Part 3

Thirty Years' Experience with Euthanasia in the Netherlands: Focussing on the Patient as a Person

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Although the Netherlands is an extremely flat country, it appears to have slopes that can even be skied down when it comes to euthanasia.1 At least, that is what many authors commenting on the Dutch experience with euthanasia want their readers to believe. We have argued elsewhere that most such comments add up different types of end-of-life decisions based on unacceptable simplifications.2 Rather than repeat our critique, here we would like to try to further the discussion by analyzing the Dutch situation.

The Importance of Context: The Netherlands and the Dutch

Why was the Netherlands the first country to pass euthanasia legislation? This question is hard to answer in a way that explains everything. Nevertheless, some relevant observations can be made. First, one could hold that although their response was unique, the Dutch were responding to the very same developments as many other countries. At the end of the 1960s there was a shared feeling that medicine's propensity to prolong life had gone too far. As a result, in several countries debates were reinforced about non-treatment decisions and euthanasia, inspired by the idea that patients should be recognized as *persons*, who should control their own end.

The focus of debate, however, differed much among countries. Some, like the United States, focussed on non-treatment decisions (such as the famous case of Karen Ann Quinlan),

while the Dutch mainly discussed euthanasia, a difference probably best explained by differences in culture, legal system, and health care.3 The Netherlands has become home to a wide variety of beliefs. Over the centuries the Netherlands became a refuge to dissidents and religious groups who were oppressed or expelled elsewhere—for example, French Huguenots, free thinkers such as Spinoza and Descartes, Seardic Jews from Portugal, and Ashkenazi Jews from Eastern Europe. Despite a predominantly strongly Calvinist religious tradition—with a large Roman Catholic minority—tolerance in religious matters and freedom of thought prevented a single dominant view from being imposed on everybody. Among other things this resulted in a long tradition of public theological debate. The Dutch can argue for hours about every aspect of good and evil. At the same time, they have learned over the centuries to live with each other in an atmosphere of tolerance despite some major theological differences, and to respect each other's beliefs.

The Netherlands was certainly not the first country to debate euthanasia. This debate began in the middle of the nineteenth century when drugs became available to physicians with which they could influence the way people die. At that time, euthanasia was discussed in England, Germany, and the United States, but not in the Netherlands. In fact, the first proposal to legalize euthanasia was made in 1906 in the state of Ohio!4

In more recent decades, however, Dutch society has rapidly become more secular and less divided along religious lines, and this has placed decisions about life and death in another perspective. Responsibility for one’s life, once safely in the hands of the church or the medical profession, shifted back to the individual. Many Dutch people believe that they must be free to make their own decisions about their lives and when and how life should end. These ideas have gradually gained ground, even among practising Christians. At the same time, the Dutch have great respect for human life. The Netherlands has no death penalty, individuals are not allowed to own firearms, and the abortion rate is one of the lowest in the world. A

large majority of the population is of the opinion that abortion and euthanasia must be possible, but sees both as last resorts.

The second reason for the Netherlands' different response to the issue of euthanasia, is its legal system. The Dutch system of criminal justice is not based on a principle of legality, which holds that all cases should be prosecuted, but instead on a principle of expediency. The principle of expediency holds that there can be cases in which prosecution of a possible criminal act would not serve the public interest; it thus creates room for public policy in the area of criminal justice. This, together with the recognition of "necessity" (*force majeure*) in the penal code, made it possible to keep euthanasia within the purview of criminal law, yet at the same time accept it under certain circumstances. (Of course the law of 2001 has changed all this, a matter to which we will return.)

Finally, the Dutch have a freely accessible and affordable system of health care. Everyone is assured of care, from the cradle to the grave, including long-term nursing care for the elderly and those who are chronically ill. There is no financial incentive to end the life of a patient who needs expensive care for several years. All these elements have played a role in the debate of the last thirty years on euthanasia and other medical decisions at the end of life.

The Debate

In 1973, the whole country was suddenly forced to confront the issue of euthanasia. In that year, the district court in Leeuwarden heard a case involving a doctor who had ended the life of her seriously ill mother, who had made repeated and explicit requests for euthanasia. The daughter wanted to spare her mother pointless suffering and loss of personal dignity. She felt that her mother—who was experiencing intolerable pain and suffering, knew that she was near death, and had made it very clear she did not want go on living—should not continue to

suffer to the bitter end. The court held that doctor had committed a criminal offence. In fact, formally speaking she had committed murder.

However, the court also said that a doctor is not always obliged to keep alive against his will a patient who is suffering severely, without hope of a remedy. The doctor ultimately received a short, suspended sentence.

Like all doctors, Dutch physicians are trained to cure patients. But they also learn that they shouldn't allow people to suffer needlessly. A doctor may therefore end up with conflicting responsibilities in the case of a patient who is suffering unbearably without prospect of improvement, and who is asking for euthanasia. In the years that followed the Leeuwarden case, debate on this dilemma continued. Initially divided, the medical profession later moved toward developing criteria for euthanasia, and in 1984 the Royal Dutch Medical Association (KNMG) codified the emerging professional consensus in five requirements that can still be recognized in the law that we will discuss below. From the beginning, the KNMG also emphasised that doctors should report every case of termination of life. It was also the KNMG that persuaded the Minister of Justice in 1990 to establish a formal notification procedure to harmonize regional prosecution policies and to eliminate those practices that resulted in physicians not reporting cases, such as interrogation of relatives and physicians by uniformed police officers.

For years politicians, lawyers, doctors, and ethicists struggled to find a way to enable doctors to accede to a patient's request for euthanasia without laying themselves open to prosecution. The medical profession wanted to be certain that they were acting within the law, as did their patients. The courts, however, refused to recognize a “medical exception” to homicide law, a option explicitly rejected in 1984 by the Supreme Court , which found that euthanasia could not be regarded as a normal medical procedure. Nonetheless, the Court did

open the way to allowing nonprosecution of physicians who performed euthanasia, as we we'll see.

In 1982 the government asked a state commission to consider the question and its report was published in 1985. Looking back, it is clear that the commission's findings had considerable impact on later developments. It established a definition of euthanasia that has been in use in the Netherlands ever since: actively terminating the life of another person on the explicit request of that person.

The commission also drew up a series of "due care criteria" to be met in every case of euthanasia, as well as proposing that new legislation be passed. although this suggestion initially had little impact, it later became enormously influential. The commission's proposal was, in fact, that under certain conditions euthanasia should no longer be regarded as a criminal offence.

In 1984 a ruling by the Supreme Court, the Netherlands' highest court, led to a breakthrough. The Court held that a doctor who ends a patient's life at his or her request because the patient's suffering is unbearable and without prospect of improvement, faces a conflict of obligations. On the one hand, he has the duty to try to cure the patient or to relieve his suffering. On the other, he cannot allow the patient to suffer unnecessarily if no remedy is available to relieve the suffering. In such a situation a physician who ends a patient's life can invoke the legal defence of necessity (*force majeure*). In practice, this meant that a court could decide that a doctor was not criminally liable if he had complied with a number of specific due care criteria in making his decision and in carrying out his actions.

The core of the due care criteria set out in the Court's decision were the very same as those of the KNMG and of the state commission. Over the years, these criteria have been refined by the medical profession and in case law, but essentially they have not changed. the

recently passed act that legalizes euthanasia, the set of due care criteria has been embedded in law. We shall return to those criteria later.

The Practice of Euthanasia: Empirical Studies

The Dutch government and parliament spent years struggling to establish a legal framework. But it was only after the Supreme Court ruling and the commission report that both sides finally came up with a draft bill. In the course of time it had become clear that the Dutch population was broadly in favor of legislation on euthanasia. But before the first legislation was passed, in 1990 the then government (a coalition of Social Democrats and Christian Democrats) commissioned empirical research into the incidence of euthanasia and other medical decisions at the end of life,5 which was repeated in 1995 and again in 2001.6–8 All three studies attracted considerable international attention. It is, after all, unique to have such a sensitive subject researched in an objective manner, through questionnaires and interviews with doctors whose anonymity is guaranteed. We present the main findings in Table 1.

[Table 1 about here]

The first point to be noted is the stability of the euthanasia practice: Although there has been a slight increase in the incidence of euthanasia over the years, the incidence of active termination of life as a whole hardly changes. The second point is the continuing presence of life-terminating acts without explicit request of the patient (LAWER). We will return to these cases in the next section.

These studies showed in considerable detail which doctors and which patients are involved in the decisions described. In interviews conducted in 2001, 57 percent of doctors said that they had ever performed euthanasia or assisted suicide. A further 32 percent said they could conceive of situations in which they would be prepared to do so.9 General practitioners were involved in 77 percent of euthanasia cases and nearly all cases of assisted suicide. About 21 percent of euthanasia cases are performed in hospital.

With respect to the patients involved, the studies showed that in two-thirds of cases of euthanasia or assisted suicide the patient was in the terminal stages of illness, usually cancer (77 percent). The estimated shortening of life was less than one week in 46 percent of cases; only 13 percent of patients had a life expectancy of more than one month. Euthanasia occurs relatively infrequently among vulnerable groups, such as the oldest old and nursing home residents.

The studies also revealed that physicians do not comply with most requests for euthanasia. In 2001 for instance, 9,700 patients explicitly asked their physicians to end their life. The data summarized in Table 1 show 3,500 euthanasia was performed in response to 3,500 of these requests and assisted suicide in 300. That is, only approximately two out of five requests for euthanasia were met. In the remaining cases patient's request did not lead to euthanasia or assisted suicide. In about half of these the patient died before a final decision to

perform euthanasia had been made. In the other half, the physician refused to honor the patient's request. The most frequently mentioned reasons for refusing a request were that the patient's suffering was not unbearable (35 percent), that there were still alternatives for alleviating the suffering (32 percent), and that the patient was depressed or had psychiatric symptoms (31 percent).10 In these cases the doctor took steps other than euthanasia or assisted suicide to relieve the patient's suffering.

Life-Terminating Acts without Explicit Request by the Patient

Cases of "life-terminating acts without explicit request" of the patient were described in all three reports. The absolute numbers were 1,000 cases in 1990 and 900 in both 1995 and 2001. In a number of cases the decision had been discussed with the patient, or in a previous phase of the illness the patient had expressed a wish for euthanasia if suffering would become unbearable without explicitly requesting euthanasia. In 1990 this applied to 59% of cases, in 1995 to 53% , and in 2001 to 36 percent. In other cases the patients were incompetent. In 95 percent of the cases the physician discussed with colleagues, nursing staff, or the patient's relatives (on average with persons in two of these categories). In two-thirds of cases morphine was the only drug administered.

The percentage of patients with cancer is considerably less than for euthanasia: only 40 percent (data from 2001 study). The patients involved are also closer to death, compared to patients whose request for euthanasia or assisted suicide was granted. In 42 percent of LAWER cases life was shortened by at most twenty-four hours, and in a further 35 percent by at most one week. Only in 18 percent life was shortened by a longer period. These characteristics are largely the same for the 1990 and the 1995 cases. The 2001 study also showed that about one-third of LAWER cases can also be described as terminal sedation, that is, cases in which high dosages of

sedatives were given without hydrating the patient. However, also in these cases the physician had described his own act as intentionally life-shortening.

The publication of data on the LAWER cases introduced a new dimension in the Dutch euthanasia debate. Since the mid-1980s, this debate had been focused on euthanasia and assisted suicide in which the patient's explicit request was a central feature. In part the discussion had been deliberately narrowed in this way because it was felt that consensus was closest for these cases. As we noted above, the Dutch even changed their definition of euthanasia to include only cases in which there was an explicit request by the patient.

The description of LAWER cases has broadened the discussion again. But what does their appearance in the reports mean? Does this prove that there is a slippery slope? Prior to 1991 Dutch commentators on euthanasia talked only about cases that fell within the narrow definition of acts carried out at the patient's request. Only later did the existence of the LAWER cases become known, giving the impression that the Dutch began with hastening the end of life on request and ended doing so with non-voluntary cases.

This, however, is not necessarily true. We simply do not know whether life-terminating acts occurred without the patient's request less or more frequently in the past. What we do know is that the occurrence did not increase in the Netherlands between 1991 and 2001.

We also know that the prevalence of such practices is much higher in other countries, such as Australia and Belgium, that only briefly permitted euthanasia and could not have 'slided down the slope' by tolerating it for years.11, 12 The Belgian numbers for 1998 merit a little more attention. The percentages found for euthanasia, physician-assisted suicide, and life-terminating acts without explicit requests of the patient (LAWER) in that year are 1.1, 0.1, and 3.2 percent, respectively. One thing is striking in the Belgian data: the ratio of cases not on explicit request of the patient versus those in which the patient asked to hasten death , three to one, is the reverse of that in the Netherlands.

Recently, the results were published of a study carried out in Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland using the same design as previous studies in the Netherlands and in Belgium.14 In all countries other than the Netherlands and Switzerland, the incidence of LAWER was higher than the incidence of physician-assisted death on request of the patient. Perhaps an open debate and a tolerant policy is not that bad after all.

But even though they do not prove the existence of a slippery slope in the Netherlands, the cases of nonvoluntary euthanasia do pose a very serious problem. They are obviously not justified by the principle of respect for patient autonomy and therefore can only be tolerated (if at all) in extreme situations where life-termination is really a last resort and nonvoluntary euthanasia becomes, therefore, "mercy-killing." Legally, these cases remain a criminal offence.

Reporting Euthanasia

To accept euthanasia in an individual case is one thing; to accept it as a matter of public policy is quite something else. It is often argued that proposals to legalize euthanasia can never contain absolute safeguards. We think this is true; there is no rule that cannot (and will not) be broken. But this goes for the prohibition of driving drunk as well. The question is whether the fact that safeguards can or might be ignored justifies a prohibiting euthanasia in an individual case. The Dutch at first tried to have it both ways by creating a public policy based on individual cases. The least one can say is that this resulted in an unsatisfactory situation of accepting and prohibiting at the same time. This created uncertainty and vagueness both for patients and physicians and no doubt contributed to some extent to reports critical of the Netherlands.

Persuading physicians to bring cases of euthanasia to the knowledge of the authorities is a problem for any euthanasia policy. The Dutch notification procedure helped to raise the notification rate from 18 percent in 1990 to 41 percent in 1995.13 The 1995 study revealed that doctors who did not report cases of euthanasia usually had acted according to the criteria.

Why then did they fail to report their actions to the Public Prosecutor? The main reason was that despite the fact that they had exercised due care, they felt they were being treated as criminals precisely because they had to report to the Public Prosecution Service, and then face long periods of uncertainty during which they were technically murder suspects.

The government therefore tried to further diminish the number of unreported cases by developing a new notification procedure, in which much of the assessment is done outside of the legal system. To this purpose, in 1998 five regional multidisciplinary assessment committees were created to assess all reported cases of euthanasia. These committees consist of a lawyer (chair), a physician, and an ethicist. They meet approximately once every three weeks to discuss about thirty to forty cases per meeting. The outcome of these discussions can be one out of three things. In most cases the committee will conclude (in 6 percent after receiving further information from the reporting physician) that the physician has acted carefully and has met the standards. If the committee feels that the physician has not acted in a careful way, that case is handed over to the prosecutor, who will then start a legal investigation. To date, this has happened in 0.1 percent of all cases assessed. In other cases in which legal standards were met but the doctor did not exercise sufficient professional care, the medical inspector was alerted.

The effect of this procedural change on the notification rate is not completely clear yet, but the first results can be given. In 1996, 1,700 cases of euthanasia were reported; in 1997, 1,900. In the first ten months of 1998 authorities were notified of 2,241 cases. These cases were all handled under the old regime. Since the assessment committees started with their work the number of reported cases has dropped. The last two months of 1998 yielded 349 cases (resulting in 2,590 for the whole of that year). Subsequent years have shown fewer reported cases each year. The numbers for 2002 have not reversed this trend (Table 2).

[Table 2 about here]

Interpreting these numbers is not without difficulty; one cannot simply deduce a percentage for the reporting of euthanasia in one year since these numbers represent only the numerator. To generate percentages one would need to know how many cases occurred in that year. The most recent nationwide study showed that in 2001 there were 3,800 cases of euthanasia and assisted suicide. Of these, 2,054, or 54 percent, were reported. This response is clearly less than was hoped for. Somewhat paradoxically, the new study also found that doctors in general were satisfied with the new procedure.15 Yet still the reporting rate lags behind.

Another development may be more successful in raising physicians' willingness to report cases of euthanasia or assisted suicide. A network has been set up of general practitioners and other physicians trained to assist doctors facing decisions about euthanasia or assisted suicide, (SCEN: Support and Consultation in case of Euthanasia in the Netherlands). These consultants have had special training in palliative care and in all aspects of the law on euthanasia. Moreover, they are also there to help the physician with the existential questions that he may have himself—most physicians find it a heavy task to perform euthanasia. Attending physicians dealing with requests for euthanasia should preferably consult one of these consultants. There is reason to believe that cases in which a SCEN consultant was involved are reported more frequently.

A New Law on Euthanasia

As we noted above, the government wanted to create an assessment system that did not call for the Public Prosecutor to be involved in every case. This wish was in accordance with the outcome of the 1995 interviews in which doctors had said they would rather be judged by a broader committee, containing at least one physician. The coalition parties therefore developed a proposal to grant immunity from prosecution to those doctors whose cases had come before a review committee and in which the committee had decided that the

doctor had acted with due care. This immunity from prosecution was to be regulated by law. The cabinet adopted this proposal in 1998, and so was born the Euthanasia Act that came into force in April 2002.

The act states that although euthanasia remains in principle a criminal offence, a medical doctor will not be prosecuted if he has reported to the committee and the committee finds that he has acted with due care. The Public Prosecution Service then is no longer notified and the doctor cannot be prosecuted. Only if the review committee finds that the doctor has not acted with due care will it contact the Public Prosecution Service, which then decides whether or not to press charges. The review committees are obliged to report the number of cases of euthanasia they have assessed in their annual report.

The review committees have authority to judge cases of euthanasia or assisted suicide only, both of which require there to have been a voluntary, well-considered request on the part of the patient, as we will discuss below. In all cases in which there was no request of the patient or in which it can be doubted that the patient would have been able to make a well-considered request (e.g., in the case of a psychiatric patient), the committee is not entitled to pass a final judgement. The coroner must report such cases directly to the public prosecutor.

The government has thus tried to regulate these matters in a transparent way, combining openness and legal certainty. Doctors know what they have to take into account in coming to a decision and can report what they have done without anxiety. They know that if they act with due care they will not be prosecuted.

What are these “due care criteria”? As set out in the act they are as follows:

The doctor must

- be satisfied that the patient’s request is voluntary and well considered;
- be satisfied that the patient’s suffering is unbearable and that there is no prospect of improvement;

- have informed the patient of his or her situation and further prognosis;
- have come to the conclusion, together with the patient, that there is no other reasonable alternative;
- have consulted at least one other independent physician, who must have seen the patient and stated in writing that the attending physician has fulfilled the criteria listed in the previous four points;

and finally,

- have exercised due medical care and attention in terminating the patient's life or assisting in his or her suicide.

In addition there is an article stating that patients may draw up a written request for euthanasia in advance to be effective should they no longer be able to express their will when the time comes. The physician may consider such a document as a form of guidance in his decision making.

It is clear from the criteria what a crucial role the doctor plays. The patient must make a voluntary and well-considered decision, and the doctor will of course consult the patient at every step. But ultimately it is the doctor's actions that are under scrutiny and he bears final responsibility. This sets a limit on a patient's right to choose. Patients have no right to euthanasia in the Netherlands, and doctors are not obliged to grant a request for euthanasia. Doctors must decide for themselves whether they can meet the due care criteria in a specific situation. The decision must be genuinely voluntary, so they have to be sure that the patient's request is not the result of family pressure. Whether the suffering is unbearable or not is—of course—a subjective judgement. Every individual has his or her own limits in terms of how much pain and suffering and loss of dignity is bearable. The prospect of improvement, however, can be assessed more objectively in medical terms. Recent advances in palliative care have made it even more relevant to discuss alternative options with the patient. The

obligation to consult a second, independent physician, preferably a SCEN consultant, is an essential part of the review system. The second physician must see the patient in person and submit his opinion in writing to the review committee. Later the committee examines whether the attending physician exercised due care in reaching his decision and in his actions. And finally, the review committee must render an opinion on each case submitted.

Euthanasia: A Last Resort

The Dutch medical profession itself believes that euthanasia must always remain an exception. Euthanasia may be the conclusion to a careful medical process, but it must always be the last resort. Many requests are driven by the fear of pain, of loneliness, of becoming a burden on others, or of dying an undignified death. So a request for euthanasia should in the first place be seen as a cry for help, and only when other ways of relieving suffering have been exhausted should such a request be granted.

Two characteristics of the Dutch health care system provide reasons to believe that this describes reality instead of just being the socially desirable thing to say. First of all, the Dutch health care system is accessible to all and guarantees full insurance coverage for end-of-life and palliative care. This insurance is mandatory. We can safely conclude, therefore, that there will be no financial pressure to end a patient's life.

Second, the Netherlands now has a good level of palliative care. In the past, the Netherlands was often criticized for its presumed lack of palliative care. The existence of only a few hospices, for example, was interpreted as proof of a neglect of palliative care. Although much of this criticism was based on misunderstanding the Dutch health care system (most palliative care takes place at home, in the nursing home or in special hospital departments), it is also fair to say that in the beginning of the euthanasia debate, palliative care did not get the

attention it deserved. In more recent years, however, much effort has been made to improve palliative care, partly in response to the international critique.

At present, there is a broad range of palliative care available in the Netherlands.16 There are many options for obtaining palliative care at home. The care that terminally ill patients need can also be provided in nursing homes, hospitals, and hospices. In mid-2002 there were hospice units in thirty-seven nursing homes and in twenty-six homes for the elderly. Also, there were sixteen independent, professionally staffed hospices and twenty-one volunteer-run hospices. Most palliative care, however, is provided by the Netherlands' 7,800 general practitioners, since 65 percent of the 40,000 people a year who die of cancer, die at home. More and more, GPs receive support from so-called "transmural" palliative care teams.

As we have discussed, the physician must always look for reasonable alternatives to euthanasia. Moreover, the second physician must determine whether the options for palliative care have been sufficiently explored. Thus efforts are made to assure that euthanasia remains a last resort. Once a patient receives optimal palliative care, the question of euthanasia may not arise again. But even the best palliative care cannot always prevent a patient from deciding that his suffering and loss of dignity have gone far enough. For such situations we need the possibility of euthanasia, within a context of careful decision making and openness.

Conclusion The Dutch debate on euthanasia was this country's response to medicine's propensity to prolong life. It was inspired by the idea that patients should be treated as persons. What have thirty years of experience with euthanasia brought the Netherlands? We think the main result of the national debate is a well-developed framework for decision making in individual cases, now embedded in law. Physicians who must decide whether or not to comply with a patient's request for euthanasia know what they must take into account and can report what they have done without fear of being prosecuted as long as

they act with due care. The debate has also contributed to a certain peace of mind among patients. They can be sure that they will be treated by physicians who respect them as persons and have no intention to prolong life as long as possible against their will. Also, maybe somewhat paradoxically, the euthanasia debate has given a large impulse to the development of palliative care.

There is no empirical evidence to support the suggestion that the Netherlands is on a slippery slope (let alone ones that can be skied down) when it comes to physician-assisted death. At the same time, the number of cases of life-terminating acts without explicit request of the patient has not decreased.

Having said this, we certainly do not want to imply that a solution has been found for all individual cases. Requests from elderly people who are tired of life and for whom life has lost all meaning, but who do not suffer from any serious illnesses, cannot be complied with under the present framework. This was confirmed in the 2002 ruling of the Supreme Court. Also, physicians remain reluctant to follow advance directives containing a written request for euthanasia for patients who are no longer competent. In both cases the Dutch debate has met its own limits. By emphasising the role of the physician in the normative framework for euthanasia, cases that are more or less exclusively grounded in the patient's evaluation of his or her life fit in less well.17

On the societal level, we now have a law that is supported by a large majority of the population and that is grounded on a thorough knowledge of what is going on in medical practice. In spite of this, physicians still seem insufficiently prepared to be transparent. The frequency with which cases of euthanasia are reported clearly lags behind the expectations. It is not clear yet what steps can be taken to improve this. We doubt, however, that the necessary steps can be found in new regulations. There will have to remain room for discretionary power of both the physician and the public prosecutor to judge what is best in

individual cases. Only then can the debate on euthanasia serve its real end: to treat the patient as a person.

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