Relevant
Magazine of Right to Die-NL (NVVE)
Volume 43, no. 3, September 2017
Summaries by Corry den Ouden-Smit

Geriatrist specialist Kees van Gelder finds his colleagues unnecessary afraid.

'EUTHANASIA IN FAR ADVANCED DEMENTIA IS POSSIBLE'

Euthanasia in dementia is difficult. You have to be able to say you want to be dead. If you wait too long the dementia may be so far you have forgotten what you wanted. And a doctor cannot help you anymore. But sometimes euthanasia is possible.

By Inge Klijn

Last year three persons with advanced dementia have received euthanasia. Specialist geriatrist of the Life's end clinic, Kees van Gelder, is one of the physicians who gave the euthanasia. He finds his colleagues unnecessary afraid. 'If you act carefully and transparent you can give euthanasia to demented people who suffer greatly and have repeatedly said they did not want to come into this situation.' It stings him those people are not being helped. 'If you see a patient suffering greatly and you do nothing, you leave him alone.'

Suffering every day

Together with a qualified nurse Jeannine Salvino, also attached to the Life's end clinic, Van Gelder explains when euthanasia is possible, on the basis of a case of a man with far advanced dementia, whose desperate wife asked for it.

The patient had a living will which says he does not want to live on if becoming demented and that he did not want to enter a nursing home. After the diagnosis was made he visited his physician to talk about his wish. The plan was he was going to receive euthanasia at a stage of dementia he still could express his will.

But that moment has passed. At a certain moment he did not know anymore what he wanted. He ended up in a nursing home. There he is extremely afraid and panics for the least happenings. Medication does not work. His wife sees him suffering every day and tries to find a physician who is willing to give him euthanasia. His name is Kees van Gelder.

Medical-ethical counsel

Nor the living will nor the conclusion of the spouse are sufficient to Van Gelder and Salvino. They want to see for themselves that the patient suffers and medication does not work. Besides they have to be able to convince the Regional euthanasia review committee.

Fort that purpose they formed a counsel with three of the persons who tended for him, the psychologist, the physician, the spiritual assistant and his family, to gather all sorts of information about the patient.

They will observe the patient systematically to see if he suffers. Van Gelder explains: 'A medical-ethical counsel is a proofed method to attain a concerted decision, in complex medical issues.'

Van Gelder steers the process. He will see to it the observer will say explicitly what he sees and not going along with other views. Salvino fills up: 'You can look for moments of happiness by the patient. If there are no periods he seems to enjoy living that is significant too.'

She states she wants to make her own observations apart from the dossier to have all things considered to come to a decision.

Comfort and attention
The persons tending for the patient have an important role in the observations. Van Gelder says: 'Many demented people do not suffer. They do have quality of life because the personnel comforts them and gives them attention. Jeannine Salvino emphasises euthanasia in far advanced dementia is an exception. 'It takes place in a small group of patients of whom you can prove they suffer greatly and fulfil the other criteria of carefulness.' Van Gelder: 'Often the family thinks the patient suffers, but moments of sadness and anxiety come exactly at the moment the family visits or when they leave. In dementia the higher functions like speech are gone, but the deeper feeling of familiarity stays. That is why the patient may feel lost if the family comes or goes.'

Part of the systematic observations by the attending team and the family is that they make video- recordings of the behaviour of the patient. With this can be demonstrated the patient suffers. These recordings will be part of an educative documentary Van Gelder lets make of all the steps to be taken in the preparation to euthanasia. So he will persuade his colleagues euthanasia in far advanced dementia is possible within law.

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Agnes Wolbert is the new NVVE -CEO

'THEME SELF-DETERMINATION PLAYS A ROLE IN MY LIFE FOR A LONG TIME '

Ample before the national elections Agnes Wolbert member of the PvdA, a political party of the left wing, let know ten years membership of The House was enough. It was time for a new challenge which she took up with the NVVE. Since June 1 she is CEO.

By Leo Enthoven

Born in Oldenzaal (1958) Wolbert has studied Behaviour Sciences at the Groningen University. She started as a teacher to go on as scholar Behaviour Sciences in outpatient treatment of young people. From 2006 till March 2017 she was member of the Lower Chamber House for her political party, lately as spokeswoman on medical-ethical subjects.

Meaningful challenge
When she was looking for something else, by chance she heard of this vacancy. A party member, NVVE volunteer, asked her to be, with him, in charge of an information meeting, on the subject end of life. 'My part was to talk about the PvdA policy and my personal ideas. That evening he told me the NVVE was looking for a CEO. The next day I looked it up and wrote a letter that I wanted to fill the vacancy.'

Wolbert answers to the question why she has chosen for the NVVE: 'I am deeply moved by people who want euthanasia and, in a vulnerable period of their life, depend on decisions of other people. Always the questions of life have played an important role in my life, even when I worked for youth care. In 2006 I dedicated myself to the Deltaplan Dementie (ed. an important plan on dementia) There was no policy on that topic, whatsoever. Self-determination, keeping the direction in your own hands, is a theme that plays a role in my life for a long time. It is a pity the last ten years of my mother's life turned out differently. Alas, when her dementia revealed itself, dementia and euthanasia were an unthinkable combination. Thank goodness, not anymore now.'

By heart

It touches her deeply there are physicians who say: I cannot do this. 'A physician may refuse, that is legitimate. The why intrigues me. We may want physicians go into this subject thoroughly. According to the third evaluation of the euthanasia law, less than half of these physicians is acquainted with the *Code of Practice* of the Regional euthanasia review committees. Every physician should know this Code by heart.'

The new NVVE- strategy note *Freedom from Dying* is not only an excellent base for the coming years, she finds, but also a meaty challenge to inform the members and to have interaction between them. The NVVE should adjust better offer and services to the needs of the members. She thinks her experience within the PvdA with member meetings and discussions will help to involve members with the association.

In the meantime she became NVVE-member. A euthanasia declaration is not (yet) filled up. Surely she will talk this over with her new physician. 'Dying is of all times. Likewise the questions, insecurities and vulnerabilities people have around their life's end. The NVVE plays an important role that is still going on.'

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About role nursing people in the last phase of life

'TALKING ABOUT THE DEATH IS SOMETHING INTIMATE'

The nurse is often the first to which a patient talks about his fear of or longing for death. Nursing people see regularly persons die. What is their role in the last phase of life? A discourse with palliative nurse Annemieke Brouwer, and ethic person Jasmijn de Lange of V&VN, the professional society of nurses and care takers.

By Inge Klijn

Nurses are acquainted with the dying of patients. And patients talk more easily with a nurse than with the doctor about their death wish. 'The contact has a low threshold, there is a relation of confidence and they see the patient more often and lasting than the doctor' explains ethic person Jasmijn de Lange. She states: ´Not all nursing people find it easy to talk about life's end questions. Those who work in lasting care are acquainted with it, but it is something intimate. You have to have the feeling if the patient wants to talk about it. To be able to do this depends also on the question if you can think about your own death. My first confrontation with death came when I was 17 years old and working as nurse. The intimacy around the dying process makes the profession beautiful. Often you become part of the family and they ask you to be present at the moment of dying.'

Palliative sedation
Annemieke Brouwer is specialised in palliative care. Care for patients who cannot be cured. She works at a home care centre and talks easily and often about death. She gets questions about practical and physical affairs, but patients want to know also how the illness will look like, what is possible if medication does not work anymore, and if they can die at home. 'I always try to go along with what the patient wants to know. When the patient pushes the conversation about the coming death forward. I try to bring the conversation round to this point. Yesterday I was with a patient with metastatic cancer of the prostate. No cure was possible and he was desperate what to do. His pain was awful. The conversation turned to what to do if the pain becomes even worse. He said he was afraid of more pain, so I knew he wanted palliative sedation and not euthanasia.'

Fly on the wall
Apart from her work at the home care centre Brouwer is consultant at the Life's end clinic. She assesses, with a physician, the euthanasia requests of people who cannot get by with their physicians. With her clients of the home care she will never start a conversation on euthanasia. 'But if someone really wants to talk about it, I will tell what is possible. Many colleagues do not do that. They are afraid to enter the domain of the physician.' Contrary to palliative sedation, where she decides together with the physician the policy, euthanasia is pre-eminently the domain of the physician. In euthanasia only the physician may give the potion. In palliative sedation the nurse puts on the infusion.
On account of the close relationship with the patient the nurse is often present at the euthanasia, tells Jasmijn de Lange. She has experienced different scenarios. 'At one occasion you are a fly on the wall, another time you hold the hand of the patient when he breathes his dying breath.' For the patient it can be nice the nurse is present at the euthanasia, but also for physicians it is better, finds De Lange. 'It makes it more bearable. Performing euthanasia is burdensome for a physician. People do forget this rather often.'

Switching easily
Annemieke Brouwer find nurses should know about the rules around euthanasia, because this is part of good care in the last phase of life. But many a nurse does not have this knowledge and often physicians lack knowledge on this point. A nurse with solid knowledge of the requirements to become eligible for euthanasia, can help the patient with a referral for another physician or the Life's end clinic, puts Brouwer. Jasmijn de Lange subscribes there is much to gain on this field, but she is not surprised nurses do not know these specific rules. 'The field of care is so wide, they cannot know everything.' That nurses often witness death, makes their work heavy. 'It is difficult to see a person suffering. And it depends if you see the suffering of an old lady who does not want to go on living, or a deadly ill patient with pain or someone who has killed himself by hanging. With this last example the nurses do ask themselves what could have been done to prevent this happening.'
Brouwer does not find it heavy to be confronted with death every day. 'I can easily switch. I see six to eight persons a day, so I cannot dwell on too long to this. If someone dies on a good way, with as less pain and discomfort as possible, than I have a god feeling. I cannot change his illness but I can do everything to make the last phase pass off as good as possible. If someone dies the way he prefers, I am at peace with it.'

Completed life
In the concept bill for euthanasia in completed life the nurse is mentioned as possible social worker for the dying process. Annemieke Brouwer sees herself in that role 'but in a team, like at the Life's end clinic. The co-operation with a physician works fine. Are there psychic or

physical complaints which can be helped? Is there a problem underneath the euthanasia request like a depression or the person is in mourning? You should weigh this thoroughly.'
An examination of the V&VN discloses less than half of the nurses see a role for them in guiding euthanasia in completed life. 40 percent have scruples. They can see elderly do not want to go on living but they see loneliness, fear for dependency and the feeling to be superfluous as origin. In that case you should pay attention to that.
This examination shows also it is not clear when a life is 'completed.' There lies the bottleneck, finds De Lange. 'So it is too early to say we can be social worker in the dying process.' She, an ethical person, also puts question marks on the need for autonomy. 'That is a great good, but as a nurse we say: ''you may be a burden, you may make an appeal to us.'' Dutch people find coping is part of a good life. In other cultures like Moroccan or Turkeys, sick elder people are being cared for. The patient does not lose his dignity. There is less fear for dependency.'

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Physician Life's end clinic Sjef Boesten received (and gave himself) euthanasia

'OUR LORD WAS LOOKING FOR A GENERAL PRACTITIONER'

Physician of the Life's end clinic Sjef Boesten has done everything to fulfil the euthanasia wish of his patients. Last year he was diagnosed with oesophagus cancer. He wanted euthanasia right away. Yet it did last some time. 'You have to take along your nearest with you in that decision.' Sunday June 11 he died, 68 years old.

By Koos van Wees

Sjef Boesten says, some days before his death, he has lived longer than he initially wanted. Professionally he knew you have to take along your nearest in the decision making, but it took a while before he came to the conclusion: do what you preach.
'After all euthanasia is the best if everyone can go along with it, only then it is really "the good death".'

Beyond- suffering

Boesten has postponed the euthanasia for his acquaintances. They could not miss him yet. 'I said I did not want to go into the curative route. As general practitioner I knew what oesophagus cancer meant. I have talked with my nearest about the coming end. Now the cancer has become metastatic and I am suffering, everyone sees it cannot go on any longer. In fact I had decided, contrary to my original decision to see a specialist. But there were metastases in the lungs and liver so I knew a cure was no option. 'Euthanasia is the best way to end life, when living becomes unbearable' says Boesten. 'I have been able to help so many people and have seen them path away satisfied. I want to go that way too. If suffering becomes too much I want to be lifted up beyond the suffering, according to my wish.'

Happy event

He sees his euthanasia as a happy event. At the moment of this conversation the suffering was evident. 'I become more and more short of breath, the pain is heavy in spite of morphine. I hardly can walk, the pain makes me touchy, medication has such side effects I am not myself anymore. The dignity has gone. I do not want to be remembered this way.

My dying should be a happy event, a festive end of my splendid life, with all its ups and downs. Euthanasia suits me. My father and sister died immediately, without goodbye. My mother became demented, then you cannot say goodbye either.

Boesten starts the euthanasia by opening the tube for the potion to bring him in coma. A colleague physician injects the deadly means. He had drawn up his living will only two and a half year ago, when he retired. Sooner the plans did not materialise.'

Like a bomb
Only shortly he could enjoy his retirement. 'During a bicycle vacation in Spain I could not swallow a piece of bread. My wife said even: hopefully it is not oesophagus cancer. These past weeks I had the feeling of a full stomach which I interpreted as stress. The gastroscopy made an end to the uncertainty. It was as if a bomb exploded. He has resigned to his fate and he says to his environment not to mourn over his death but to enjoy having lived with him. He answers to the question what he expects after the euthanasia: 'I am not a believer although I have been brought up catholic. Death is the end of life, and after this life there is nothing else. One of my patients said: "I do not understand why you are picked out. The only explanation I can think of is that Our Dear Lord is looking for a good general practitioner". I cannot think of a finer compliment. I will go and look what is the matter with Him.'

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Nilüfer en Bas Vogels over his euthanasia after three stirring years

'WE REFUSED TO BECOME VICTIM'

March 8, NVVE-fellow worker Bas Vogels received euthanasia, 47 years old. At his invitation *Relevant* looked him up in the hospice, four days before his death. Three months later his wife Nilüfer (40) looks back on those three stirring years. Bas wanted to tell about his choice for death, the conversation with his wife about the choice for life. 'Illness will not take over the affairs.'

By Els Wiegant

January 2014 Bas Vogels and Nilüfer Gündoğan went steady. They knew each other already since a year. Both were active in the political party D66. They planned to go on tour to Vietnam and Cambodia. First Bas payed a visit to his general practitioner on cause of cramps in his bowels. He was diagnosed with intestinal cancer. Follow-up showed there were metastases in the liver. It was hard times. Bas said to Nilüfer he could understand if she was going to leave him. He would not blame her. But she was really in love and wanted to stay with him.

Rash couple
Bas and Nilüfer went on living as if nothing had happened. The impact of his illness came later. Bas was feeling good, did sports three times a week even ran the half marathon in Amsterdam in 2015. 'The illness was not at the foreground. But once in a while panic and fear prevailed. From a rash couple we became couple who took up the challenge' says Nilüfer Both wanted to go on living as before. They made journeys and enjoyed living as much as possible. They refused to become a victim of the illness.

The best
September 2014 Bas and Nilüfer were married. A year later, October 2016 their son Mikail was born. 'Nilüfer wanted badly a child, I was less eager but later on I wanted a child too. Mikail is the best what has happened to me' says Bas. 'We had hoped to have some time without trouble but my illness became worse.' Nilüfer: 'of course his illness has played a role in our decision for a child, but a child born out of love was an enormous enrichment in our life. I knew I had to do the biggest part of raising our child. But the choice to have a child was the right one. Absolutely'.

No Lourdes-wonder
In the beginning of this year Bas health beamed real worse. When the doctors told Bas he had not months but only weeks to live he decided for euthanasia. Nilüfer supported him in his decision. Both are member of the liberal party D66. 'I am happy to live in a country where this is possible', says Nilüfer.
Bas for felt sooner than his wife there was no possible rescue. Nilüfer: 'I am an optimistic person. I did not expect a Lourdes wonder but had hoped the cancer would slow down. When I saw reality I knew Bas could not go any longer. His euthanasia should not have been performed sooner or later.'

How hard reality has been for Bas and Nilüfer they do not look back in regret. Bas says: 'of course I find it awful not to see my son grow up, and to have lived so shortly with the love of my life. But I am glad I have known her and I have experienced the wonder of a son.' Nilüfer agrees with him. 'I find I have been lucky. I had to say goodbye too early to Bas, but thank God, I had the chance to meet him. I would do it again, even if I knew the outcome.'

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Derek Humphry, 40 years right-to-die pioneer publishes his memoires

'MY GOAL STAYS A GOOD LIFE AND A GOOD DEATH'

Derek Humphry (87) passes internationally as the godfather in the struggle for legalising euthanasia and assisted suicide. In 1975 he arranged deadly potion for his deadly ill, severe suffering spouse. Three years later he published the book Jean's Way about her struggle against cancer, her suicide and his role in it. That meant a drastic change in his life: from journalist to activist. Recently his book came out, *Good Life, Good Death: The Memoir of a Right to Die Pioneer.*

Leo Enthoven

His frank *Jean's Way* leaded international to the same mass attention of the media and heated living room discussions as the case Postma in The Netherlands. Increasingly louder rang the call for law alteration and information on a gentle form of suicide. Humphry would dedicate the next forty years of his life to this, and write eight books over this subject, among them *Final Exit*, the first suicide instructions for use, with nearly one million sold copies, a straight hit, which stood at the top of the bestseller list of the New York Times. It came out in thirteen languages, in The Netherlands (1992) with the title *Waardig Sterven*. From his house in Oregon he tells chuckling through the telephone: 'Í was flabbergasted! Never had I thought you Dutch were waiting for my advice.' He emphasises it was rather the other way around. Piet Admiraal (euthanasia –physician of the first hour), Klazien Sybrandy (key person in the case Postma and founder of the NVVE) and others assisted him in word and deed.

Take ignorance

Humphry met his first wife when he as journalist interviewed her about her activities for young people in Manchester, England. Shortly after they married, they had two sons and adopted a boy. In March 1974 Jean (41) was diagnosed with breast cancer. She has been treated with radical mastectomy, radiotherapy and chemotherapy. She asked Derek to find out what the prognosis was. 'Those days the physicians took ignorance', he writes 'Jean wanted to know the truth.' The attending doctors told him Jean had no chance whatsoever. Jean told him she did not want to go till the end if the suffering became unbearable. 'Quality of life is not a matter of the doctor but a choice of the patient'. With these words he phased her point of view in his memoires. .

Jean asked him to arrange deadly means. Humphry approached a doctor who he ever had interviewed. After a long discussion about Jean's illness, treatment and prognosis the doctor handed over a deadly dose secobarbital and codeine. This made both men culpable of a crime: assisted suicide. Humphry never disclosed the name of the doctor. The Public Prosecutor in Great Britain went into Humphry's acts but no prosecution followed.

The metastases to her vital organs and her bones made her confined to her bed. Some ribs broke spontaneously. March 28, 1975 she told her sons about her intention. The next day she asked Humphry for the deadly potion. He gave her: coffee with the means and an awful lot of sugar.

He writes: 'When I seized her empty cup, she had just enough time to say '*goodby my love'* before she got into coma.' Within an hour she had passed away. The unsuspecting doctor marked as cause of death: lymph gland cancer. Time and again Humphry has been asked if he regrets he has helped her. His answer: 'Never. I had felt guilty if I had refused her request and had seen to it she had to continue suffering. I have helped to escape the last devastation by terminal cancer.'

Puritan land

Jean's Way came out in 1978 and 130.000 copies have been sold. Humphry moved to the United States where he was offered a job at het *Los Angeles Times.* This function made he could be traced easily. He has been him showered with questions on help with dying (which potions are most deadly? How can I obtain them?), and how to fight for alterations into the law.

He founded the Hemlock Society which dedicate itself to the right to assisted suicide and euthanasia for terminal patients. On its peak Hemlock had nearly fifty thousand members. The next twenty, thirty years he gave thousands interviews worldwide, wrote manifesto's and articles, came hundreds of time on television and radio, gave lectures in all the continents and became the president of the World Federation of the Right to Die Societies.

In the meantime assisted suicide is permitted by law in some American States, euthanasia not. 'This is a puritan land', he tells by telephone. 'Right-wing politicians and church leaders oppose euthanasia with tooth and nail. Over thirty, forty years the United States will be as far as you are now.'

At first his second wife, Ann, was his help and stay at Hemlock. Later on problems arose on account of her psychic disorder (borderline). They parted in a battle divorce. Ann defamed him by trumpeting he murdered his first wife. Her fourth suicide attempt succeeded.

Half paralysed

Asked about his greatest success Humphry says *Final Exit* and Hemlock, which in the eightyish years, paved the way with bills to make alterations into the law in a number of American states. Hemlock has merged with other organisations. Humphry now runs the

Euthanasia Research and Guidance Organisation (ERGO), writes a newsletter, a blog, gives advices and dispatches his books.

How does he see his own passing away? ‘When I have a stroke I hope it will be lethal. When I stay half paralysed I hope someone will be so merciful to help me die. If in terminal illness pain relieve and quality of life stay acceptable, I will hold it. If not, I myself will end my life or ask, as resident of Oregon, a doctor for a deadly potion. My goal in life stays a good life and a good death.’
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