers to wonder whether there isn’t a set of criteria developing for the performance of euthanasia that could in effect serve as indications. If physicians reject up to two-thirds of the requests for euthanasia, it is argued, they must be entertaining some set of criteria according to which some cases are to be accepted and others rejected—criteria other than patient choice. But if this is so, it is argued, it may invite a certain readiness to perform euthanasia whenever these criteria are met, independent of the patient’s choice. The Dutch would reply by arguing that there are no positive criteria for euthanasia, but that there are indeed negative criteria for when it is inappropriate to perform euthanasia—for example, when the request is motivated by depression or when suffering can be relieved by other means acceptable to the patient. Without positive criteria, “indications” for euthanasia cannot develop: that is, factors in the presence of which the physician ought to perform euthanasia and hence ought to “see to it” that the patient accepts this recommendation. While some Dutch physicians say they do sometimes introduce the topic of euthanasia if the patient has not raised it, they insist that it be performed only at the patient’s request, not as the result of consent to a procedure the physician has proposed. However, whether criteria are developing—perhaps under the guise of justifications—for life-terminating acts without explicit request, or LAWER, is another matter, perhaps the central (though not fully articulated) issue in the ongoing debate about how life may best end for incompetent patients, since in these cases patient choice is not possible anymore.

9. The Dutch see the role of law rather differently. Not only is Dutch law a civil law system rather than common law one; not only does it contain the distinctive Dutch doctrine involving practices that are statutorily illegal but gedogen, or tolerated, by the public prosecutor, the courts, or both; and not only does it involve very little medical malpractice activity, but the Dutch also tend to see law as appropriately formulated at a different point in the evolution of a social practice. Americans, it is sometimes said, begin to address a social issue by first making laws and then challenging them in court to fine-tune and adjust them; the Dutch, on the other hand, allow a practice to evolve by “tolerating” but not legalizing it, and only when the practice is adequately controlled—when they’ve got it right, so to speak—is a law made to regulate the practice as it has evolved. That the Dutch do not yet have a law fully shaped to accommodate their open practice of euthanasia may not show, as some have claimed, that they are ambivalent about the practice, but perhaps rather that they are waiting for the practice to evolve to a point where it is under adequate, acceptable control, at which time it will be appropriate to finally revise the law. Both early and recent attempts to completely legalize euthanasia have failed to satisfy enough parties (especially the Christian Democrats) within the Dutch coalition governments, though the 1993 changes, if passed, will provide much more protection than previously to both physicians and their patients. Some observers still think that there will be greater agreement before long, reflecting the end of the debate and the emergence of a social consensus. Of course, some commentators see the delicate balance in which the practice is technically illegal under Dutch law but also legally protected from prosecution by Dutch court decisions and legal policy as a desirable bulwark against abuse, but others argue for a more comprehensive revision of the statute, amending the penal code and spelling out in the Medical Practice Act the
conditions under which a physician could not be prosecuted. Full legalization, they argue, is crucial to providing legal security for both physicians and patients.

It has also often been suggested that it is not the delicate legal situation of euthanasia—tolerated by the courts, yet still technically prohibited by the law—that accounts for the underreporting of actual cases of euthanasia, but that the unreported cases were different and indefensible. Now, however, we know what the unreported cases are. Both the Remmelink and the van der Wal studies provide extensive detail about such cases, since they explored both reported and unreported cases. According to van der Wal, whose study included police reports among the sources of data, the reported cases and the unreported cases described by doctors in responding to the questionnaires differed with regard to procedural matters; the cases not reported tended to be those not meeting the procedural requirements, but the reported and unreported cases closely resembled each other in satisfying the substantive requirements concerning voluntariness, adequate information, the presence of intolerable suffering, and the absence of any acceptable alternatives for treatment. Thus, the unreported cases are those in which there are only procedural lapses to hide, not cases in which there is any greater frequency of substantive irregularities. The number of cases reported is currently climbing rapidly, partly due to simplified procedures and the requirement being dropped for investigation of the physician and the relatives by the police. In 1992, with simplified procedures, reporting reached almost half: 1,318, or 49 percent of the estimated total cases.

10. The economic circumstances of euthanasia in the Netherlands are also easily misunderstood. The Netherlands’ national system of mixed public and private health insurance provides extensive care to all patients, including all hospitalization, nursing home care, home care, and the services of physicians, nurses, physical therapists, nutritionists, counselors, and other care providers, both in institutional settings and in the home. Virtually all residents of the Netherlands, 99.4 percent, are comprehensively insured for all medical expenses (those who are not are those who, with incomes above a stipulated level, are wealthy enough to self-insure), and 100 percent are insured for the costs of long-term illness. All insurance, both public and private, has a mandated minimum level that is very ample. Americans who raise the issue of whether some patients’ requests for euthanasia are motivated by financial pressures or by fear of the effect of immense medical costs to their families are committing perhaps the most frequent mistake made by American observers: to assume that the choices of patients in the Netherlands are subject to the same pressures that the choices of patients in the United States would be. While there may be some administrative changes in the national health insurance system in the Netherlands in the near future, cost pressures on the system as a whole are met by rationing and queueing (neither currently severe), not by exclusion of individuals from coverage or by increased costs to patients. The costs to oneself or one’s family of an extended illness, something that might make euthanasia attractive to a patient in the United States, are something the Dutch patient need not consider.

11. Differences in social circumstances often go unnoticed. In American discussions of euthanasia, considerable emphasis is placed on slippery slope arguments, pointing out risks of abuse, particularly with reference to the handicapped, the poor, racial minorities, and others who might seem to be ready targets for involuntary
euthanasia. The Netherlands, however, exhibits much less disparity between rich and poor, has much less racial prejudice, virtually no uninsured people, and very little homelessness. These differences underscore the difficulty both of treating the Netherlands as a model for the United States in advocating the legalisation of euthanasia and also of assessing the plausibility of slippery slope arguments opposing legalisation in the United States.

12. *The situation isn't getting worse; it's getting better.* Many of the foreign commentators have interpreted those cases of which the Dutch are not proud and do not wish to defend as evidence that the Dutch are indeed sliding down the slippery slope, moving from sympathetic cases of voluntary euthanasia to morally indefensible, broader-scale killing motivated by such matters as impatience, money, or power. They cite several celebrated outlier cases involving gross violations of the guidelines, such as an infamous nursing-home case in which nurses administered euthanasia to a group of terminally ill, mentally disturbed cancer patients when a physician refused to do so, and the cases the Remmelink Commission report identified as falling outside a strict interpretation of the guidelines. The recognition that there are cases of life-terminating acts without explicit request, or LAWER, not counted as euthanasia contributes to this view. Furthermore, several commentators—especially Carlos Gomez and John Keown—have argued that the Netherlands' legal and other protections against future abuse are wholly inadequate.

But the Dutch themselves see things in quite a different way: that bringing euthanasia and related practices out into the open is a way of gaining control. For the Dutch, this is a way of identifying a practice that, in the Netherlands as in every other country (including the United States), has been going on undercover and entirely at the discretion of the physician. It brings the practice into public view, where it can be regulated by guidelines, judicial scrutiny, and the collection of objective data. It is not that the Dutch or anyone else have only recently begun to practice euthanasia for the dying patient, nor is this a new phenomenon in the last decade or so; rather, the Dutch are the first to try to assert formal public control over a previously hidden practice and, hence, to regulate it effectively. Both open public discussion and the development of formal mechanisms such as guidelines, hospital protocols, and reporting requirements are seen as crucial in developing a social consensus, understood and accepted by both physicians and patients, about what can and cannot be permitted.

These dozen caveats are intended to point to differences between the American and Dutch health care climates that are often unnoticed in the discussion of euthanasia, although they are only a few of the principal cautions that should be exercised in entering this discussion. There are a great many other differences between the United States and the Netherlands that pose further risks of misinterpretation and misunderstanding; however, because these two highly sophisticated, industrialized, modern nations resemble each other in so many ways—including the general forms of their economic systems, their common cultural roots in the European Enlightenment, their sophisticated medical systems, and so on—these differences often go unnoticed. It is unlikely that Americans can fully understand why the Dutch support their practice of euthanasia, and conversely, it is unlikely that the Dutch will understand why the Americans are so ambivalent about its legalisation or why they are so
likely to distort the Dutch practice, until these differences are incorporated into both sides of the debate. In doing this, our principal problem is to detach ourselves from the antecedent biases we Americans bring to this issue, rooted in our own troubled health-care climate, and to examine Dutch practices and the reasons for them with comparatively open minds.

Notes

I'd like to thank Hans van Delden, M.D. and Loes Pijnenberg, M.D. for comments on this expanded version.

1. The maximum sentence for euthanasia is twelve years' imprisonment; for assisted suicide, three years. See the Dutch Penal Code, sections 293 and 294.

2. *Force majeure*, entered as a plea by the physician, appeals to a conflict of duties in which he or she is both obligated to obey the law and, at the same time, to obey the demands of medical ethics and the explicit wishes of the patient who relies on him or her. It is the physician's professional obligations that force him or her to act against the formal provisions of the law. See Robert J. M. Dillmann, Gerrit van der Wal, and Johannes J. M. van Delden, "Euthanasia in the Netherlands: The State of Affairs," manuscript in progress, Royal Dutch Medical Association, P. O. Box 20051, 3502 LB Utrecht, The Netherlands, p. 5.

3. The following are the questions to which the physician must respond after performing a case of euthanasia.

GUIDELINES FOR THE ATTING PHYSICIAN IN REPORTING EUTHANASIA TO THE MUNICIPAL CORONER

The following list of points is intended as a guideline in reporting euthanasia or assistance provided to a patient in taking his or her own life to the municipal coroner. A full written report supplying motives for your action is required.

I. CASE HISTORY

1. What was the nature of the illness and what was the main diagnosis?
2. How long had the patient been suffering from the illness?
3. What was the nature of the medical treatment provided (medication, curative, surgical, etc.)?
4. Please provide the names, addresses, and telephone numbers of the attending physicians. What were their diagnoses?
5. Was the patient's mental and/or physical suffering so great that he or she perceived it or could have perceived it to be unbearable?
6. Was the patient in a desperate situation with no prospect of relief and was his/her death inevitable?
   a. Was the situation at the end such that the prognosis was increasing lack of dignity for the patient and/or such as to exacerbate suffering which the patient already experienced as unbearable?
   b. Was there no longer any prospect of the patient being able to die with dignity?
   c. When in your opinion would the patient have died if euthanasia had not been performed?
7. What measures, if any, did you consider or use to prevent the patient experiencing his/her suffering as unbearable (was there indeed any possibility of alleviating the suffering) and did you discuss these with the patient?
II. REQUEST FOR EUTHANASIA

1. Did the patient of his/her own free will make a very explicit and deliberate request for euthanasia to be performed:
   a. on the basis of adequate information which you had provided on the course of the illness and the method of terminating life, and
   b. after discussion of the measures referred to at 7?

2. If the patient made such a request, when and to whom was it made? Who else was present at the time?

3. Is there a living will? If so, please pass this on to the municipal coroner.

4. At the time of the request was the patient fully aware of the consequences thereof and of his/her physical and mental condition? What evidence of this can you provide?

5. Did the patient consider options other than euthanasia? If so, which options and if not, why not?

6. Could anyone else have influenced either the patient or yourself in the decision? If so, how did this manifest itself?

III. SECOND OPINION

1. Did you consult another doctor? If so, please provide his/her name, address, and telephone number. If you consulted more than one colleague, please supply all the names, addresses, and telephone numbers.

2. What conclusions did the other doctor(s) reach, at least with respect to questions 1.6 and 1.7?

3. Did this doctor/these doctors see the patient? If so, on what date? If not, on what were his/her/their conclusions based?

IV. EUTHANASIA

1. Who performed the euthanasia and how?

2. Did the person concerned obtain information on the method used in advance? If so, where and from whom?

3. Was it reasonable to expect that the administration of the euthanasia-inducing agent in question would result in death?

4. Who was present when euthanasia was performed? Please supply names, addresses, and telephone numbers.

   * * *


9. The study is being conducted by John Poole and John Griffiths.

10. The study is being conducted by Chris Carlucci and Gerrit Kimsma.