Relevant

Magazine of Right to Die-NL (NVVE)
Volume 43, no. 2, May 2017
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Dwell on fifteen years euthanasia law

'WE MAKE A FOOL OF OURSELVES IF WE DO NOT REPORT THIS'

On April 1, it has been fifteen years the euthanasia law came into force in the Netherlands. The official name is the Termination of Life on Request and Assisted Suicide Act. Dick Bosscher, who became Relevant chief editor on March 1 this year, provides the history with a personal annotation.

Dick Bosscher

Herbert Cohen, general practitioner in Capelle aan den IJssel, said in 1991, eleven years before there was an euthanasia law 'in the beginning I signed a declaration of natural death but at a certain moment at the euthanasia of a MS patient, so many persons were involved that the physician and I, the consultant, said to each other ''we make a fool of ourselves if we do not report this''.' I was interviewing him on behalf of journal Trouw (ed. a well-known Dutch journal on reformation base). To the dismay of many journal readers he revealed about the euthanasia practice of these days. On a large scale was fiddled with the declarations of death, said Cohen, He put over the helm and decided to declare all 'his' euthanasia cases.

Rather clinical
This interview has made a big impression on me and has influenced my view on euthanasia. Cohen could talk rather clinical on it. 'You should consider in the memory of the family the point of time will live on as a mile stone, so you should not plan it on a wedding day of one of the children.' But in continuing education courses he spoke warm and wise words 'you should not be frightened the first time is difficult. You should be frightened the second time is easily.' General practitioner Cohen did pioneer work by giving frankness about his euthanasia practice in a time euthanasia was punishable. It is nearly pathetic anno 2017 to see how it worked out around 1991. 'One day you have to have the guts. Once I made it to the examining judge, usually it stopped at the office of the Public Prosecutor. In Rotterdam the relation with the Public Prosecution was good. We got within two months a notification you can expect the first inquiry has been closed. If you did not receive a notification you could call the office of the Public Prosecutor: what's happened to the notification? Then the case goes to the meeting of the attorneys general. Last week I received a notification about Mrs. Van Dam that the attorney general, in complete agreement with the opinion of the meeting of the attorneys general had decided not to prosecute. That was five months after warts.'

Not needless accomplice
Physicians like Cohen were completely dependable on the benevolent cooperation of individual civil servants, coroners and policemen. Of course one should work with due care and your dossier should be sorted out. But Cohen tipped of the police in advance ''you can expect a call Thursday night.'' So they could take in account something was going to happen. I never told where or who, because you don't want to make them accomplice. Now they could give police sergeant ''Hendriksen'' evening duty. The daily work could go on and Hendriksen could settle this case.'

In 1990 five hundred euthanasia cases have been reported. That is a fraction of what was really going on. The guesses vary from two thousand to six thousand cases on yearly base. Often a natural death was quoted on the death certificate. Fear for prosecution was one reason, but also the bother and lengthy procedures with uncertain outcome restrained physicians to put their cards on the table. General practitioner Cohen wanted to break through the deadlock. In the interview he said 'you have to declare euthanasia, I think. You cannot give euthanasia carefully in secret. I think physicians who declare euthanasia go on more careful than physicians who do not declare. '

In secret

Thank goodness after 26 years nothing has to be done in secret. The Termination of Life on Request and Assisted Suicide Act, of which we celebrate now the third lustrum, gives the possibility to choose for dying in dignity. But still there are people who cannot get euthanasia because the physician will not do it and even does not refer to a willing physician. Still there are questions about (legal) hold, protection and security. Even now the judge and legislator haven't got that far yet to save the situation. In March the High Court remitted the case Albert Heringa, backed up by the NVVE, to the court, adding timorous the political and social debate should give direction first.

These months euthanasia in dementia and completed life was and is an important issue in the debate around the formation of a new cabinet. In February a NVVE inquire showed 63 percent of the Dutch people would support a law on completed life but the main political party does not want to burn their fingers. The social debate shall have to do its purifying work and the NVVE, with 167.000 members will go on with its pioneering work.

And Herbert Cohen? The Public Prosecutor took legal action against him for a euthanasia case, but the lawsuit ended in acquittal. Because of health problems he stopped as general practitioner but was active as medical confident for many years for the NVVE. Typical of the soft landing of the euthanasia discussion in the following years was his honourable appointment as member of the Medical Disciplinary Tribunal in The Hague. Herbert Samuel Cohen died April 6, 2016 at the age of 85.

1981) October 19 the State Committee Euthanasia was installed. Their task was giving advice about government policy (particularly legalisation) in euthanasia and assisted suicide. At that moment 54 percent of the Dutch people found euthanasia should be possible.

1984) Elida Wessel-Tuinstra (D66) introduces an initiative bill to make the regulations around euthanasia and assisted suicide less rigid (art. 293 and 294 of the criminal code). Politics makes no decision.

1993) The Netherlands becomes a euthanasia regulation in the form of a mention procedure. Euthanasia stays a punishable offence but physicians will not be prosecuted when they conform to the requirements of carefulness of the mention procedure.

1994) D66 comes into power. Jacob Kohnstamm does not succeed to get the subject euthanasia in the cabinet's formation but his party-member makes an initiative bill with support of the VVD and PvdA.

1994) In the Chabot-ruling, named after psychiatrist Boudewijn Chabot, the High Court broadens the concept 'suffering' to 'not-somatic, psychic suffering' Chabot gave euthanasia to a severe depressed patient.

2000) November 28 the Bill for the Euthanasia Law has passed the Lower Chamber House. The ministers Benk Korthals of the VVD and Els Borst of D66 have adopted the Bill literally.

2000) The court of Haarlem dismisses the case against the physician of former PvdA-senator Brongersma. The physician had assisted the former senator in suicide, because this very old man 'suffered from life'.

2001) The Euthanasia Bill passes the First Chamber House.

2002) April 1 the Euthanasia Bill is enacted to Euthanasia Law.

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Mourning expert Daan Westerink does not find her work depressing

EVERY ONE HAS HIS OWN MOURNING PROCESS

There are no manuals or instructions for mourning. How to deal with the loss of our nearest and dearest is personal. And the circumstances do make difference. Everyone has his own mourning process.

Leo Enthoven

Mourning expert Daan Westerink (48) tells about her experience: 'Our family was harmoniously until my mother died, in 1982. I was fourteen years old. My mother died of stomach cancer and her family reproached my father he had not foreseen how ill she was. The sorrow for the loss of their daughter turned into anger to my father. They never talked it out. What a pity.'

Unsolved troubles
Mourning does not always concerns exclusively the loss of a beloved person. Unsolved troubles between parents and children, brothers and sisters deepen the sorrow and helplessness of those who remain. Westerink sees that often in her work. There should be more attention to this aspect by caretakers and teachers. But not everything can be healed.

The death of her mother has made her reflect on this subject. She talked with people of the Catholic Church in which she was brought up, but to which she has turned her back at last. Two years she has worked in nursing homes. She met there a MS patient who only could use his eyes and his vocal cord. His eyes to read, what he enjoyed, and his vocal cord to communicate. 'He said to me: "Do not judge on the quality of life, Daan. I am the only one who may do it." His words have made a lasting impression on me.' The work in nursing homes has confronted her with subjects as self-determination, and anew, the death. And what comes afterwards coping with loss and coming to terms with it.

Elasticity
She has finished school for journalism, has worked as a journalist but decided to become an expert on mourning. She has written many books and articles on all sorts of mourning and gives workshops and training to professionals (undertaker's business, teachers, care takers) It is important to be practical and not getting stuck in 'how sad'. She does not find her work depressing. 'These people and I are at work on our elasticity. Everyone searches for his own way of coping with loss, for a new balance. It is a dual process seeking the confrontation with loss and keeping up with daily life.'

Men want to go on working, women like to talk. After the death of her mother she went with her friends to a disco, letting myself go. But I also needed talking and crying. 'The acquaintances should ask "what are your needs" and not "how do you feel". Mourning is not only tears. It is important to pick up your life. Life circumstances, personal factors, your environment play a role in dealing with mourning. Mostly after a while people succeed to pick up their life. Loss and grief will never disappear completely. The loss becomes apparent at certain moments for example at the birth of a grandchild, when you have lost your partner.'

Relieved
Some people get stuck. Some work hard to avoid the pain of loss, others stay at home and drown in their grief. In those cases it is a good idea to ask for help. You do not have to do it alone, says Westerink.

‘In unexpected death, like an accident or cardiac arrest many pieces of the jigsaw do not fit. This can worry those who stay for a long time. In heavily confronting occurrences like a suicide it counts even more, but in a planned euthanasia it can occur also. The father of a woman of 21, whom I have counselled, got euthanasia. The doctor had not told the man would die within seconds after the deadly means had been administered. For her it was a shock to see the man she talked to became a dead person from one moment to the other. It gave her a trauma. The doctor should have prepared the family better.’

The age of those who stay makes a difference. ‘Grown-ups prefer to say goodbye over a sudden death. For children an ill parent is intense. An illness of many months is a long time in a child’s life. I heard a father say to his young children: “I am glad a little bit that mama has died”. The children had felt the same and were relieved he had said this. Their mother had taken all the treatments because she could not let go. Her character had changed. That their father also was relieved the suffering was over gave the children leeway to remember her as a dear mother.’

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NVVE facilitates meetings of small-scale members contact.

‘ADVANTAGE IS WE SHARE CERTAIN IDEAS’

It is often difficult to talk about euthanasia with friends or family. Therefor the NVVE made an appeal to form discussion groups. More than thousand reactions came and seventeen pilot groups have started. ‘The flame is burning, it will get fire.’

Marijke Hilhorst

Twelve man and women come together in a care centre. One of them, Hans Dunselman, takes the lead. His enthusiasm and energy are contagious. All the members of the group have the experience you cannot talk about death with everybody. ‘It is difficult to talk about euthanasia with friends or family’. ‘When I share news or messages from NVVE on Facebook that is not appreciated’ and ‘Let it be known that we talk about the end of life out of free will’ and ‘what is the difference between the end of life out of free will and euthanasia’ are some of the questions.

Emotionally charged possession
This is the fourth time this group meets. The NVVE facilitates the first three meetings, there after the group has to take the initiative. The first three meetings deal with making an inventory of the subjects, giving information and talking about going on and if so how.

This time the discussion is about punishable offence in assisted suicide, and about juridical and moral right. ‘An aged person has asked me to help her getting the means so she can make an end to her life if she does not want to go on anymore’ says one of the members. ‘Is that permitted?’

Another member knows how much peace it can give if someone has the possession of deadly means. The other side is emphasized that it can be an emotionally charged possession. ‘I suffer from depression. It can be very tempting to take these means while the depression comes and goes.’ The suggestion to give it in control to a person you trust is turned away unanimously. ‘You cannot burden someone with it.’

No chatting
Hans Dunselman proposes to divide the group in working groups who go into literature and casuistic and report in the next plenary session. But this runs into opposition. It is too time consuming. But the

conclusion is there is a common base. We share certain ideas. Living in dignity, dying in dignity, sharing knowledge and experience with respect to the views of others and to help each other in a trusted environment.

A woman who, like Dunselman has experience with steering groups proposes to keep the next two meetings plenary with two points of interest, to avoid chatting. 'Where originates your wish for autonomy? And how can you communicate this with friends, family and your doctor?' Everybody is happy with this proposal. The next meeting will be at someone's home. Dunselman invites five members to go into a certain subject and report on it in the next plenary session.

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End of Life Clinic passes their knowledge on to physicians by continuing education courses.

'I WOULD LIKE TO FEEL LESS INCONVENIENCED'

The man crawls groaning and moaning on the floor. He gets up, his back bent, his hands twisting. He walks to and fro, up and down. Then he screams angry and desperate. In the room thirteen physicians look, quiet as a mouse, to those pictures of this man with advanced dementia unable to give informed consent. In 2016 he got euthanasia.

Els Wiegant

Sjaak van Meeteren, SCEN-physician and specialist geriatrics at the End of Life Clinic gave him euthanasia. He gives a continuing education course to a group of physicians, general practitioners, geriatric specialists and SCEN-physicians. With the help of the video and another case he puts them wise in the world full of pitfalls of euthanasia in advanced dementia.

Tense case

The need to know is big. 'I want to know what is permitted and what not' says a student. 'I would like to feel less inconvenienced' says another. And a third one sighs 'Euthanasia in advanced dementia is a tense case.'

IN A THIRD OF THE REQUEST FOR HELP THE PHYSICIAN REFUSES BECAUSE OF PRINCIPLE REASONS

In 2016 the End of Life Clinic received 1796 requests, 46 percent more than in 2015. Of this number 498 have been honoured. This percentage of 28 is nearly the same as that of 2015 states the annual report.

Director Steven Pleiter: 'This year we probably will attend to 2500 request of which 30 percent will be honoured. That means 750 cases. Therefore we need 75 teams, an increase of 25. It is difficult to form them.' A fifth of all requests come from patients with cancer. In a third the attending physician refuses because of principal reasons. Pleiter: 'It would be good if the End of Life clinic could concentrate on complex requests. We bring the conversation to this with the physician's organisations.'

The solution according to Pleiter is that physicians make agreements regional to take over a euthanasia case of a colleague who refuses because of principal or persona reasons. This procedure is known as the Hoogeveense model, which has proofed to be successful.

Euthanasia in advanced dementia means the person cannot express his will, so it is a knotty issue. It is one of the most controversial issues in the present euthanasia debate.

Aafke (30)*, specialist geriatrics saw in her work the increase of questions around euthanasia in advanced dementia. In connection with this she decided to follow the continuing education course. 'Also the discussion in the media makes patients uncertain. I see people become more demanding, they see euthanasia as their right and do not realise what it means to the physician. That is why I want to stand sturdy. The idea to use pictures was an eye opener to me. And it is comforting to know I can call the Life End clinic for advice at all times.'

Keep abreast

Fleur (41)*, ten years general practitioner and since half a year SCEN-physician has many older patients and sees more and more dementing persons at her consulting hours. They have seen pictures about euthanasia in dementia and want to know more about it, and she want to be abreast of this subject

So she followed this course. During her study she was interested in dying support. 'Dying is a very intimate process; it is such an existential part of life. I find it should be supported in a good way. That is my task as general practitioner.' Fleur has regularly conversations with some patients about euthanasia. 'I keep a finger on the pulse. I keep it debatable, inquire after it and place it on record.'

Once she has given euthanasia to a demented man at an early stage. 'My patient was ready before I was able to do it. He accepted I had to conform to the criteria of due care. I only can do it when I am ready for it and feel safe. Otherwise I won't do it.'

Impressive

Clinical geriatric Loes van Nuland (39) has hold conversations with two demented persons about a possible euthanasia, and half a year ago a general practitioner asked her about a euthanasia request of a 68-year old woman with dementia at an early stage, Van Nuland had to estimate if the woman had a mood disorder. 'Before me sat a healthy, relative young woman who did not want to be on the decline. Very impressive, I was doubtful about her mood disorder so I have referred her to a psychiatrist. It is a difficult judgement, because the consequences can be severe. So you want to be sure.'

About another demented patient she tells: 'the man was talking again and again about: ''going to the Creator''. But did he really want to say: now I want to die? At the moment I did not know the possibilities but I would have liked to confer with the End of Life clinic about it. That's why I followed this course. It is good to know you can talk with inspired people who have the heart in the right place and are an old hand in it.'

** In order to protect their privacy the names of patients and doctors are feigned.*

END OF LIVE CLINIC MORE AND MORE A KNOWLEDGE- AND EXPERTISE CENTRE

The End of Life Clinic has three building blocks for filling in their function of knowledge- and expertise centre: continuing education courses; advisors who guide physicians giving euthanasia to their own patients; the newly lanced website expertisecentrumeuthanasie.nl, special for care givers.

Since 2016 the End of Life Clinic, which celebrated her fifth anniversary, gives continuing education courses. Two are about euthanasia in advanced dementia, and about the basic request for euthanasia. This year will follow courses about euthanasia in psychiatric illness and euthanasia in pilling up of complaints of the old age. 'The first reactions are good' concludes director Steven Pleiter satisfied.

Safety net

Besides dealing with euthanasia requests, gathering knowledge about this subject and passing it on was important to the founders of the End of Life Clinic (especially Petra de Jong, former NVVE CEO). After two years there came room for this aspect. Pleiter: 'the number requests raised enormously since the beginning. From 2015 till 2016 even with nearly 50 percent, So we had to see to it caretakers could deal with it themselves.'

The End of Life Clinic was established as safety net, not as an everlasting project. 'The idea we should be superfluous in ten years has been abandoned. I think it is good to have a centre of expertise' says Pleiter. The first action to pass over knowledge was establishing an institute of euthanasia consultants, mostly experienced nursing people who coaches the physician on the euthanasia route. Pleiter: 'In 2015-2016 was a try-out. This was highly appreciated. Applications for consultation came mostly for complex euthanasia requests, but also from physicians who had not done it before. 60 percent of the physicians did not feel competent enough to deal with a specific euthanasia request. In one of four cases a patient had consulted the End of Life clinic directly. Then we contacted his physician and offered support of a consultant. In the other three cases the physician approached us.'

Not complex anymore

The education courses are meant to help physicians so they can deal with (complex) euthanasia requests. 'We mean with a complex euthanasia request if a patient has three months or more to live. For us most of these requests are not complex. In somatic disorder like ALS or MS we know it is a hopeless situation and we can estimate if a patient suffers unbearable. In psychiatric illness, in pilling up of complaints of the old age and dementia we can assess that also. We can pass on this knowledge so the attending doctor can handle this kind of requests himself. And we prefer that always.'