

Relevant

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Summaries by Corry den Ouden-Smit**

Jan Suyver, chairman of the Foundation Life's End Clinic

TO RELIEVE SUFFERING

Jan Suyver (65) has been asked to become chairman of the executive committee of the Life's End Clinic. He has worked with the judiciary and the Ministry of Justice, where he was drawn into the euthanasia policy. He considers himself a conservative liberal and a sympathising Protestant.

By Anja Krabben

Jan Suyver was not surprised being asked for the executive committee of the new foundation. He had already for 12 years served as chairman of the Regional Euthanasia Review Committee of South Holland and Zeeland and last years even as general chairman. Though he didn't accept immediately. He wanted to be sure this clinic would operate within the limits of the law. 'I have consulted NVVE-CEO Petra de Jong and she made clear to me that a real need for a Life's End Clinic exists.'

The NVVE receives, by telephone and letters, harrowing stories of patients who are entitled to euthanasia but have been refused by their physician. Many letters have been written to the website GeachteTweedeKamerleden.nl. Suyver has read them too. 'For me it was an eye-opener. In the controlling committee I saw cases in which euthanasia had been carried out, not the ones who had been denied. Now I know that a denial is not always right. The chairman is convinced that a clinic will fill a need. 'I back this initiative. I don't know how many people are involved annually But we will see.'

Prudent

Suyver and his wife are long-time NVVE-members. 'I am a prudent and conservative member. I do believe that euthanasia is part of the care we should have in giving people a humane end to their suffering, but I have hesitations about the absolute right for self-determination. I do not support the citizen's initiative Uit Vrije Wil (Out of Free Will) because I can't see the full consequences of the right for self-determination. I find the present euthanasia law a perfect and genial law. Short, forceful and clear.

Suyver realises that the relationship between physician and patient will be seen as the soft spot of the Life's end Clinic. Patients will turn to this Clinic because their physician has refused their euthanasia request, and a second independent physician has to take over. 'I know this does not have to be a problem. As a lawyer I will look extra carefully at this. The law does not require a relationship between physician and patient. According to the law the attending physician should be convinced of the unbearable and hopeless suffering of the patient. Such a conviction is feasible only after intensive conversations with the patient and after examining the patient's file of the former physician.

Time is running short

'It has happened before, that a second independent physician had to carry out the euthanasia. If the physician was on holiday the locum had to decide rather suddenly. The Royal Dutch Medical Association (KNMG) is critical of this. The physicians of the Life's End

Clinic should realise this and should take it into account. It is important to have a good relationship with the KNMG. After all, the physicians have to do the work. And, once again, I can understand their position. The whole process of euthanasia and assisted suicide is very burdensome to physicians.'

The two other members of the executive committee are Jan Schnerr, former chairman of a hospital board, and Adrienne van den Wildenberg, former chairwoman of the board of care centres Volckaert-SBO and also member of the NVVE-board. 'The Life's End Clinic is an initiative of the NVVE, the NVVE cooperates with the project, but a distance from the NVVE must be maintained. The executive committee sets out to open the clinic this year. We are working hard. Time is running short.'

Urgency

The important thing is to form mobile teams, says Suyver. 'A physical location for the Life's End Clinic is less important. Since most people want to die at home, our priority goes to the mobile teams. There will be a need for beds, for it will not always be possible to die at home. So we have to find a location, but we could rent a place in another clinic. But there are more things to take care of: protocols, finances, costs. People have to pay, but if someone can't pay, we will have a fund. Our starting capital is sufficient, thanks to the generous gifts of NVVE-members. At the same time this generosity is evidence of a broad basis for the Life's End Clinic among NVVE-members'.

Respect

When the first mobile teams become operational it will be very important to provide information. 'Media contacts will be taken care of by the public relations of the NVVE but, if desired, I will do my share. I find it important to show that not all NVVE-members are atheist. I am a practising Christian, but politically a liberal. I am for relief of suffering, because this is evidence of respect for life. I don't have any problem with it. I think it can help to know that the chairman of the Life's End Clinic has a liberal and Christian background and is still connected to a church'.

The state of affairs after ten years.

FOR MISTER A. THE LAW IS NOT YET A SOLUTION

Ten years ago the Dutch euthanasia law has *come into force*. In this decade have the expectations and the promises been fulfilled? Yes and no.

By Hans van Dam

In these ten years opinions have see-sawed and the practice appeared unruly.

Reluctance

In the first years most physicians were reluctant to perform euthanasia. In clear cases like cancer in a terminal stage it was no problem, but in cases of chronic illness and debilitating illness like dementia this type of terminal care was not granted. And in the public domain voices came forward to say euthanasia should not be too easily accessible.

After a while suffering in silence, like dementia and chronic psychiatric illnesses, became negotiable. Loss of dignity became a basic reason for suffering, and the problem of the completed life may follow.

Basic trust

'Help in afore mentioned cases is within the boundaries of the law', was the opinion of the Controlling Committee. Physicians don't worry any more about the rules, and the population sees more and more the hidden suffering of so many people. TV programs have helped to open eyes.

There is a growing yearning to decide for oneself over one's end of life. Debates are continuing about this topic. Three routes are being discussed: physician assisted suicide, assisted suicide by a qualified caregiver, or suicide by means available to the person himself.

The NVVE has had a leading role in those discussions for dying with dignity – and still has.

The fact is that many a physician rejects euthanasia, refuses to perform euthanasia and is unwilling to refer their patients to a colleague. This problem has been discussed as high up as Parliament. That has not have lead to an obligation to refer. But the Royal Dutch Medical Association KNMG, has announced loud and clear that referring to a colleague is part of good care. In the meantime a life's end clinic will help out as kind of plaster on the wound.

In the practice of euthanasia the advance directive, also called 'living will' has become less decisive than first thought.

An oral statement is always asked for and if the person is unable to answer properly the written request is judged null and void. Once in a while a physician with his heart in the right place is brave enough to grant euthanasia on the written request only.

The account of mister A., 69 years old, tells different story. In 2005 and 2007 he suffered a stroke. In the beginning he could manage, but he is deteriorating now. He can't walk any more, is incontinent and lives in a nursing home. His repeated requests for euthanasia have been answered by his physician with referring him to a psychiatrist. The psychiatrist gave him medication 'because the man suffered from depression'.

Mister A. does not want to live anymore and has decided to stop with eating and drinking. Since it is hard to fight thirst, and his damaged brain can't control the reflex to drink, he drinks. The physician and caregivers have seen this as a sign that mister A. definitely wants to stay alive. The result is that Mister A. stays alive and suffers unbearably.

Lowest dose

Normal pain relief did not help. The physician decided to administer Dormicum, a sleep medication often given in palliative sedation. It was given in the lowest dose, and he had to ask for it every time. So he has to be awake to ask for sleeping medication! His restlessness and anxiety became worse. At last he received a twice daily injection of 15 grams of Dormicum on which he sleeps for a few hours and awakens again, restless and with pain. A caregiver says with a sigh 'I would like to give him an injection every six hours so he could get some sleep. This was the situation at the time of writing this article.

Ten years euthanasia law: a lot has been gained, but a lot is left to be desired.

Dorothea Touwen specialist on medical ethics, about the law and the practice.

‘THIS STRESS IN PHYSICIANS KEEPS THINGS ON THE RIGHT TRACK

Dorothea Touwen can explain to physicians that he should act in favour of the patient's request. ‘It is easy for me to say, I don't have to carry out the euthanasia’ she says.

By Fred Verbakel

Dorothea Touwen is bewildered that a select committee of the Second Chamber of parliament came to the conclusion in December that severe dementia is a legal basis for euthanasia. She observes: ‘it is legal, and has been for 10 years or more.’

Touwen (45) is a teacher and researcher at the department ‘Ethics and law in Health Care’ of the Medical Centre, Leiden University. In the early stages of the euthanasia legislation the problem of severe dementia had been foreseen by the minister of Health, Els Borst, and at that time the interpretation was given that severely demented people can receive euthanasia on the basis of a living will – if all basic requirements have been met.

‘Another problem is the willingness of physicians to carry out euthanasia. The possibilities in legal jurisdiction are much greater than most people realise.’ She refers to the above mentioned conclusion of select committees and to the article in the *Volkscrant*, a leading Dutch journal. (See the article: ‘Euthanasia demented woman sharpens the discussion’)

Decisive

The annual reports of Regional Control committees showed that people who wanted to die after the diagnoses of dementia came up with the argument: ‘The outlook of dementia is unbearable to me. Life can only get worse.’ Decisive in the suffering was not the dementia itself, but the outlook of going through the whole process. That is the conclusion of Dorothea Touwen, who obtained a doctor's degree in 2007, on the thesis “For someone else. Deciding responsibilities in nursing home health care”

‘For many people the thought of becoming demented is terrifying. The NVVE and other organisations plead for self-determination. The law ‘Considerations of Ending Someone's Life on his Request, and Assisted Suicide’ is based on mercy. A physician may end someone's life if this is the only way to stop unbearable and hopeless suffering. The request by the patient is a prerequisite, but it is not decisive’.

Anxiety

‘The law is addressed to the doctor, not to the patient’ says Touwen. ‘It is hard for the doctor to perform euthanasia on a person if he can't communicate with the person any more. In some cases you see that this anxiety is diminishing. Then the persons close to the demented patient suffer more than the patient himself.’

Is it possibly to see if someone suffers?

‘Yes, those people are anxious, often panic stricken, they cry a lot.’

Is it possibly to suffer when the person involved is laughing?

‘Yes. Some demented people are aware that they depend on their caregivers. It is to their advantage to be nice and friendly. It is possibly though that they suffer. When a person can't explain what he is feeling, it becomes difficult. I recall a deeply demented

woman. She did not have a euthanasia declaration. She was eating whatever she was being offered. Her caregivers said 'she has a good appetite'. Her children said 'she eats whatever you put in her mouth, even if it is a paper handkerchief.' The doctor was powerless. He could not let the person die just because the family said: 'mother would not have wanted to live on like this.'

'Nobody knows what it is to be demented. Researchers Cees Hertogh and Marieke de Boer have asked people in the beginning stage of dementia 'How is that?' 'What do you feel like?' Not everyone says the suffering is unbearable. But they live one day at the time, and say it does not make sense to look ahead. People are more resilient than previously thought. They can push back their limits.'

Extortion

If Touwen has to choose between self-determination and mercy her choice is mercy. So the doctor decides? 'Yes, I think so. A demented person is very vulnerably. He can't argue anymore. A balance between what the patient wanted originally and relieving his suffering prevents that the doctor will be forced to do things he does not want to. Or that the patient feels forced not to be a burden to his family. Or that the people close to him extort things which are not in the interest of the patient. I believe in checks and balances. Is euthanasia the only way to relieve the suffering of the patient?'

Touwen does not advocate non-medical caregivers in assisting suicide. The organisation Uit Vrije Wil (Off free Will) advocates giving non-medical caregivers a special training. Euthanasia should be the domain of physicians. They have also patients with other problems like ringing ears. That contrast, that tension, keeps things on the right track'.

Touwen is not against mobile teams on the Life's end clinic, an initiative of the NVVE. 'Euthanasia should preferably take place after a lengthy relationship physician-patient. But since quite a few physicians refuse at the last minute to assist with suicide, many people are left out in the cold. I find that inhumane. People who are in distress should be helped. I am convinced, after talks with Petra de Jong, the NVVE does justice to the criteria of 'due care'.

What is the attitude of the new generation physicians?

Touwen talks with her students about euthanasia. She sees that everybody is impressed by a 'patient interview' where patients talk about their wishes for life's end. She teaches her students that there is always an ethical component in their method of treating *patients*. 'You have to ask yourself what is right for this patient. If you really care for your patient you can't really say: I don't help out with euthanasia. But for me it is easy, I don't have to carry out euthanasia.'

Students with different cultural background often have even more restraints. Touwen: 'Once I had a student who wanted to become gynaecologist, but she was absolutely against abortion. I have told her that standing on this principle she would be hard pushed find a training venue and later a place in a partnership. No gynaecologist likes abortion, but sometimes they have to do it. If you are absolutely against abortion you should choose another speciality. And she has done so.'

As for euthanasia, physicians should be clear about it, says Dorothea Touwen. 'Lately you see oncologists, urologists and other specialists pass euthanasia on to general practitioners, while they are the attending doctor. That is cowardly. If you are against euthanasia on principle you should *state* that in your information brochure. Life is beautiful, but sometimes it lasts too long.'

EUTHANASIA DEMENTED WOMAN SHARPENS THE DISCUSSION

Minister Edith Schippers of Public Health is not in favour of legal obligations for 'refusing physicians'. She supports, however, the idea of mobile teams working in cooperation with the Life's end clinic. The political discussion was highlighted by the news of euthanasia granted to a demented woman.

In November the journal *The Volkskrant* published a story about a 64 year old woman who had received euthanasia in March 2011, after consultation with SCEN-physicians*.

This was the first time the death wish of a person, incapable to express her will, has been granted in The Netherlands. The person, a demented woman, had made a written euthanasia declaration and had discussed this with her physician comprehensively. At this stage of dementia she could remember only fragments of her motivation.

The decision to perform euthanasia had been well-considered according to the SCEN physicians. More SCEN-physicians have been consulted than was legally required. One of them remarked that if the wish of the patient can't be expressed, the decision can be judged by means of the description the next of kin provide of her and her personality. Also important was that the physician wanted to keep his word to her. He had known her very well and they had often talked about death.

All the SCEN-physicians judged unanimously that the physician had acted appropriately.

The Second Chamber of parliament Commission of Health has discussed this case in their debate about euthanasia. The law is clear on this point: euthanasia for demented people can be legal. The suggestion to force refusing physicians to refer their patients to willing physicians did not get support, because 'there is no right to euthanasia'.

But the minister was positive about the idea of mobile teams, in cooperation of the Life's end clinic. She praised the NVVE for their knowledge and carefulness in this matter.

* SCEN Support and Consultation for Euthanasia in the Netherlands

LIFE'S END CLINIC AND MOBILE TEAMS TAKEN ROOT

In the media, in politics and in the public domain, the formation of a Life's End Clinic by the NVVE has largely been accepted. That mobile teams will do most of the work gave rise to discussions last year. NVVE-CEO Petra de Jong has explained that most people prefer to die at home. That is the reason why mobile teams have been formed. 'Just call the NVVE' is not realistic. The mobile teams work very thoughtfully and carefully in assisting suicide.

MANY WHO FIND THAT THEIR LIFE 'IS COMPLETED' DON'T SEE AN EXIT

Elderly persons who consider their life has been completed don't ask for assisted suicide just to spare their next of kin. This is one of the outcomes of a study "Elderly who find *that* their life is completed, future expectations and experience of hopelessness" by the Medical Centre of the Free University in Amsterdam. Of those persons, 31 of whom have been interviewed, most hoped for a speedy death.

The results of this study have been published at the end of 2011 in the *Journal for Gerontology en Geriatrics* and in the publication *Crisis*. Those are scientific journals of gerontology, and suicide prevention.

The role of the general practitioner has been discussed. Most of the elderly had spoken to their general practitioner about their wish to die. In most cases their physician had recommended psychological help or anti-depressive medication. Some of them found one consultation too little to build up the needed relationship.

GENERAL PRACTITIONER MAKES MISTAKE IN EUTHANASIA REQUEST

A general practitioner has been given a warning because he had not acted according to the rules. He had granted euthanasia to a person at the early stages of dementia.

His family supported the request except one daughter, who did not have any contact with the family. The physician had wavered several times in his decision, because of the daughter's opposition. That had caused problems within the family.

The disciplinary board judged that the physician should have known the rules. The rules say that approval by the family in a euthanasia request is not required. By requiring the approval of the family the physician had caused problems in the difficult situation around terminal care.

OVER 4000 LETTERS FOR 'COMPLETED LIFE'

On the website 'DearMembersofParliament.nl' (www.GeachteTweedeKamerleden.nl) over 4000 letters have been received with moving stories of people who ask politicians to take seriously the citizens initiative 'completed life'.

The citizen initiative 'Uit Vrije Wil' (Out of Free Will) to obtain political support for self-determination of one's life and death has been supported by more than 117.000 people in 2010. That means that Parliament is obliged to put this item on its agenda.

On November 9th 2011 the NVVE started a website to give support to this citizens initiative. An overwhelming response followed, and the NVVE made a selection of a 1000 letters, which will be offered to Parliament January 17.

An ever recurring theme is the deepest wish to have autonomy over one's own life and death. And the concern that young people, including physicians and politicians, can't understand what it means to experience the feeling that one's life has been completed.

Inter parliamentary Benelux conference about euthanasia in Brussels.

Physicians who refuse to carry out euthanasia should have the obligation to refer, says Maya Detiège, chairwoman of the inter parliamentary Benelux conference about the self chosen end of life, on December 2, 2011 in Brussels.

The conference has been organised by the NVVE, LEIF* and the Benelux parliament, consisting of representatives of people from Belgium, The Netherlands and Luxembourg. This parliament gives advice about tasks that overstep the boundaries, for example transportation by ambulance.

Differences

The Belgium and Luxembourg euthanasia laws have been inspired by the Dutch law. There are a few differences though: In Belgium and Luxembourg the registered written living will stays valid for five years, in the Netherlands forever. The written living will in the Netherlands is a substitute for an oral request if the patient is unable to express his will personally; in both other countries this only counts in case of irreversibly coma. In the Netherlands minors from the age of twelve may request euthanasia, in the other countries only adults are entitled to ask for it. 'We should make the laws similar' says NVVE-CEO Petra de Jong.

Harmonisation must be feasible since a poll has shown that 80 % of the Benelux population is of the opinion that a physician, who refuses to implement euthanasia should refer to another physician. And 77% are of the opinion that everyone with a written euthanasia request should, in the entire Benelux, get medical help for the self-willed end.

The opinions are divided about 'completed life' as basic reason for euthanasia. The Netherlands has more advocates in favour than Belgium and Luxembourg. This subject has been more explicitly discussed in the Netherlands. That may be the reason.

Belgium goes further

SCEN* and their sister organisations LEIF* and EOL* in Belgium and Luxembourg work differently. A SCEN physician controls the requirements of due care. In Belgium a LEIF physician goes further, he guides and may coach the physician who will carry out euthanasia, and in exceptional cases he will take over a patient from a conscientious objector physician.

The conference ended with consensus and recommendations for the three governments. The advices: an obligation for physicians to refer; make a list of physicians who are willing to carry out euthanasia and to whom patients can be referred; persons with a written request for euthanasia should get help throughout the Benelux.

Chairman Detiège closed the Benelux conference with the appeal to politicians that they should listen to what lives within the population and reopen the debate about revision of the law.

*SCEN: Support and consultation for Euthanasia in the Netherlands.
LEIF and EOL are comparable to SCEN in Belgium and Luxembourg.