A Refuge for Patients

In the Netherlands, the peddled promise of a so-called "good death", or euthanasia, has evolved into a dark threat to the elderly and vulnerable patients who must now fear for their lives.

In 2002, the Netherlands officially legalized euthanasia, which had been tolerated for decades and viewed as standard medical practice. Prior to that, five regulations supposedly protected patients:

1. The patient must make voluntary, well-considered and persistent requests for euthanasia.
2. According to prevailing medical opinion, the patient's suffering must be unbearable and without prospect of improvement.
3. The doctor must consult at least one other physician with an independent viewpoint.
4. Euthanasia must be performed in accordance with good medical practice.
5. A close doctor-patient relationship must exist. A doctor may only perform euthanasia on a patient in his care. He must know the patient well enough to be able to assess whether the request for euthanasia is both voluntary and well-considered, and whether his suffering is unbearable and without prospect of improvement.

However, Dutch medical studies revealed that these regulations were routinely disregarded. Cases taken to court rarely yielded a conviction and penalty.

Astrid Bokhorst

This pattern of winking at violations put patients at deadly risk. A landmark study published in the *New England Journal of Medicine* revealed that in over 57,000 cases per year where Dutch doctors intervened to cause death, in only one of four of those cases had the patient actually asked for it.[i]

The fear of involuntary euthanasia and the perceived lack of truly compassionate patient care in a euthanasia-embracing culture have prompted the growth of a patient advocacy group, the Dutch Patients Organization (*Nederlandse Patienten Vereniging).* The 70,000-member organization's medical advisor, Dr. Kees van ‘t Spyker and legal expert Astrid Bokhorst explained the mission and motives of the group during an interview at their headquarters in Veenendaal, Netherlands.[ii]

Euthanasia performed in the absence of pain or symptoms

Dr. Kees van ‘t Spyker, who serves as Medical Advisor for the Dutch Patients Organization and also as a coroner, related the case of a 72-year-old man diagnosed with stomach cancer. Dr. van ‘t Spyker explained that the man was in very good condition and was not experiencing pain or symptoms. He had not had any chemotherapy or surgery. Nevertheless, the patient asked the doctor to end his life immediately, saying he could not live with the idea that he was going to die soon. The doctor nearly immediately complied without challenging the patient or suggesting alternatives.

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After the euthanasia death, Dr. van ‘t Spyker examined the procedures the doctor had followed.

Dr. Kees van 't Spyker

“As a coroner, I had to come afterward to sign the papers and see if everything was all right. I found that the family supported the patient very much and that there was no conflict there. But I had a personal conflict. I had to say, ‘This is not a situation for which euthanasia legislation was introduced in this country.’ I mentioned my concerns to the legal system people and said, ‘I think this is not correct. Something has gone wrong.’

“And I learned that afterwards the physician who had committed the euthanasia was taken into a hearing. They told him, ‘Look, this was not correct what you did. We know that you did it with best intentions; it was not to kill. So therefore we will let it pass, but it should not happen again.’”

Euthanasia doctor marries the patient's widow

Dr. van ‘t Spyker recounted another incident that illustrates how regulations cannot protect patients from a doctor's mixed motives.

"A man of 60-something had a tumor of his kidneys and was having metastasis widely through his body. There was an obstruction of the bowel and he got a classical picture of bowel obstruction and was vomiting fecal material—a horrible situation. An operation was not possible.

"The man was home—not in the hospital; he wanted to die at home. And death was coming. Everybody knew it. The own doctor of the patient refused to do euthanasia.

"He said, 'No, I will give him something to protect him from pain and make him not suffer too much, but I am not going to kill him.'

"The family was not happy with that, and they asked another doctor from the hospital to come and commit euthanasia. This doctor came and did it and took care of all the correct legal steps. All the documents were there and nobody could do anything to say he was wrong.

"To my opinion, he killed this patient but in this situation one could say, in fact, this is a situation that the law was for. A horrible situation indeed. Well, it is not my choice but I can feel a little bit of sympathy for wanting to terminate in such a situation.

"I wouldn’t have mentioned it again--until I learned, about three months later, that this doctor *married the widow*.

And I said, “Ooh. What has happened?’ And then it got a smell to me. I said, ‘What’s going on?’ But I had no leg to stand on."

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70,000 patients seek a refuge

Dr. van ‘t Spyker described the need for a patient advocacy organization in a country where doctor has become king.

"The doctor in our Dutch system is in a very powerful position. He is the one who knows. He is the one who makes decisions. And if he decides there is ‘no medical sense’ in treating a disease, then that’s it. Patients in general are not very critical. If the doctor says it is so, then it is so. Often they are not well informed.

"That is where our organization plays a role. We try to inform people to be a little bit critical--to say, ‘The doctor may say so, but is it really like that? Are there alternatives?’

"Sometimes, of course, we must say there is no medical use and just throw up our hands and give pain treatment to try to diminish suffering. But we wouldn’t commit euthanasia. There are situations in which you cannot do anything. But there are many situations in which you can at least stabilize the situation or give comfort to people."

Dr. van ‘t Spyker observed, "The ‘medical public’ makes a picture of us as the people who are against euthanasia and who want to keep people alive even though they are dead. That is not true. We want the medical measures that are taken to stand in proportion to what is to be achieved. That is something different than killing people."

Legal expert Astrid Bokhorst noted, "People mix the two [euthanasia and artificially prolonging death] because they are afraid for the exceptional things. Then they say, ‘That is what I do not want.’ And then they are going to the other side [euthanasia] when they are not well informed about the difference."

Astrid explained how individuals benefit from the Dutch Patients Organization.

"Seventy thousand are members of our organization. [As a member] you can have your own [database] where you can put your information. Otherwise we try to get involved in situations where patients need [a voice]. In every place where there is discussion about patients, we try to be there--not only in the ethical aspects."

Dr. van ‘t Spyker added, "A couple years ago, there was a conflict between medical specialists and health insurance. We tried to be there to settle the conflict. I don’t think we succeeded totally, but we tried. Because it was in the best interest of our members. Most of them have a religious connection with us."

Astrid explained further, "We were not started as a Christian organization. But after a year or two there was a discussion about what our foundations were. Therefore, we said we have our foundation in the Bible. So we have been a Christian organization since then. Part of our members especially became a member because they knew our opinion about euthanasia and the ethical subjects. And others are members because we are taking our share in healthcare as a whole."

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Dr. van ‘t Spyker noted, "Also, in medicine, when technical mistakes are made, we try to defend the patients."

Astrid cautions, "We hesitate a little bit about the American situation, because in Holland we do not like to become the same as we think it is in America—'I sue you when you do this.' That’s not what we want. But when a mistake has been made, you have to settle it; therefore we are working."

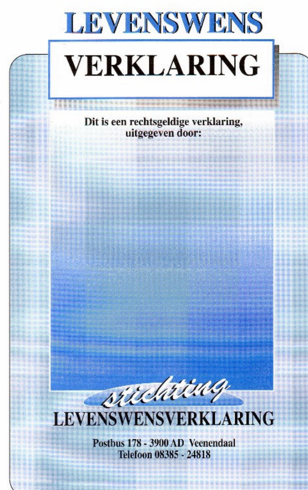
Dr. van ‘t Spyker emphasizes, "We try to settle by negotiation more than in court." The organization employs ten staff and a large number of volunteers for this purpose and for other patient advocacy and care functions.

"There is a branch of our organization," Dr. van ‘t Spyker explains, "that works in support of people who have to make vital decisions—not only for euthanasia but also for other very heavy decisions. ‘What can I do, what can I not do, what are the consequences?’

"We call this ‘Consultation Point.’ There is a telephone number, and we have a number of volunteers who can be reached on the telephone 24 hours a day, seven days a week.

"We have three doctors who are available in case there is a difficult medical problem to tackle. Ordinary things can be handled by volunteers—usually nurses or social workers. These are people who are trained in conversation with people, in learning what people’s intentions are, in knowing how to support people. If real medical background is needed, then they refer the situation to one of the three doctors."

Patients carry anti-euthanasia cards for protection



Card for patient protection

The threat of a doctor taking steps to end patients' lives without consent has led many vulnerable individuals to seek protection measures from the Dutch Patients Organization. Members can carry an official card developed by the organization that specifies, among other provisions, that the card carrier does not want to be euthanized.

"We felt there was a necessity for the cards," explains Dr. van ‘t Spyker. "There is another organization in Holland, NVVE, that has a kind of life testament in which they say, ‘If this and this happens to me, then I want to have euthanasia.’ And we felt that we needed a statement telling the opposite.

"At least time should be gained with this card. Patients will have time to consider things, and family and relatives and other people around the patient can say, ‘In this situation, he or she would have wanted things like this.’

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"The legal climate in Holland nowadays is that the patient has a lot to say officially—more than in the past. The only problem is that especially the elderly population does not know how to utilize this possibility."

Astrid notes, "The card has four parts—one for the patient himself, one for a proxy, one for the organization so that we know which people are registered here, and one for the doctor who is treating the patient. Then you can take this and have it put in your medical dossier."

Dr. van 't Spyker interjects, "Then the doctor knows, 'This patient wants it like this.'"

Astrid continues, "It was never meant to be an anti-euthanasia card. It is not from a defending standpoint. But when the Dutch healthcare is organized, the patient has to be able to make clear what he wants. This helps the patient. And it is never meant to be, 'Oh, when I don't have this card, they will euthanize me.' It is from a positive standpoint. Just one part is saying, 'I don't want euthanasia. The other things are describing how you want to be treated and that kind of information."

Dr. van 't Spyker clarifies, "It is meant to be, 'This is the way I look at the foundations of life. I wanted to be treated according to these principles."

"Victims of the majority" fear euthanasia

"Among certain people," Dr. van 't Spyker confides, "there is a level of fear. I think there are two groups—the people who are not well informed and the people who are afraid. With the things I am seeing now, I have to ask, 'Is our medical profession working in this way? Then I get a little bit afraid and say, 'If I were to get ill, how will they treat me? What will they tell my wife? How will they [manipulate information to] get the things that they want?"

Astrid reveals her own personal apprehensions should an illness incapacitate her.

"I am not afraid when I am able to speak out what I want. But what will happen when I am not able to do that? That sometimes comes over me and I think, 'Oh, what will happen then?' You have to make clear what you want. And when you can't do that…

"Most of the people in Holland have an opinion that is contrary to our opinion [about euthanasia]. We are a minority in Holland. That means you have no more power. Sometimes you are—or you feel you are—a *victim* of the majority."

Dr. van 't Spyker adds, "It means you have no more power, and the majority can do with you what they want. Even if you have an [anti-euthanasia] card like this, the doctor can still say, 'Yes, but the situation we are dealing with at this moment is not mentioned in the card. So we must talk. And then he starts to convince the relatives. It would be difficult.

"The card will not stop euthanasia; it will at least create time to get people thinking."

Astrid adds, "Especially in situations of a coma.

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"For example, we met a doctor, and he said, ‘No—this situation the patient would never [want]. It was not [the patient's] intention to write about this situation. Nobody wants to be in a coma. So this declaration is not about this situation,' the doctor said.

"And we said, ‘Yes, the situation we are now in is the situation the patient described.’"

"He could try euthanasia [in such a case]. But if the doctor were to be taken into court, it would be said, ‘Look, here is this signed document and you were aware of it, but still you said, ‘I won’t keep it in mind.’ Then he might get into trouble.

"But if euthanasia is not allowed, he [can also] just say, ‘Then I’m not treating [this patient] any more. He will not give the shots with this declaration. He can say, ‘I’m not treating anymore because I do not think there is any medical use in the treatment.’"

Dr. van ‘t Spyker explains further that if the family wanted euthanasia, "I think [the doctor] would be able to do it. But if one of the family opposed it, then he would hesitate because he knew there was the card."

Astrid explains that to commit euthanasia without a patient's consent, the doctor "has to construct the will of the patient. When it’s quite clear that the patient had a different opinion from the family, then the doctor cannot do it. When there are members of the church who are saying, ‘No, no, no. The mother was very religious; she would never mean to euthanize in this situation. Then the doctor cannot do it."

Doctor presumes the desires of patient

"We had a situation in court," Astrid recalls, "and the judge said that when a doctor wants to decide euthanasia or not—or treatment or not—he may only use medical norms, and not his own private ethical point of view."

Dr. van ‘t Spyker explains, "We knew beforehand we were going to lose, but we wanted the judge to say something that we could use. There was a situation of a man who was treated, and it was a difficult, complicated situation. The man had been widowed and then married for a second time. And the daughter from the first marriage was opposed to euthanasia and life-shortening medical things.

"The second wife decided it was now time to finish it. The man was indeed very ill and very much handicapped, in fact. So she said, ‘No, this is the time. Stop treatment.’

"Then we had a problem--because of the two conflicting parties. And the case was taken into court. The daughter took her father from the hospital and looked after him and nursed him so well that he survived.

"After that, she started a complaint against the hospital. The judge said that the doctors in the hospital should do everything that is medically useful and if the family wants something, then he should ask himself if there is a medical goal that the family wants to achieve. And if there was a

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possibility that it could be achieved, then he would have to put aside his own norms. And that is what we wanted the judge to say, and he did so, and we were very happy with it."

Astrid counters, "Of course, there is another side. The Christian doctor has to put aside his ethical opinion in this case. That's tricky about it."

Dr. van 't Spyker explains, "Most doctors would say that every case must be seen on its own and seen if [euthanasia] is acceptable or not. We know that there is a difference in norms between doctors, so we have to accept a certain gray area in which one says yes and the other says no."

"A Belgium study published some six months ago," Dr. van 't Spyker points out, showed that "terminating of lives by doctors in one way or another in Belgium is even worse than in the Netherlands. Official euthanasia is far less than in the Netherlands, but stopping treatment or giving overdoses of medication is very common there. When I got the figures for the first time, I thought, 'What is happening there?' I had thought the situation was bad in Holland."

Pain not a primary motivator for euthanasia

"It is not pain," Dr. van 't Spyker observes, that drives patients to euthanasia. "It is other kinds of suffering."

Astrid interjects, "Fear and loneliness."

"Fear," Dr. van 't Spyker agrees. "The fear of suffering. And the law says does not say there must be unbearable pain, but unbearable suffering. They are not exactly the same. I think that pain is horrible, but itch is even more horrible."

And if there are no symptoms at all?

"That's the whole problem," Dr. van 't Spyker says. "And that's what I speak to in my position as a coroner. It's always my question: 'Why was this suffering unbearable?' The man I was talking about with the bowel obstruction, it was clear. The man was vomiting fecal material. Well, I can feel that somebody could find that this is unbearable. That I can feel myself, even though I don't agree with what he did.

"But the man with stomach cancer, there was no pain—nothing. Just fear."

Astrid adds, "The fear of suffering in the future can be so legitimate, they say, that you have to put an end to a life. And we say, 'No, you have to teach people to handle the fear. You make clear that loneliness is not necessary. You have to stay with people and you have to give attention to people. Then they are not asking for euthanasia. Then they can bear a lot of pain."

Euthanasia doctors can have mixed motives

Why would a doctor, trained and pledged to heal and comfort, decide to kill his patient?

"[There may be] positive intentions," Dr. van ‘t Spyker offers, "to relieve suffering of the patient and maybe the suffering of the relatives of the patients.

Astrid suggests another motive.

"Can it not be that the doctor cannot handle the situation? Can that be a motive to put an end to it?"

Dr. van ‘t Spyker concedes that a sense of failure may motivate his colleagues toward euthanasia.

"I suppose that this factor and other psychological factors that might enter into it and influence his decision, yes. His feeling of powerlessness. ‘I can’t do anything.’ That might play a role. Officially, it should not, but it might."

Astrid continues, "Or that he does not have enough knowledge about painkilling?"

"Yes, that’s possible," Dr. van ‘t Spyker allows, "but now there is much emphasis on palliative care. And we’re trying to create a situation where you can find a doctor you can consult if you don’t know.

"It is not difficult for me to say to a person who is having eye trouble that he must go to an eye doctor, to refer. So why should it be difficult for me to say, ‘You are having a lot of pain and I can’t handle it, so I refer you to a doctor who specializes in pain control?’ Well, that is quite a common [problem]. That should not be."

Change may be "rumbling"

What would it take to get the Dutch people to begin to question the wisdom of euthanasia?

"It is starting at this moment--in the newspapers," Dr. van ‘t Spyker suggests. "Even people who have no Christian background are starting to say, ‘Wait, now. Is this what we really wanted?’ There is a rumbling starting. I hope it will end in a good discussion."

Noting a decided difference between the attitudes of younger and older patients toward the authority of doctors, Astrid says, "The older people are saying the doctor is always right. He studied, and what he says, I am doing.

"The young people are more critical. They have learned themselves. They will not follow the doctor in everything. And they think, ‘Not every plumber is honest. Why should every doctor be honest? When you put on a white jacket, you are not ethical above our society.’"

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[i] 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. http://www.nejm.org/content/1996/0335/0022/1699.asp
[ii] Interviews conducted by the author in Veenendaal, Netherlands, on February 8, 2000.

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