

Relevant

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Summaries by Corry den Ouden-Smit

Ten years euthanasia law. What's up madam Borst?

'WE ARE CAREFULLY DOING OUR WORK'

In private and political life she has experienced the time becoming ripe for the euthanasia law. That the law, as for now, does not offer any help with the 'completed life' is in her eyes a tragedy. A conversation with Els Borst.

By Leo Enthoven

Around 1980 anxious nurses came to her director's room in the Academic Hospital Utrecht. They had seen that physicians made an end to the life of patients, who had asked for it. 'It happened in the middle of the night. Nobody was supposed to talk about it, since it was a punishable offence.'

Clear directions were absent. At the hospital management meeting Els Borst argued in favour of an open euthanasia policy. She started consulting to the public prosecutor. 'He told me the chance of prosecution of physicians would be small, if they followed the prevailing guide lines. We would let the patients know that we were willing to help them. And we would report all euthanasia cases'.

In her role as vice president of the Health Council she sat on committees with lawyers, ethical experts and physicians who were asked by the government to offer advice. 'Our recommendation was clear. There should be an official settlement that a physician, who acted in accordance with the criteria of due care, was not punishable if he practised euthanasia.'

Hopeless

She had experiences in her private life. A family member had cancer of the intestines and had asked for, and received, euthanasia because her suffering was unbearable and hopeless. If the gut is blocked the person will vomit faeces. That is awful. At the same time the husband of Els Borst was dying. He also had asked for euthanasia and was eligible because he suffered from a blood disease with metastasis in the bones. That can be very painfully. The oncologist had told him he would give an injection if he could not stand it anymore. But that was not necessary. Her husband died without help.

As member of the political party D66 she closely followed all the political discussions around euthanasia closely. The discussion was intensified after an initiative to law by Elida Wessel-Tuinstra (D66) in 1985, which was not carried though. And after a report on the euthanasia practice in 1991, by the committee Remmelink in which Els Borst participated: 'Medical decisions around life's end'. Slowly the time ripened to introduce a euthanasia law. But as long as the CDA, a Christian party was part of the government that would be absolutely impossible. An important breakthrough came from the ruling of the Supreme Court of Judicature in 1984 about the conflict of duties. A physician can't relieve pain and maintain life at the same time. If a patient suffers unbearably and he requests time and again the termination of his life, and the physician helps him, the physician is justified in providing his assistance.

Ten years euthanasia law

The euthanasia law has remained in force since April 1 2002. Officially it was called: 'Termination of Life on Request and Assisted Suicide Act'.

The law came into (operation) force after thirty years discussion. Important data:

- August 6 1999 the cabinet (PvdA, VVD, D66) submits the Euthanasia Bill.
- November 28 2000 the Lower Chamber passes the law.
- April 10 2001 the Upper Chamber passes the law.
- April 12 2001 Queen Beatrix signs the law.
- April 26 2001 The Government Gazette publishes the law
- April 1 2002 the euthanasia law comes into force.

Majority

In 1994 Els Borst became minister of Health and served eight years in a cabinet without the political party CDA (Christian Democratic Appeal). Years of brainstorming about the delicate subject of euthanasia resulted in a regulation of euthanasia by law, initiated by the cabinet. Inquiries had shown that support was growing and a broad social basis in favour of euthanasia had been formed, even among members of the CDA party. The CDA politicians were stricter than their grass roots! Els Borst remembers delegations of foreign countries asking for a copy of this law, in order to implement that at home. 'But it is not that easy. You can't implement a law if there is no broad social basis. It is like agriculture. You have to plough and farm the land before you can harvest. It took us 30 years.'

No columns

The discussions in parliament were hard and intense. The problem was the radius the law should reach. Advanced cancer was not the problem, but psychiatric patients, children who can't express their will, persons who are unable to give informed consent, demented persons became the problem.

Together with Benk Korthals, VVD-minister of Justice she had to defend the law proposal. 'He was very skilled in politics. We took care not to work with columns: this disease yes, that disease no, so practice would mould the concept in the passing of time. In this way we managed not to exclude psychiatric diseases'. In talking with most of the political parties she could argue and find solutions for problems, but with the Christian parties she encountered a stone wall. During the debates in the Chamber Korthals and Borst emphasised that no physician should be obliged to practice euthanasia.

Medical expert and minister

Dr. E. (Els) Borst-Eilers has studied Medical Science at the University of Amsterdam where she took her doctor's degree Immunology later on. She became professor, director of the Academic Hospital of Utrecht and vice president of the Health Council. From August 1994 till July 2002 she was minister of Health, Sport and Welfare: she made preparations for a new basic health insurance. The medical-ethical issues related in particular to euthanasia. She was honoured as Knight in the 'Order of the Nederlandse Leeuw' and as Officer in the 'Order of Oranje-Nassau', two highly distinctively marks of honour. This year, the eight of March, she received the Aletta Jacobs award 2012 of the State University Groningen for the balanced way of sorting out medical- ethical issues. Madam Borst is honorary member of the NVVE.

Last means

She recalls that she has been an advocate for palliative care. She had visited hospices in England 'where the palliative care was much better organised than in The

Netherlands. I have always said: you should not make a euthanasia law if you don't have good palliative care. Euthanasia is the last means at the end of the route which includes palliative care. That has played a big role in the debates. With that argument I countered the arguments of the Christian parties'. And with proper pride she tells that this yearly annually, at the International Day of Palliative Care, where the Els Borst award is being presented.

With satisfaction she looks back at the careful process, but one subject has been excluded: the 'Drion pill'. Els Borst: 'Korthals and I would have liked a broader concept. We held on to the criterion of unbearable and hopeless suffering, but did not want to pin that down to any particular disease. The word disease does not occur in the law. The law does talk about patients and physicians; the Chamber has emphasised that relationship explicitly. That means that implicitly there should be a medical ground for euthanasia'.

During the Chamber debates there has been talk about 'suffering from life'. 'But the Chamber did not want to go along with the idea of helping out in cases of suffering when there is no explicit illness. Korthals said: Els we must let go, otherwise we will lose the whole Euthanasia Bill'. Borst finds it still a 'great tragedy' that this topic remains unresolved. With a loud voice she emphasises: 'the suffering of those people is visible, moving and perceptible'.

Age limit

She did not go along with the initiative group 'Uit Vrije Wil' (Off Free Will). 'I find the age limit of 70 years strange. I support the underlying idea, but I find the carrying out of the plan unsatisfactory. Maybe the Levenseindekliniek (End of Life Clinic) can play a role'. 'A necessary evil but a well thought-out construction' is her opinion. 'Maybe the patient can get a declaration from their physician that he is unable to help with the suffering that the patient experiences. The clinic has the advantage that where the deadly means are not on the bedside table at home and the physician's are at hand'.

She emphasises that physician's organisations should explain to their members about the possibilities of the law. 'The law is broader than expected. I am not afraid that the process degenerates. We work carefully. The number of deaths as a result of euthanasia and assisted suicide is a two percent. Physicians don't like to perform euthanasia. Rationally they agree, but emotionally it feels differently'.

Euthanasia as 'comfortable' alternative

'AS IF HE SAW WATER BURNING'

Mr B.H. Strubbe (1924) wanted to end his 'on going degradation process.' He asked the NVVE for information on stopping with eating and drinking. Thea van Dam of the van de LOD (Member's Support Service) has advised him.

By Anja Krabben

Thea van Dam recalls mister Strubbe, as an intelligent, sympathetic and humoristic man. He had lived his life and was ready to die - and was very determined about it. Thea van Dam met with him the first time as member of the support service on September 9, 2011. He died October 28, 2011 by euthanasia.

The first contact with the NVVE dated back to June 2011. Strubbe had sent them an e-mail for advice to end his life by stopping with eating and drinking. He did not have a

sense of smell or scent and was stone deaf. Besides he suffered from Parkinson, and had problems with swallowing. He fell down often because of a balancing problem. The 87 year old widower did not want to go on with this 'on going degradation process.' He thought he fell in the category 'completed life' and asked for help in the process of stopping with eating en drinking.

Brochure

The NVVE has sent him the brochure 'Stoppen met eten en drinken' (to stop eating and drinking), contacted his granddaughter, who lived with him in his house, and advised a talk with a member of the LOD. Strubbe did not want a talk about his decision. He was afraid the member of the LOD would discourage him.

Strubbe decided to go to a hospice and asked the NVVE for addresses which hospice would go along with his wish to stop eating and drinking. He had talks with a 'willing' hospice but became suspicious when he heard that water was given when a patient, in delirium, would ask for it. He contacted the NVVE and this time he agreed to talk things over with a member of the LOD.

The NVVE decided to send Thea van Dam, an experienced member of the LOD, who had worked forty years in Health care. She visited Strubbe several times and they had intensive contact by e-mail. He called his i-Pad 'my help and support'.

At the first visit Strubbe's daughter, son-in-law and granddaughter were present.

Since Strubbe was deaf the conversation was done in writing. Van Dam: 'I encountered a man who did know what he wanted. When it was clear to me that his wish to die was genuine I suggested euthanasia. Thereupon he looked at me as if he saw water burning. He really thought that, since he was not terminally ill, euthanasia was out of the question. I suggested writing a letter in his name to his physician. He agreed to that, so did his family. Two days later the physician called. He was not against euthanasia in this case, especially after the KNMG (Royal Dutch Medical Association) had explained in a report in 2011 that the margins of the law where larger than earlier realised. He made the condition that the report of the SCEN*-physician should be positive. And that went without saying.' The SCEN-physician judged positively over the euthanasia request.

*SCEN = Support and Consultation of Euthanasia in the Netherlands

To get accustomed to

Thea van Dam: 'To the family everything proceeded very fast. They had to get accustomed to the new situation. But euthanasia was a better option than starvation'.

Would it not have been preferable if the physician had proposed euthanasia?

Thea van Dam: 'A physician will not easily propose euthanasia. He is afraid the patient will think: he wants to get rid of me. He knew that Strubbe wanted to stop eating and drinking, but Strubbe did not ask for euthanasia. When euthanasia was asked for, the physician was extremely cooperative. It was Strubbe himself who thought he was not eligible. He was member of the NVVE, did receive Relevant, but it is disappointing to see what people fail to pick up from the given information.'

After the euthanasia request was granted Strubbe sent Thea van Dam flowers to say that he was very thankful to her. This gesture confirmed her in her opinion she had given the right advice. Strubbe was happy that he did not have to stop eating and drinking. That is a long and difficult way. Even for the people around him. Euthanasia was for him a 'comfortable way' of dying.

LIFE'S END CLINIC STARTED ACTIVELY MARCH 1, 2012

The Life's End Clinic (www.levenseindekliniek.nl) has started March 1 and people could register online. The interest was great: people with a wish to die, the press and prospective employees.

After two days sixty patients applied for a consultation. Most of them with physical complaints, although psychiatric complaints had been expected.

The conservative political parties have tried to delay the opening of the clinic, by asking for more guarantees but the majority of the Lower Chamber of Parliament found this superfluous.

The majority of the population has confidence in the Life's End Clinic. According to De Telegraaf, a popular Dutch daily, 90 percent answered YES to the question if the clinic meets a need.

The Life's End Clinic does consist of ambulant teams of physicians and nurses, working part-time. Rapidly the pressure on the six existing ambulant teams became so great that other ambulant teams had to be created. Financing this is a big problem.

The international press like *The New York Times* and *Der Spiegel* have kept an open mind on the Life's End Clinic, but *The Independent* talked about 'euthanasia squads'.

CONDITIONAL SENTENCE FOR ASSISTED SUICIDCE

In February the court of justice in Arnhem has given Gerard Schellekens (75) a suspended sentence for a year, on account of assisted suicide to an 80 years old woman.

The then chairman of the Stichting Vrijwillig Leven (Foundation Voluntary Living) had given a deadly drink to the woman. He is not a physician and the law only permits physicians to assist in suicide.

Schellekens had helped out, because the woman was met with no response in the nursing home where she lived. After her decease Schellekens destroyed the evidence and falsified part of a letter.

The court confronted him with the fact that he should have called in a physician. Schellekens replied that he had not succeeded in doing so.

If his health would have been better, his sentence would have been unconditional imprisonment.

NVVE IS THE WORLDS BIGGEST [LARGEST] RIGH TO DIE SOCIETY

The Dutch Right to Die Society is now officially the biggest [largest] Right to Die Society in the world, with more than 134.000 members. During the Week of the Euthanasia a thousand new members have applied.

After 2009 (the figure was around 104.000) the membership has gone up in an explosive way. More and more people are realising the need to put down in writing their wishes for the end of life.

The campaigns of the NVVE and all sorts of other publicity have attributed to this. Since two years it was possible to register online, and 60% of the new members have applied in this way.

The Right to Die Society in Japan is the second biggest with 125.000 members. But Japan has 127 million inhabitants and The Netherlands not even 17 million.