

# Waves over the Dikes

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### ***What forces of change led to acceptance of euthanasia?***

First of all, the acceptance of abortion. Although there is not a direct causal line from abortion to euthanasia, I do think that behind the abortion issue is a kind of approach to human life that makes it easier for a society and people to accept euthanasia.

People get cross when you say that. But I think there is in the mentality a kind of relationship.

Abortion was practiced in the 1970's. It was accepted in society in the mid 1970's. Abortion came before euthanasia. Euthanasia was not really an issue in the 1970's. The first case was in



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1974. That caused some stir but was pretty much considered by most people in society as [just] an incident.

The full public and political discussion of euthanasia got a tremendous push in 1984. The Supreme Court accepted the application of euthanasia and the Dutch medical association [KNMG] issued a point of view—a statement in which the criteria were put forward. They were not saying then that euthanasia was a good thing. They were saying that ‘If you do it, at least take care of these requisites.’

The KNMG knew, and there must have been internal discussions, that doctors felt the need to perform euthanasia in certain circumstances and didn’t want to be bothered by the legal authorities. The Dutch association wanted a legal regulation so that physicians would not have a bad conscience or would not feel guilty or would not have the problems with the legal authorities when performing euthanasia.

The Supreme Court used this statement by the KNMG in their decision to legally accept euthanasia under certain circumstances—an appeal to the defense of necessity.

I think to a certain extent that euthanasia is being practiced everywhere. But the fact that sometimes the law is transgressed is not necessarily a reason to change the law, of course.

### *Privacy and autonomy*

In the mentality of people, euthanasia is not conceived primarily as a right, even though physicians say that patients now more and more demonstrate an attitude of ‘claiming’ this right. But it didn’t start that way. It was a combination of things.

There are contradicting elements. On one hand, the Dutch pretty much have the idea, ‘I know better myself. I can decide for myself.’ On the other hand, the whole [individual] choice mentality that is so strong in the United States is not as strong here as a society. There is much more *collectivism* here, I would say, than in the United States.

### *Calvinist and anti-establishment traditions*

When the Dutch consider something to be private, they want it to be private. There are two points here. First, the Dutch mentality has been formed by its history. At the time the Dutch became an independent state, two currents were very strong. One of the elements was Calvinism. The other element was a kind of irregular people, so to speak. People who were fighting the establishment—the Spanish king, and so on. Seafaring people—very independent kind of people. These two currents have formed Dutch mentality.

Calvinism very much stressed personal responsibility—much more, for example, than Roman Catholicism, to which it was opposed. But when that personal responsibility is dissociated from a normative religious framework (which Calvinism provided but which is now gone for most people), it becomes a kind of independence.

Another element in Calvinism may be that Calvinism wanted to put things straight, in the sense that there shouldn't be too much of a contradiction between doctrine and life. Roman Catholicism in history has been able to live with quite a distance. If you just confess... It is not approved, but it is much more condoned than within Calvinism [which says] 'If this is what you say, then this is what you should do. And if we don't do it, then change the law. And this is a kind of trend which has also contributed to the felt need to change the regulations. Because we're doing it, we shouldn't pretend that we are not doing it--so regulate it.

The collectivism of Dutch society has first of all to do with its fight for liberation and independence, but also for the fight against the water. It is often considered an element in the Dutch mentality; we have to fight together against the water to maintain our dikes, because otherwise we will be flooded. And you have to do it together. And this may be one of the backgrounds of wanting an orderly society. Otherwise we don't make it. Whereas in the United States, you have all this space. You can do it for yourself; everybody can go elsewhere.

Dikes are a symbol like euthanasia regulations.

### *Cultural revolution*

There is another element. In the Netherlands in the 1960's, we had a kind of social revolution like in the rest of Europe. It was a revolution of doing away with the establishment—bourgeois ethics that didn't have any basis any longer in the eyes of the revolutionary people.

These revolutionaries were not all violent; most of them were not. But they changed the whole mentality of morals and values.

At the same time, we had in the Netherlands the rise of the welfare state. Again, the collectivism and solidarity mentality, which I think is also part of the Dutch mentality, helped establish the welfare state. And it could be paid by the natural gas [revenues]. Natural gas was found, and a lot of it was put into social welfare--the modern welfare state.

Apart from the good sides of social welfare, it may have taken away the idea of personal responsibility for your own circumstances—which is very American—but is far less the case here. There is a collective responsibility for everybody's welfare, to an extreme. This is changing now, by the way; but in the 1960's and 1970's, it was very much the mentality that society is responsible for everybody's welfare.

People developed a mentality that all problems can be solved, that there is no need to be in trouble, that we can and should solve any kind of suffering and misery. By the whole development of the welfare state, by the rise of science and technology, we have developed a mentality that we must be able to solve problems. And if we can't solve them by medical treatment, then you can solve it by killing. There is no need for further suffering.

An underlying element is secularization—without a doubt very important in our development.

### *Church acquiescence*

You can roughly make a distinction about church response into three [divisions]. First, the Roman Catholic Church, then the major Protestant churches, and then smaller Reformed and evangelical churches.

The Roman Catholic Church—at least at the lower clergy—has accepted to a large extent the modern view in many issues. Take, for example, birth control by the Pill. The Pope rejected it, but most of the priests say, ‘Go ahead.’ The bishops not, though we had some who would. At the local level it is different.

So from the Roman Catholic Church in the ethical issues, from the official church there was an opposition to abortion, birth control, and certainly euthanasia. But at the lower level, at least for abortion and euthanasia ... there are people who would go along with it—quite a number.

The same is true for the main Protestant churches. The main Protestant churches have warned against abortion and euthanasia that it is going too far, and that one should take into account the value of human lives and so on. But they have not taken a radical stand.

Euthanasia in the course of the 1980’s has been officially theologically accepted. It has not been embraced, but it could be acceptable. This is certainly the position of a significant number of pastors in these churches. The main traditional Protestant church has a significant orthodox wing that would reject it. But at the synod level, they are in a minority, so they can’t prevent these positions from being published.

The smaller Protestant reformed evangelical churches would be opposed. But their voice in public debate is very weak. There is no permanent input. They do have some people who are acknowledged widely as spokesmen for this part of the population. And there have been mass actions quite a bit against abortion in the beginnings of the 1980’s--manifestations of the orthodox part of the population. The percentage may not be that high, but if you bring the people together, there are quite a lot of people.

Demonstrating their disagreement, sending a letter to the Parliament, the Minister, and the Queen. That [protesting] is acceptable, depending on the events and the form it takes. Any kind of violence or marches, most people wouldn’t do. But a manifestation in a mass meeting, voicing the concern and opinion, sending this to Parliament and to the papers, this is considered even an obligation. Of the orthodox Protestant churches, few people would march on the street with a sign. Among evangelicals it would be easier.

Euthanasia has become so much a part of life that in Dutch society [mass marches and protests are] not the most effective way. It is helpful and important to have these things to keep the conscience. Personally, I think [such an approach] is valuable because it continues to be an issue. But the effectiveness, politically, is doubtful. I always regret when people who choose one strategy or another are fighting each other. I think these strategies should be and are complementary.

### *Doctors' influence*

The influence of the doctors has been decisive. Time and again, the courts have based their decisions on the documents and statements of the medical professional bodies—the KNMG or specialist organizations. When in court, there are always experts from the medical profession, carefully chosen. The courts were basing their judgments on the doctors' opinions to a major extent. They also have asked experts in medical ethics, but of course they choose them, too.

I think one scholar in the Netherlands who is both a physician/psychiatrist and a lawyer has analyzed this time and again. And he concluded, I think correctly, that the Dutch judges do not want to punish a decent physician who appears to be very caring, with a lot of empathy for the patient, and has found it unavoidable to finish the life of the patient in certain circumstances. Apparently they just don't do it.

When you bring cases to court, there is a reconstruction of what has happened. Without saying that these people brought to court to testify are aiming at misleading the court—I wouldn't say that—nevertheless, there is a kind of reconstruction. The aim of the reconstruction is to take the physician through it [safely]. Most of those who are asked to the courts to testify in these cases think that [euthanasia] should be allowed--under certain circumstances and well controlled, and so on.

I don't think that euthanasia for subjective reasons is accepted by all physicians or even by the majority. There is quite a category of physicians who never perform euthanasia. They wouldn't say on surveys that they are on principle opposed to it, because it's not politically correct to say that. So they say that they could imagine circumstances in which they would do it. Have they ever done it? No.

When a physician once in a lifetime of 40 years or so of practice has a case of what you could call euthanasia, I think you can say he's a euthanasia doctor. And I think there are quite a bit of these doctors.

So I think we are in a dangerous sphere now, and things are happening that we don't agree with, [but we] shouldn't dramatize. We should not exaggerate the situation, as if for every single physician, euthanasia is just daily practice.

Eighty-four percent of physicians say they have had a request for euthanasia at some point. Fifty-four percent of all physicians, 63 percent of family doctors, 37 percent of specialists, and 21 percent of nursing home physicians have performed euthanasia or physician-assisted suicide. So the majority is by family physicians. Twenty-three percent of doctors said they performed euthanasia without request.

This demonstrates that there is a category of physicians who never did it. They would never say that they would never do it. But they would be very hesitant to ever do it.

There have been cases of physicians who did it once but had so much trouble—either practical trouble with the investigations or personal trouble such as remorse—that afterwards, they said they would never do it again. So it is not necessarily the case that if a doctor does it once that it will be easier afterwards. Not everybody reacts like that.

In general, if you would ask them [of support for legal euthanasia], they would say yes. But again, this is part of the political correctness.

### ***What has been the effect of euthanasia regulations?***

Some would say when the doctor feels secure and comes out into the open and there is control, that this would also favor the security of the patient. This has always been the argument.

But I think that practice has shown that the argument is not valid. Because there is as much *not* in the open as there is in the open now. So there is no increase overall—not really more security—for the patient than there was before.

Doctors [may still not report cases] because they don't want the control [over them]. They don't want to bother themselves or the family with an investigation. In the research it comes out that this is a main reason. They feel that if they have done it according to the regulations, that it is a matter of relationship between the physician and the patient; Justice has nothing to bring to this—they should keep out.

### ***"Defense of necessity" trumps regulations***

[Let us say] the courts conclude in a case that life has been intentionally terminated; the law has been trespassed. The Dutch court has this article of defense of necessity [*force majeure*] which says that in a conflict of duties—which is the main argument that has been granted in these cases—a person may have a reason to trespass the law. Sometimes to save one life, you have to risk another. Then you can be excused for having done so. The person is in such a kind of urgency—such an impossible kind of choice—that either choice has a wrong side. It makes that person the transgressor of one law. But it can be excused if it was the lesser of two evils.

The point in the 1984 decision of the Supreme Court was that the defense of necessity was accepted by the Court in cases of euthanasia. [The Court said] that the physician found himself in a conflict of duties—the duty to save or protect life and the duty to alleviate suffering. Under certain circumstances, according to objective medical knowledge, and according to medical ethics, it was correct--defensible--for the physician to come to the conclusion that he had to finish the patient's life. So they gave preference to alleviating suffering over protecting life.

### ***Penalties remain rare and minimal***

Requirements have been formulated--requiring the request of the patient and a consultation--to make sure that there was, in fact, such a situation in which the only choice was between alleviating suffering or protecting life. So when it has been obvious that there has not been this careful examination of the wish of the patient and of the situation, then the physician could be convicted. But that is very few cases. Even if convicted and punished, the penalty would be very little. But even for a physician to be condemned would be in itself quite a serious thing, because it would be a very public reproach.

### *Involuntary euthanasia goes unreported*

Those [1,000 involuntary euthanasia cases in the first Rimmelin<sup>iii</sup> survey report] were never reported. Five years later, they found about 900 cases. They would say that in about a quarter of these cases, there had been a request earlier. But at the moment euthanasia was performed, the patient was incapable of requesting it.

To a certain extent, it is a lack of knowledge and a lack of facilities to provide adequate care in these cases. It was not just a whim of the physicians that the patients should be [euthanized]. No, I don't think so. It might have been—you never know. But not in general. I think this is a limit physicians should not go over. But it is not the case in general, I think, in which physicians just decide to kill a person.

I do think that by now, over the years, [in] a certain category of physicians, it is becoming easier in a sense. Now the pressure on physicians by patients, family members and others can be quite heavy. The danger of performing euthanasia in which there would be medical alternatives is become greater.

Though on the other hand—this is a kind of ambivalence in the present situation—there are quite a bit of activities now to train physicians in palliative care and to provide more facilities and spread this knowledge and this approach to terminal care. This could, in my conviction, prevent at least the majority of requests for and cases of euthanasia.

Both of these lines of development can now be seen. On one hand, a mentality of relaxation, of accepting [euthanasia] as part of patient care. On the other hand, an increase in the possibilities and knowledge of palliative care, which could prevent quite a number of cases of euthanasia.

### *Patients feel pressured to die*

Involuntary euthanasia is against the expressed will of the patient. That is not accepted. Non-voluntary euthanasia has been accepted by the courts, in the cases of the infants.

But if you call abuse the euthanasia of a competent person who has not given explicit consent, then apparently there are these abuses. But it's a minority of cases.

If you wonder to what extent the request of the patient is being induced by the physician or the family, there are no figures.

It is also difficult to find out in how many cases when euthanasia is performed at the request of the patient, in what percentage of these cases was this request induced or provoked by either the attitude of the physician or caretakers or family? I fear--I don't know percentages--but stories of physicians indicate to me that this is happening.

This is precisely what we always predicted would happen. Once you take away this line, it will happen. Not even necessarily from a kind of evil mentality. But when you consider it to be a lot better for a person to die than living with circumstances, the conduct, the attitude and the tone can really induce that--provoke that.

Only a small part of communication is the words we speak. There is no need for saying, 'You had better ask for euthanasia' when in essence the attitude, the whole way of dealing with people, is inviting this request.

This is a gray area; we don't know. In my opinion, this is a very serious and dangerous development which is taking place. It is terribly difficult to document. There have been cases reported.

### *Euthanasia pushed for non-terminal conditions*

I know of a person—this was told to me by [individuals] involved directly--whose brother-in-law was seriously ill. He had problems with infection and with kidneys not working, and he also had terrible breathing problems.

Later, it appears, his salt concentration was not balanced well, and he became disoriented. But they hadn't at the time found the reason for his being disoriented and becoming aggressive. So they had given him psychiatric treatment and pills to calm him down—[even though] the reason was purely physiological. So [the case] was critical.

This man who was looking after this person talked [to the family physician] about further specialist care and consultation and further examinations. The family physician said, "No, we'd better not. We'd better take him home. Your brother-in-law wants euthanasia, and I'm willing to do that. But I would like to ask you to cooperate."

Well, this person is not of the type who agrees with euthanasia and certainly was not going to be told by a doctor what he should do! So he said it is out of the question. [The patient] was further examined and treated. He is [now] a person in a wheelchair—a handicapped person. But he is in a pretty good condition at home. The salt imbalance was the main reason for his disorientation. He had an infection and breathing problems. But in any case, it was critical. He was in intensive care for a certain time.

It could well have been that [the caretaker] had said to his family physician, 'I want to stop all this trouble or anything of the kind—it is possible. His being disoriented and so on—the whole situation—he was kind of desperate. He could have made this proposal to the family physician.

This case demonstrates that there is a mentality and a willingness to go along with euthanasia in which [it cannot be justified].

[See also *Journal of Medical Ethics* 1999: 25:16-21. *Voluntary Euthanasia Under Control?* Jochemsen and Keown.]

### *Euthanasia condoned for children, infants*

I doubt whether infant euthanasia would be legalized. This probably will be taken out of [pending legislation]. About ten years ago, we had a discussion on infant euthanasia--especially with children who had cancer. A specialist in treating children with cancer who has done a lot to develop the field—a very capable medical doctor—admitted to having given pills to minors and

that some of them had taken these pills to finish their lives. He defended that, and there was discussion. It was decided not to accept it formally, in any case.

What strikes people now is that this [proposed] law would permit euthanasia for minors under 16 years even without the consent of their parents. But that is even rejected as a regulation by most physicians. Because, they say, it hardly happens at all, and it is a disaster if you go against the parents. I think very, very few, if any, physicians would do that against the parents.

But they do agree with euthanasia of children with the consent of the parents. I would imagine—again, purely at the political level—that the possibility of doing it without the consent of the parents will be taken out—but not the whole thing.

I testified in a second [euthanasia] case of a baby--the Groningen Case. Kadijs was the physician. This was a child with Trisomy 13 or 18—they are very similar and not considered viable at any kind of term. The parents learned to tube-feed and care for the baby. They took the baby home. So they cared for the child at home, and the medical care was handed over to the family physician (Kadijs).

After about a week or two, there was a hole in the cranium. Then tissue came through it which seemed to be—this is the medical record—very painful. Then he put certain things on it. His palliative care was very, very little. In fact, he did it with aspirins and certain kinds of relaxation [medicines] and stuff on the wound. [The parents] feared that this would go on and that at the end, the child would die a terrible death at a moment when the parents were not there. The parents wanted to be present when the child would die.

So the fear for, let's say, 'death without dignity,' without the parents being there was essentially the reason for terminating the life of the child, who would have died probably within a week or two weeks at most. But the medical data suggests, according to the physicians who were also involved, that it was in fact just a matter of days. So in a sense, you could say, 'What's the difference?' But on the other hand, you can say there was no need.

Therefore it was very clear: Is it at all appropriate to kill the child or patient? And because there had been criticism that the experts were all pro-euthanasia in the first case before that, now the public prosecutor also decided to ask experts who were opposed to euthanasia. That was a pediatrician opposed to euthanasia and me.

So we also wrote a report on the whole issue. There were also other experts who condoned it, who said it was good. The judge didn't go into any argument at all. And he said, 'Well, apparently among ethicists and medical doctors there is a difference of opinion, but what this doctor did was in a range of opinions. So it's all right. No arguments.

That demonstrates that the judges accept as a standard what the medical profession believes. 'This is within ethically acceptable medical conduct.'

*Criteria are ignored*

The point is that in this case, the presentation before wasn't exactly what the situation was. Some of these experts, these doctors involved, admitted later on that it wasn't the pain of the child that was the reason. Because the criticism was, 'Look—you are treating the pain with aspirin. That is not full palliative care!' And they admitted that.

The reason for accepting the appeal to the defense of necessity is intolerable suffering. So they brought it into that category. Though in fact at the moment there was not intolerable suffering by the baby. They feared maybe if the process continued that it might have become a kind of awful, acute, painful situation for the baby. But the pro-life pediatrician felt there was certainly no need to do this.

Handling the baby was painful for the baby, the parents said. It had taken a week or more. It was very difficult to continue with one of two parents always being there. From the point of view of the baby, there was no need for that apparently.

I have written an article about these two cases for *Issues in Law and Medicine*. Volume 13 No. 4. It was a controversial case in a sense, but not among the establishment. The medical and political establishment thought this should just be a precedent for accepting these cases.

Infant euthanasia is practiced but not very much. Investigations demonstrate about ten to 15 cases a year of intentionally terminating life. There are a number of cases—90 or so—in which life support has been stopped and at the same time medication given to hasten death. .

### ***How has euthanasia affected palliative care?***

This is a very frequently asked question. It is difficult to prove any statement. My feeling is, and this is shared by quite a few people in palliative care who had tried to promote it some time ago, that the political attention was much more on euthanasia discussion than on palliative care. I don't think it was a conscious plan by most politicians and doctors. They didn't say, 'No palliative care, because if they get palliative care euthanasia won't be accepted any longer.' It has not been planned.

I think rather there was a feeling of self-sufficiency. "We have palliative care. What we have is okay. And if our possibilities are not sufficient—if we are not able any longer to alleviate the suffering, then it can't be done. So that is the situation in which euthanasia should be acceptable."

### ***Euthanasia has overshadowed care***

Nevertheless, the debate and concentration on [euthanasia] has probably contributed to a lack of attention for palliative care. Quite recently, people came from international sources visiting the Netherlands discussing it and criticizing the Dutch situation and telling publicly about more possibilities for palliative care. This contributed to a sense that "Maybe we don't know everything. Maybe it is not available sufficiently."

In fact, the Rummelink report also says that palliative care should be improved. The point is that the establishment in medicine and in politics is quite ambivalent. On the one hand, they admit

that it wasn't as sufficient as it should have been. It wasn't available. But also in talking about cases of euthanasia, if asked if good palliative care would have prevented euthanasia, they probably would deny that! They would say, 'No, no, everything has been done. This was good.'

This is contradictory.

It is interesting that now the KNMG is organizing a course in palliative care, and that regional centers have been established for developing expertise in palliative care. So there is quite a movement now of improving this.

### *Patients' demands trump criteria*

When physicians—and not only physicians—when the patients have come to realize and accept euthanasia as a possibility, it is difficult to say to what extent the availability of palliative care would push back the practice of euthanasia. It depends also on whether in the courts and the physicians would maintain this requirement that there must not be any alternatives [to euthanasia]. It is only to be allowed when there are no reasonable medical possibilities to alleviate the suffering.

In this recent proposal for law, there is a contradiction that to some extent they maintain this, but at the same time they say the treatment must be acceptable to the patient. If then the patient has the final word, there is no longer any [meaningful] criteria—just that the physician should at least mention to the patient the possibility of palliative care. If the patient says, 'No, I don't want it. I want you to kill me,' then the whole criteria is no longer apparently operating.

Among the physicians, there is also a need to define intolerable suffering. Because among physicians, there is certainly a significant proportion who do not want to just perform euthanasia at the request of patients. The large majority wouldn't want that.

So they resist this complete subjectivism. But from the patient's side nowadays, this is stressed more and more. Of course, given the Dutch association for euthanasia, which is a very big and strong association, they are pushing this as much as they can.

### ***Will euthanasia in the Netherlands ever end?***

In the Netherlands, we have a small society. At a certain level, everybody knows everybody. Here everybody is involved in the clique.

There has been lobbying, discussions in Parliament, hearings, committees of Parliament ask for submissions. In that sense, the Parliament knows what is going on and what people think. At the media level, I have the feeling that those who oppose euthanasia have not had enough space; they have been marginalized.

Such a moment [to end euthanasia] must come from the spiritual side. Humanly speaking, it is difficult to envision this in the Netherlands now. But I believe God can do miracles. It could happen. From a rational, political point of view, it is not to be expected.

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<sup>iii</sup> The Rummelink report refers to two major Dutch medical studies conducted in the early and mid 1990's, examining the practice of euthanasia. The authors, themselves pro-euthanasia, surveyed doctors on condition of anonymity and immunity from prosecution. The study not only revealed that about half of all euthanasia cases were unreported; it also found that many physicians had ended patients' lives in thousands of cases in the absence of any patient consent. The study was published in the *New England Journal of Medicine* (van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia physician-assisted suicide and other medical practices involving the end of life in the Netherlands 1990-1995. *N Engl J Med* 1996;335:1699-1705).