The Postma case

There was no alternative. Five months earlier she had suffered a stroke. Although the treatment in the Assen hospital had resulted in a gradual improvement of her condition, she continued to suffer from partial paralysis and problems with her speech. Mrs van Boven-Grevelink could not return home. She needed permanent care. So she was transferred to a Catholic nursing clinic in Oosterwolde, a small village in the northern Dutch province of Friesland.

Unfortunately the transfer turned out to have a detrimental effect on her condition. One of her two daughters, visiting her on the first day, was shocked to see her mother in a confused and absent-minded state, unable to communicate. Mrs van Boven’s condition continued to fluctuate during the ensuing days. She remained wheelchair-bound, had difficulties in hearing and talking, and could not move her left arm. She had lost interest in the people around her, her family and grandchildren. Often she recognized her daughters, mentioned their names, and repeated that she wanted them to leave. At times, she even told them that she no longer wanted to see them.

One day in October, her daughters found her tied up in bed with the bed rails raised. She was pale and her face covered with bandages. It turned out that she had fallen out of bed. A few days later, she explained that she had thrown herself out of the bed deliberately in a primitive attempt to kill herself. She repeatedly told her daughters that she did not want to be in this situation, that she wanted ‘something to die’.

Approximately one month after her transfer to Oosterwolde, the nursing clinic physician was informed by the head nurse that Mrs van Boven was dying. This deterioration in her condition was unusually sudden, for only
an hour earlier a laboratory analyst had visited Mrs van Boven to take a blood sample for a haemoglobin test; he had entertained a normal conversation with the patient. However, so the nurse explained, there was no need to hurry; Mrs van Boven was in the company of one of her daughters and son-in-law.

In fact, this daughter was a physician, and so was her husband, Dr Postma. Both had been working as family practitioners in Noordwolde, a village not far from Oosterwolde. The Postmas had come to the conclusion that Mother was lacking the will to live ever since she had been hospitalized in Assen. Several times Mother had blamed the medical doctors, and her own medical family members in particular, for having saved her life. She had always been fond of life, but also stubborn and unwilling to make compromises. Being conscious and competent, she had realized that she was disabled and unlikely to recover. Nevertheless, her physician daughter had encouraged her to continue trying and to enter rehabilitation programmes. These efforts had only yielded partial success. After the transfer to the nursing home, Mother’s condition had deteriorated, perhaps due to new cerebrovascular incidents. Whatever the cause, ever since she had become less and less communicative. The fact that she began to dislike her daughters’ visits was taken to be another signal that she felt abandoned in her requests to end her suffering.

The Postma doctors discussed the case at length and decided to end Mother’s life. When they visited the nursing home that October day, they found Mrs van Boven unconscious and tied up on a toilet chair. Her daughter tried to wake her up. Unable to do so, she kissed her mother and took the syringe from her purse. While Mr Postma was guarding the door of the room, Mrs Postma injected 200 mg of morphine intramuscularly. A few minutes later, they called in the nurse; together they moved Mrs van Boven to the bed.

When the nursing clinic physician arrived at the patient’s room about an hour later, he found Mrs van Boven lying in bed, dead, in the company of her family members. The next day, he called the authorities and a legal investigation was initiated. The year was 1971.

The Dutch euthanasia debate

Ever since the 1970s, euthanasia has been a topic of continuous debate in the Netherlands and elsewhere. This volume presents a detailed description of the debate as well as a critical analysis of the most salient aspects of euthanasia practice. We will argue that euthanasia should be understood within a historical context as a protest against medical power. Paradoxically, the final outcome appears to be an unprecedented increase in medical power. Criticized by society for holding dying patients hostage
with medical technologies and drugs, thus precluding a good death, Dutch society has granted physicians the right to end patients’ lives with medical means. Physicians have thus acquired a level of power that nobody in the Netherlands has, not even the state, for the death penalty has long been abolished.

Debates about euthanasia commonly start with a ‘paradigmatic case’ to illustrate the relevancy and plausibility of euthanasia. The popular and scientific literature abounds with such cases about patients with incurable metastatic cancer, suffering from unrelieved pain, living in inhumane conditions, begging for an end. However, as the debate has developed over time, more and more cases have surfaced that differ significantly from these paradigmatic cases, suggesting that euthanasia might also be justified in other conditions and circumstances. We will analyse the evolution of the euthanasia debate in the Netherlands because there are evident parallels between the dynamics and politics of the Dutch debate and similar debates elsewhere in the world. Indeed, the same paradoxes tend to surface. In this volume, we will focus on two of the most troublesome paradoxes.

The first paradox results from the dialectical relationship between the moral principle of respect for individual autonomy and the moral principle of beneficence, in particular relief of suffering, as the two major justifications of euthanasia. Although euthanasia is an ultimate effort to give the individual patient control over his dying, the debate appears to have resulted in an increase of medical power. Perhaps even more troublesome is the second paradox. It concerns the very goal of euthanasia, that is, to bring about a good death. Although euthanasia originally emerged from a strong commitment to foster a good death, we will argue that the Dutch preoccupation with euthanasia may have actually threatened the range of options for patients to die a good death.

Modern medicine has yielded extraordinary benefits for mankind, extending life considerably and improving its quality. Unfortunately, there is no escape from death and hence no escape from dying. For many, the dying process has remained a very difficult period of life, filled with pain and suffering. Indeed, for some the power of medicine to prolong life has meant a prolongation of this dying process. This is a vexing problem for patients and caregivers alike, indeed for all of society. This book at once acknowledges the problem and argues against euthanasia as the solution to the problem. It is both a plea for more humility on the part of physicians, for acceptance of the inevitable limitations to the power of medicine, and a plea for a greater investment in genuine medical care for dying patients, that is, in the art and science of palliative medicine.
Beginnings of the euthanasia movement

Approximately one year after Mrs van Boven had died at the hands of her physician daughter, Dr Postma, the national newspaper *De Telegraaf* revealed that a euthanasia case was being investigated by the legal authorities. Previously, physicians had confessed on television that they had occasionally practised euthanasia, but no legal action had ever been taken. The revelation about Dr Postma and the subsequent media attention sparked several developments. First, the inhabitants of Noordwolde started a movement to support the Postmas. They considered it unjust that their family physicians were now the sole focus of legal attention, whereas euthanasia was more widespread throughout the country. This local action attracted the interest of several other national newspapers and television channels. Notifications of support from all over the country poured into Noordwolde. Almost 30 physicians from the province of Friesland officially declared that they considered euthanasia an act of compassion and therefore did not reject it in the context of medical treatment. Likewise, Baptist ministers in the northern parts of the country declared their solidarity with the Postmas.

Second, a lively public debate started with medical, theological, legal and ethical experts addressing various aspects of the issue of euthanasia. In retrospect, it is clear that the concept of euthanasia used was ambiguous. Expressions like ‘not prolonging life’, ‘hastening death’, ‘choosing death’, ‘not obstructing the dying process’ and ‘forgoing medical treatment’ were all classified under the generic label of ‘euthanasia’. At the same time, all experts emphasized that euthanasia in practice was much more prevalent than accounted for in the media. They argued that medical practice had changed. The transitional line between life and death had been obliterated by modern medicine. Medicine had become capable of prolonging the life of patients, keeping them alive beyond any reasonable state of existence. Consequently, many patients now end up existing in a kind of no man’s land between living and not living. The fear of ending up in this no man’s land had already been ingrained deeply in the mind of the Dutch public as a result of an earlier case.

In 1966, Mia Versluis, a 21-year-old sports instructor who was about to enter into marriage, had undergone cosmetic surgery on her heel bones. During the surgery she suffered cardiac and respiratory problems which were not properly managed by the anaesthesiologist. She never recovered from the narcosis. Severe and irreversible brain damage had occurred. She was placed on a ventilator. After five months, the treating physician proposed to the parents to disconnect the ventilator. However, this proposal was commonly interpreted as euthanasia and the parents refused.
More than five years after the tragic surgery, Mia died without medical interference.

The case had attracted a lot of media attention. It demonstrated to the public mind not only the unprecedented power of medicine but also the risks involved. The lingering death of Mia had made many people extremely anxious about medical interventions that could keep patients in a state between life and death. The death of Mia Versluis on 10 November 1971 occurred while the (not yet publicly known) legal examination of the Postma case by the Leeuwarden District Court was taking place.

The third sequel to the publicity around the Postma case was the establishment of several societies and associations acting as public interest fora and political pressure groups. In February 1973, the Dutch Society for Voluntary Euthanasia was founded. Its aims are twofold: to promote the social acceptance of voluntary euthanasia as well as the legalization of euthanasia. In the same month, the Foundation for Voluntary Euthanasia was established (it was dissolved in 1985). This foundation, initiated by a number of scholars, well-known lawyers and physicians, had a different purpose: within the context of the existing legislation to develop and propagate a living will for euthanasia.

As a result of these media events and subsequent developments, the issue of euthanasia had already been transformed from a medical-legal problem into a social problem and public topic even before the Leeuwarden District Court decided the Postma case. That decision was reached some 16 months after Mrs van Boven died.

**The verdict**

The hearing took place on 7 February 1973 and lasted seven hours. Two weeks later the District Court of Leeuwarden issued its verdict. Although relief of suffering of her mother was a legitimate objective, Dr Postma had not used other means available to accomplish this goal. Ending the patient’s life by administering a lethal dose of morphine is illegal. Dr Postma was therefore found guilty. However, the court imposed a probationary sentence of one week’s imprisonment only. The public impact of the verdict was tremendous. Not only was the sentence very mild, but it was also an indication that the views on euthanasia in society, law and medicine were changing. More importantly, it was the first specimen of jurisprudence that did not categorically exclude the possibility of legally sanctioned euthanasia.

In its verdict, the court had accepted a number of conditions formulated by the court’s expert witness, physician Hielke Kijlstra, the Health Care
Inspector of Friesland. He had argued that it is ‘generally accepted in the medical community’ that in particular circumstances patients may receive drugs to relieve their suffering but with the risk that life will be shortened. In these circumstances it is also accepted that life-threatening conditions such as infections will not be treated. Kijlstra had listed five conditions:

1. The patient is incurable due to a disease or accident.
2. In the patient’s experience, the physical or mental suffering is severe or unbearable.
3. The patient has expressed a wish (maybe even in advance and in written form) to end his life or to be put out of his misery.
4. The patient has entered or is about to enter the terminal phase.
5. The intervention is performed by a physician, i.e. the attending physician or a specialist, or in consultation with a physician.

The court underwrote Kijlstra’s list but also stated that condition (4) was too restrictive. Often incurably ill patients are suffering severely yet are not in a terminal state; they can continue to live in this condition for years. Mrs van Boven was an example. The court stated that these patients should also be offered the kind of palliative medical care mentioned above.

Even though the court’s deliberations seemed to pertain first and foremost to palliative end-of-life care rather than euthanasia proper, the verdict had at least two implications for the subsequent euthanasia debates. It confirmed that the medical community had accepted certain limits to life-supporting treatment (the verdict actually referred to ‘the average physician in the Netherlands’). It also listed certain conditions in which the death of the patient may be acceptable. In doing so, the court set an example of judicial reasoning about requirements of due care that could be followed by future courts. The verdict thus implied that death in the context of medical treatment need not be accidental, and that in certain specified circumstances the patient’s death may be justified. The door to euthanasia had been set ajar.

Expansion of the debate

In its verdict, the Leeuwarden Court had argued by analogy. The circumstances identified in the verdict applied to the acceptance of the patient’s death in the course of medical treatment but not due to the treatment. At the time, this was generally classified as ‘passive euthanasia’. The court then applied the same line of thinking to the case at hand, even though that case was one of ‘active euthanasia’. The court’s argumentative strategy mimicked a more widespread logic of thinking about euthanasia. The starting point was the conviction that ‘passive euthanasia’ is permissible in specific circumstances. The case of Mia Versluis had illustrated that
medicine could prolong life for a long time, indeed for too long a time. In such circumstances medical interventions to treat life-threatening events or to technically sustain life should be discontinued in order to avoid prolongation of the dying process. Next, it was argued by many Dutch (as well as foreign) philosophers and theologians that there is no moral distinction between ‘passive euthanasia’ and ‘active euthanasia’. Hence, the legal conditions that were formulated for ‘passive euthanasia’ could be applied to ‘active euthanasia’ as well.

For example, Leenen, a well-known professor of health law in Amsterdam, argued that the distinction between ‘active euthanasia’ and ‘passive euthanasia’ is irrelevant from the perspective of Dutch law. Moreover, the alleged moral difference should be rejected as well since it could imply that the suffering of the patient is prolonged if ‘passive euthanasia’ is accepted while ‘active euthanasia’ is desirable. Muntendam, a professor of social medicine in Leiden and one of the first chairpersons of the Dutch Society for Voluntary Euthanasia, likewise rejected the distinction because both ‘passive euthanasia’ and ‘active euthanasia’ require a considered decision by a physician, and in both cases the underlying motive is the same (i.e. relief of suffering).

According to Leenen and Muntendam, euthanasia is not only analogous to palliative care, but in some circumstances it would actually be the preferred option. If termination of treatment is morally the same as terminating the life of the patient, one should not risk prolonging the patient’s dying by merely forgoing treatment. It would appear more compassionate both to forgo treatment and actively end the patient’s life.

We thus find that the Leeuwarden Court’s inclusion of exonerating circumstances applicable to ‘passive euthanasia’ in its verdict about a case of ‘active euthanasia’ supported and boosted the existing euthanasia debate in the Netherlands. Now that legally sanctioned euthanasia had become imaginable, much intellectual activity was concentrated on a more detailed specification of the various situations in which it could occur.

As mentioned, the flurry of books and articles in these early years often presented paradigmatic cases showing the plausibility and acceptability of euthanasia. These cases usually contained the following elements: a competent patient with cancer is in a stage where the disease has become incurable; multiple metastases have led to a deteriorating condition with unbearable suffering; the patient is now in a terminal phase and is requesting euthanasia; this request is voluntary and persistent. The physician, confronted with the request, has a dilemma: Either he respects human life, does not actively intervene, and accepts that the patient’s suffering continues; or he respects the patient’s wish and hastens the patient’s death through active intervention.

If this case would still not convince euthanasia opponents, a slightly adjusted case would be advanced in which the physician has absolutely no
means left to relieve the patient’s suffering other than to respect the wish of
the patient to end her life. In such an exceptional paradigmatic case, many
participants to the debate tended to accept the possibility of euthanasia.
Even those who did not advocate euthanasia, often agreed that in such
extreme cases euthanasia can be morally excusable.4

However, the most striking aspect of the Dutch euthanasia debate is not
these paradigmatic cases. Rather, it is their being dismissed again as soon as
they have been proposed. Almost all of the allegedly relevant elements of
these paradigmatic cases in time have been dismissed as being too restrictive
or even irrelevant.5 Consider the first report of the Health Council on
euthanasia which was released in February 1973, two days after the verdict
of the Leeuwarden Court in the Postma Case (although it had already been
finished in October of the preceding year). It proposed the following defi-
nition of euthanasia: ‘Euthanasia is an intentional act to shorten the life or
an intentional omission to lengthen the life of an incurable patient in his or
her own interest.’ Note that no reference is made to the request of the
patient. A few months later, the Executive Committee of the Royal Dutch
Medical Association issued a position paper endorsing the above definition.
Several ethicists (even if they did not support euthanasia, e.g. Beemer6)
agreed that the distinction between voluntary and nonvoluntary euthanasia
is not watertight and of secondary importance from a moral point of view.
Of primary importance is whether life is bearable and tolerable. Euthanasia
may be acceptable not only if there is a request of the patient, but also if the
patient assents to the suggestion of others, and even if euthanasia is in the
patient’s interest according to the judgement of the physician.

In 1978, euthanasia entered the political scene. The majority of the
political parties in the Lower House of Dutch Parliament invited the
Minister of Health to establish a national committee to develop policies in
the area of euthanasia. This committee was finally inaugurated in 1982. In
its report from August 1985, the committee defined euthanasia as ‘the
intentional termination of the life of a person by someone other than that
person, at the latter’s request’.7 The Committee explained that terms such
as ‘incurable disease’, ‘terminal illness’ and ‘unbearable suffering’ were not
included in the definition because those are conditions under which
euthanasia might be justifiable, rather than defining elements of the practice
itself. Nevertheless, the exclusion of all these terms from the definition,
versus the inclusion of the patient’s own request, changed the euthanasia
debate. The new definition became authoritative, often cited as the ‘official’
definition of euthanasia in the Netherlands, and the patient’s request
became the decisive condition. Euthanasia is justified if, and only if, it
happens at the patient’s explicit and persistent request.

However, in the late 1980s, it became evident that Dutch euthanasia
practice did not conform to this official position. Many cases of euthanasia
turned out not to involve an explicit request of the patient. But Dutch
society, including the medical profession and the courts, did not rally against these cases. Instead, a series of new reports was issued by the Royal Dutch Medical Association examining the feasibility of euthanasia on several categories of incompetent patients. In the meantime, the courts imposed only suspended sentences for physicians who had ended patients’ lives without their request.

In the 1990s, the movement towards decriminalization of euthanasia gained momentum. The labour, liberal and social-democratic parties combined acquired a parliamentary majority and the Christian Democratic Party was excluded from the government. A new bill to legalize euthanasia was submitted. The bill reiterated some of the old conditions such as the unbearableableness of the patient’s suffering and an explicit patient request. But as parliament was debating the new bill, two new cases underscored yet again that even these two conditions had long lost their decisive force.

The first involved Senator Brongersma, formerly a member of the Upper House of Parliament. He was 86 years old, had no physical or mental ailments, but was tired of living. In his view, life had become unbearable and an unacceptable source of suffering. Euthanasia protagonists argued yet again that this was the proper motive for euthanasia. After all, only the person himself can determine whether his suffering has become unbearable – even if the source of the suffering is life itself.

And then came the case of Van Oijen, the general practitioner who had figured prominently in *Death on Request*, the well-known television euthanasia documentary about himself. He was on trial because he had terminated the life of a nursing home patient at the request of the family rather than the patient. Van Oijen was found guilty of murder but not punished because he had acted ‘with integrity’ according to the court.

Thus we find that at the dawn of the twenty-first century none of the original elements that characterized the paradigmatic euthanasia case had survived. There was no need for a competent patient with incurable cancer; for multiple metastases causing unbearable pain; for the end of life to be nearing anyway; for an explicit and persistent patient request. Even though Dutch physicians were evidently euthanizing all kinds of patients who did not fit the paradigmatic case, in November 2000 the new bill was accepted by the Lower House of Dutch Parliament and in April 2001 by the Upper House. Euthanasia and Physician Assistance in Suicide had become legal.

**The lack of a theoretical foundation for euthanasia**

How can we explain these recurrent changes in the criteria for and justifications of euthanasia? We contend that a persuasive and resilient theoretical defence of euthanasia is lacking. Consider again the official Dutch...
definition of euthanasia that also underlies the new law: ‘The intentional
termination of the life of a person by someone other than that person, at the
latter’s request.’ This definition suggests that the justification of euthanasia
is grounded theoretically in the moral principle of respect for the autonomy
of the individual patient. Although individual freedom is not as decisive a
political principle as it is in the USA, Dutch people harbour strong libert-
tarian sentiments that favour an almost absolute patient’s right to respect of
his or her autonomy. Consequently, in public debates on euthanasia it is
generally taken for granted that the principle of respect for patient auton-
omy provides the necessary moral underpinning of euthanasia.

Yet on closer inspection, it is all but clear that the concept of patient
autonomy can ethically justify the practice of euthanasia. Proponents of
euthanasia have argued that autonomy implies the possibility and justifi-
ability of making decisions about one’s own death. However, this proposi-
tion is at odds with the philosophical and political tradition out of which
the notion of respect for individual autonomy arose. In this libertarian
tradition, autonomy has been deemed a basic characteristic of human beings
because it guarantees that each person is free and able to make decisions
according to his own free will. But the tradition has itself questioned
whether an appeal to individual autonomy can ever justify ending one’s own
life. If autonomy is a basic value, can a person ever eliminate the very basis
of this important characteristic? In order to be free, one has to exist at least.

This is by no means the only theoretical inconsistency. Even if one agrees
that individual autonomy is a basic value, evidently it is not the only sig-
nificant moral value. Consider the value of human life. Human life is of
value not simply and merely because it enables autonomous decision
making. Rather, human life is valuable even if persons do not or cannot
make autonomous decisions. Newborns and children cannot make auton-
omous decisions, but their lives are obviously of great value. Indeed, much
of human life defies the autonomy of the individual. The fact that we are
born was not the result of our own autonomous decisions, nor the time and
place of our birth, and neither is our gender, race, nationality and socio-
cultural background. Moreover, much of what we have become is not the
result of our earlier decisions. We are continuously confronted with con-
ditions beyond our control, not because our autonomy is weak but because
it is limited by the heteronomous conditions of life, many of which demand
our respect. The first basic question in the moral debate concerning
euthanasia therefore concerns the limits of autonomy.

If we were simply to assume that autonomous individuals have the right
to end their lives, immediately another question emerges: Is it morally jus-
tifiable for other people to assist in this? Even if suicide is morally jus-
tifiable, that does not mean assisting in suicide is too. By definition, assisting
in someone else’s suicide is not an act that only concerns one’s own life.
Nevertheless, in the Netherlands it is generally assumed that assistance in
suicide is justifiable if it is done by a physician. But why a physician? Again this is not self-evident because in other domains of life we actually prohibit physicians to end the lives of other people. Although the Netherlands does not have the death penalty, almost everybody agrees that of all people physicians should not be engaged in capital punishment.

Now even if we grant that the moral principle of autonomy justifies suicide, and that physicians may assist in suicide if so requested by the patient, it only follows that the doctor may prescribe the drugs necessary for the patient to end his own life. In order for the patient to execute his own autonomy, he must take final responsibility for his actions and end life himself by consuming the lethal drugs provided. But in euthanasia, it is the physician who administers the drugs and hence bears the final responsibility. This is clearly at odds with the primacy of the patient's autonomy. Nevertheless, assisted suicide has remained relatively infrequent in the Netherlands with euthanasia being almost ten times as prevalent.

The fact that euthanasia finally emerged as the primary and legal response to years of criticism against the power of active, interventionist medicine is ironic. From all alternatives explored in other countries, such as palliative care, hospices and forgoing treatment, euthanasia has turned out to be preferable precisely because it is a medical intervention: Not only a decision that is the prerogative of the physician, but also an act, the ultimate medical act in the face of death. We must thus conclude that respect for patient autonomy is a rather dubious theoretical justification for the practice of euthanasia by physicians.

**Dutch euthanasia as a contradiction of respect for patient autonomy**

To make matters worse, euthanasia not only lacks a persuasive and resilient theoretical foundation, hinging as it does on the principle of respect for patient autonomy. The Dutch practice of euthanasia also appears to contradict the primacy of the principle of autonomy. Research data in 1995 show that in comparison to an earlier study from 1990, the number of requests for euthanasia has grown. A distinction is made between two types of patient requests. The first is a request to have euthanasia 'in due course'. For example, when patients are first diagnosed with cancer, many want to find out about their physician's stance towards euthanasia and they do so by asking for euthanasia. In 1995, more than 34,000 patients made this type of request (compared to 25,100 in 1990). Such requests do not necessarily mean that these patients want to die. They are anxious and afraid that the doctor, in a later stage when they will be suffering, will not do his or her utmost to relieve that suffering. A request for euthanasia is quite an effective way to assure the complete attention of health-care
professionals. Indeed, many patients do not persist in their wish for euthanasia. In 1995, there were 9700 requests for euthanasia ‘in the foreseeable future’ (compared to 8900 in 1990). This second type of request for euthanasia typically occurs when the patient is at the final stages of her illness and death is imminent. The request forces upon the attending physician the decision whether or not to grant it. In 1995, of those 9700 requests 3200 were granted (compared to 2300 in 1990).

From these research data a striking conclusion can be drawn: Only a minority of explicit and persistent euthanasia requests is actually carried out. Two-thirds of the requests for euthanasia are not granted. Apparently the patient’s own explicit and persistent request is not decisive. This conclusion is supported by other data, collected by the same research team. In 1995, Dutch physicians decided approximately 27,000 times to intentionally hasten the patient’s death (whether by assisting in suicide, injecting lethal drugs, or withdrawing life-sustaining treatment). In approximately 60 per cent of these cases, this was done with the patient’s consent. But the remaining 40 per cent occurred without such an informed consent.

These findings raise serious doubts about the significance of the respect for autonomy argument within the practice of medicine. It appears that for medical doctors, respect for autonomy is not the decisive justification for action. In daily practice, the most important consideration and the main moral justification for euthanasia is relief of suffering. It is not really relevant whether the patients request euthanasia or not. If in the physician’s opinion, patients are not suffering unbearably or their suffering can be treated, their request for euthanasia will not be granted. If, on the other hand, the doctor estimates that the situation of unbearable suffering is worse than being dead, (s)he will consider the option of active termination of treatment. In such dire circumstances, the patient’s request to end life will support the decision, but it is neither a sufficient nor necessary condition. The empirical data reveal that many physicians simply assume that patients would have wanted euthanasia, even if patients have not been very articulate in requesting euthanasia or have merely hinted at the possibility of euthanasia, as well as if the patients are incompetent, psychiatric patients, demented elderly, or handicapped newborns.

These facts raise questions about the real justification for euthanasia. It is evident that from a historical perspective patient autonomy never figured prominently in the euthanasia debate. Euthanasia was always considered first and foremost a form of ‘mercy killing’, an act of compassion where killing the person is better than letting him suffer. The history of the euthanasia movement in the USA shows that for a long time euthanasia was not primarily framed in terms of a personal decision or a merciful act, but rather as a public health measure. Euthanasia was justified because it was promoting the common good. It was in the interest of society or the human race, and removing burdens on society.
In the present Dutch debate, both respect for patient autonomy and relief of suffering remain operative as justifications for euthanasia, even though it is theoretically difficult to combine the two and in practice they are often mutually exclusive. This paradoxical situation persists because consistency, that is, relying either on respect for patient autonomy or on relief of suffering, would yield unacceptable outcomes. For example, if autonomy would be truly decisive, ending human life without an explicit request would have to be ruled out. On the other hand, all serious patient requests for euthanasia would have to be granted. The number of euthanasia cases would be at least three times the present number. Very stringent rules and guidelines would have to be put in place to make sure that the patients’ requests are reliable (e.g. repeated request, second opinion, documentation, etc.). But the grounds for the request can no longer be evaluated; they are the proper domain of the individual patient’s valuation.

All of this appears quite consistent, but as the recent case of Mr Brongersma shows, the consequences of this logic are troublesome. If a patient, or rather, if a person claims that life itself is a source of unbearable suffering, one cannot argue against this claim. Nevertheless, in December 2002 the Supreme Court of the Netherlands rejected this line of reasoning. Concerned about the ever-increasing expansion of the euthanasia practice that looms when patient autonomy is the sole decisive criterion and justification for euthanasia, the court insisted that there must be some kind of medical condition explaining the suffering of the patient. But this shifts the discretionary power back to the physician, who has to independently assess the patient’s claim of unbearable suffering. Only if there is a sufficient medical explanation for that claim can it be accepted and the request for euthanasia granted. In fact, it doesn’t really matter whether the patient claims she is suffering unbearably. For even if the patient does not claim to be suffering (for example, because she is unable to do so due to advanced dementia), the physician can independently assess the patient’s suffering. Now the question arises as to what the objective criteria are that allow a physician to judge whether the patient’s suffering is unbearable indeed. Without such criteria, decision making will depend on the subjective and arbitrary values of individual physicians.12

Euthanasia as hindrance to a good death

The absence of a persuasive and resilient theoretical foundation for the practice of euthanasia has resulted in the gradual growth of medical power and the expansion of the euthanasia practice to ever more patient categories that have little or no resemblance to the original paradigmatic cases. In and of itself this is sufficient ground for serious concern. To make matters worse
– for patients that is – the Dutch developments may actually have decreased instead of increased their chances for a genuinely ‘good’ death.

The large-scale government supported empirical studies on Dutch euthanasia from 1990, 1995 and 2001 (the results of which will be discussed in more detail in Chapter 3), expectedly show that ‘unbearable suffering’ is most frequently mentioned by the surveyed physicians as reason for committing euthanasia. Next in line are ‘dehumanizing condition’, ‘loss of dignity’ and ‘pain’. Considerably more surprising is a cluster of reasons that concern the individual patient’s ability to cope with the situation: ‘meaningless suffering’, ‘dependency’ and ‘tired of life’. These reflect the expansion of suffering as a justification for euthanasia from the somatic suffering of the paradigmatic cancer patient to mental and even spiritual suffering. Most remarkable is a third category of reasons that include ‘escape from deterioration of suffering’, ‘prevention of suffocation’ and ‘prevention of pain’. These reasons show that euthanasia is no longer considered a way out of a state of unbearable suffering only, but also a sensible strategy to prevent such a state from occurring in the first place. Why wait until the suffering is becoming unbearable? The popularity of this new approach to euthanasia is evidenced by the fact that the former Dutch Health Minister herself suggested during the parliamentary debates on euthanasia that it would be wise for people in the early stages of dementia to draft an advance directive requesting euthanasia. She also advocated the distribution of suicide pills among the elderly.

The question arises whether the Dutch focus on euthanasia, emerging as an option in the search for a good death, has not at the same time reduced the range of care options available at the end of life. If euthanasia is no longer the option of last resort when all alternatives to relieve suffering have failed; if euthanasia instead has become a means of preventing such suffering altogether, there is no longer a need for alternative means of pain relief. Why develop therapies to mitigate patients’ pain and suffering when euthanasia can prevent the emergence of severe suffering altogether? Why should society create social structures and networks to involve the elderly in human interaction and social life when euthanasia is an adequate remedy for older persons such as Senator Brongersma who experience loss of meaning in life? We thus find that the emphasis on euthanasia tends to deflect attention from other approaches to good death and dying.

Unfortunately, there is also empirical evidence to support this deflection. For example, many hospitals in the Netherlands only recently developed policies for withholding and withdrawing treatment. Expert centres in pain control and management have been established only in the last decade. Contrary to other countries, palliative care became a target of Dutch health policy only a few years ago.13 Only now, after euthanasia has become prevalent and a legalized practice in the Netherlands, has a move towards the development of a wider range of available options at the end of life
materialized, so that perhaps many requests for euthanasia can be pre-
vented. Most recently, terminal sedation has become a trendy topic, which
is a remarkable fact because it had always been discarded as a morally
muddled approach, a concealed form of euthanasia and inconsistent with
the principle of autonomy.¹⁴

These new developments are of course laudable but it may be a case of
too little too late. Paradoxically, the commitment to a good death created
the euthanasia movement; in turn the commitment to euthanasia reduced
the number of options available to patients to bring about a good death.

A framework of queries

The Dutch experience with euthanasia is a social experiment that should be
examined and scrutinized carefully by all protagonists as well as antago-
nists of euthanasia, both in the Netherlands and abroad. The experiment
shows that the practice of euthanasia is paradoxical. Four fundamental
questions must be raised and addressed:

1. Is euthanasia an appropriate answer to the problem of ‘good death’?
   Those who answer negatively must show the superiority of other less
   controversial alternatives, but those who answer affirmatively still face
   other urgent questions.

2. If euthanasia is to be accepted: (a) what is the proper moral justification
   for this practice; (b) how can we prevent the dialectic expansion of
   acceptable cases?

3. If relief of suffering is the decisive justification for euthanasia: (a) how
   can we curb the impact of physicians’ subjective judgements; (b) how can
   we make sure that physicians will explore, develop and apply alternative
   medical approaches such as palliative care?

4. If on the other hand personal autonomy is the decisive justification, how
   can this be reconciled with the fact that in euthanasia it is the
   physician who brings about the patient’s death, thereby taking over the final and
   full responsibility from the patient?

Unfortunately, notwithstanding three decades of debate on euthanasia,
these questions have yet to be answered in a clear, convincing and decisive
manner. This book is an attempt to do so. To that avail, we will undertake
a retrospective reconstruction in which we identify the main moral
dimensions of euthanasia. This should enable a better insight into the
development of the Dutch debate on euthanasia and the peculiar direction it
has taken. We will find that the power of medicine defies social control and
conclude that euthanasia is particularly difficult to manage and regulate
from a policy perspective.

Some of the problems that Dutch policymakers face are related to the
peculiarities of the Dutch legal system and to cultural idiosyncracies. Still, there is much to be learned from the Dutch experiment for any country considering regulating or legalizing euthanasia and assisted suicide. After all, the Dutch experiment has been very lengthy, spanning more than three decades and involving many possible regulatory systems (e.g. the medical profession, the health inspection, patient advocacy associations, disciplinary courts, criminal courts and the legislature). All of these systems have time and again failed and continue to fail, as we will show.

Indeed, there are many countries that may want to learn from this experiment. Consider the results of a 2003 survey by the Council of Europe on laws and practices concerning euthanasia and assisted suicide in 34 of its member countries and in the United States. The first remarkable finding is the diversity in definitions across nations and cultures. For example, the distinction between ‘active euthanasia’ and ‘passive euthanasia’ is rejected in the Netherlands but used in 16 European countries. Almost no country has defined ‘euthanasia’ in its code of law. Notable exceptions are Georgia, which in its 1997 Health Law explicitly prohibits euthanasia, and Belgium, which in its 2002 Law on Euthanasia explicitly permits it. It is not even clear what it means to ‘legalize’ euthanasia, for according to the survey euthanasia is legal only in Belgium (and assisted suicide in Estonia and Switzerland). The Netherlands according to the survey has not legalized these practices. So how is it possible that Belgium, which based its law from 2002 on the new Dutch law, claims it has legalized euthanasia, yet the Dutch government in responding to this survey insists it has not?

Given that euthanasia is illegal in all other countries, how can it be explained that in only eight countries physicians have been prosecuted after performing euthanasia? Even in the 1980s when euthanasia was clearly illegal in the Netherlands, there were more than 100 cases on average each year. Thus, it seems highly unlikely that euthanasia never occurs in the other 26 surveyed countries. Whether or not it is practised, euthanasia has definitely become a topic of intense public debate in many countries. In addition to the Netherlands, Italy and the United Kingdom have had a national commission on euthanasia. In many countries, public bodies such as national bioethics commissions or parliamentary committees have issued regulations and recommendations. The need for some forms of regulation is increasing in many countries.

Finally, the Dutch experience shows that developments do not stop with legalization. Although one of the aims of the new law was to make doctors feel more comfortable in reporting euthanasia, the number of cases being reported is actually decreasing (from a high of 2216 in 1999 to 2054 in 2001), and this trend appears to continue after enactment of the law (1882 in 2002). Initially, it was hypothesized that this reporting decrease signified a decrease in the actual number of euthanasia cases allegedly due to improvements in palliative medicine, precluding the need for euthanasia.
But the latest empirical report by Van der Wal and colleagues proves otherwise. The number of euthanasia and PAS cases continues to rise (from 3600 in 1995 to 3800 in 2001).\textsuperscript{16} This would suggest that the new law is failing to achieve its main objective, that is, increased reporting and hence increased quality control.

Since the enactment of the new euthanasia law, remarkable positive developments have occurred as well. The general practitioners who in years past had been trained to become a national network of euthanasia consultants are now also trained in palliative care so that they are able to suggest alternatives to euthanasia. The number of hospices, palliative care units and palliative care consultations teams has significantly expanded over the last few years. Although the overall and long-term significance of these recent developments cannot be assessed at this early time, it appears that the legalization of euthanasia has led to a certain pacification of the debate, creating room for alternatives, palliative approaches and strategies to prevent euthanasia. A new image of death and dying is emerging – ‘palliated death’.