

Relevant

Magazine of Right to Die-NL (NVVE)
Volume 44, no. 3, September 2018
Summaries by Corry den Ouden-Smit

'IF IT CAN BE THAT WAY, HOW NICE!'

'Cancer concerns all of the family' says actress Sjoukje Hooymaayer (78). She knows what she talks about. Her family suffered the loss of her husband, René Lobo, who was diagnosed with lung cancer nearly four years ago and died fourteen months later. Now the family is confronted with the cancer of Sjoukje, cancer of the ovaries in a far advanced stage.

Martien Versteegh

In the case of René it was Sjoukje who has taken care. Daughter Jessica says: 'I was stewardess. I and my brothers helped whenever necessary. Three weeks for his end mama called upon us, and we took turns'.

After the death of her father Jessica took a 'mourning year'. Thereafter she started a training for funeral escort. Her father had mentioned that once, but then she was not ready for it. One of her best friends died two years before her father became ill. 'Thirteen months her daughter and I have taken care of her. She died in my arms. Together we have organised the funeral. Also with my father I have played a major role.'

Directly after finishing her study Jessica could start in her home town Amsterdam. 'I find my job fantastic. You can mean something to other people. For me death belongs to living. I see death not as the end, but as a transition. From that point of view you can bring some light in the process of saying goodbye'.

When Jessica heard her mother had cancer, she decided to take care of her mother and stopped working. 'The choice came easy. I wanted to be with my mother, who could not stay alone. And I would not be able to do my work properly, being emotionally involved with my own sorrow.'

A lot of laughter

'Of course there is sorrow, but we have laughed a lot' says Sjoukje. 'It is important to enjoy the good things of life, and to laugh.' When the doctor offered chemotherapy and said one of the side effects was death she and her children roared with laughter. Sjoukje did not have to think long about it. 'Chemo will drain your body without the perspective of healing. The oncologist asked me to think about it for a week, but my decision was made.' Her children backed up her decision, but should have done that anyway 'because it is her life, and her decision.'

Jessica and her mother go along very well, and her brothers are happy she takes care of their mother. Sjoukje: 'I am lucky to have four nice children, and there is no quarrel between them.' There was no discussion in the family but talks about how to implement the care. Jessica will be the stable factor but is being helped by her brothers and aunt. Every Thursday her aunt stays till Friday, her youngest brother stays Friday overnight and the other brothers come whenever they can, do the shopping and cook once in a while. For Sjoukje it is nice to have other company and she enjoys Jessica going out and having a life of her own. Sjoukje 'Jessica goes to friends and dances the tango. That makes me happy. Going out is water for your soul, and your soul needs water'. For Jessica is

tango like life. 'It scours, you have to find your balance in the embrace and it is the most equal dance there is. Yes it makes me very happy.'

Ticking time bomb

Sjoukje is not afraid what is coming, nor is Jessica. The most important thing is how she feels. Sjoukje does not have pain, but has hardly any energy left. Both know her situation. It is a ticking time bomb, it can be over every moment, but even so it can last a longtime. Jessica: 'We are prepared. We have a protocol what to do if things go wrong.' Sjoukje: 'and we have a very good relationship with our doctor.'

Sjoukje is very glad euthanasia is possible in this country. She contacted the NVVE shortly after the diagnosis. She was member already, her man received euthanasia three years ago. But now she had to regulate everything herself: the non-reanimation token, the euthanasia statement

Both women have great respect for their doctor, who told them she does not sleep for three nights after euthanasia. Sjoukje does not know exactly when for her the moment is there, but she trusts her doctor to be there if she cannot go on anymore.

Not to the hospice

One thing they know: Sjoukje is not going to hospital, nor to a hospice, and home care takers are not welcome. 'It is good we can do it this way, is not it? But we are in a luxury position.' About the funeral they have made decisions. It will be the first funeral Jessica organizes. 'With help' she adds. 'The bonding with your parents is as a chord which resonates. When your parents die, it gives a very special feeling. You become grown-up, even if you are an adult for years. How the future will be without her I do not know, but I know we will make it, also without our lioness.'

Psychiatrist Smid about the experiences of the next of kin with euthanasia

'OPENNESS IS GOOD FOR THE MOURNING PROCESS'

More than forty readers reacted on a call in last Relevant. They described their experiences with euthanasia of a next of kin, or the failing, when euthanasia was not granted. The emotions differed from resignation or feeling proud to anger or helpless rage. Does mourning after euthanasia differ from that after a natural death?

Els Wiegant

Scientifically, says Dr. Geert Smid, psychiatrist at Stichting Centrum '45/Arq Psychotrauma Expert Groep, (an expert group on psych trauma initiated after WOII) hardly anything is known about the differences between mourning after a natural death, or after euthanasia or assisted suicide. 'What we know is that any form of unnatural death gives a heightened risk to complicated mourning for the next of kin' he explains. 'Euthanasia is also an unnatural death, but it differs from accidents, murder, disasters or unexpected suicide.' We talk about 'complicated' mourning when someone drowns in his grief, or does not function after six or twelve (about that is discussion) months.' Smid writes a handbook about this with colleagues.

A research on this terrain has been done in 2003 by Nikkie Swarte-Houbolt and others on 189 next of kin of cancer patients who died by euthanasia in comparison to 316 next of kin of cancer patients who died a natural death. The first group turned out to be better in coping with loss and post-traumatic stress than the second. A possible explanation could be the openness in which death by euthanasia is surrounded. This must not be seen as a plea for euthanasia, explained the researchers,

but as a plea for the same openness and care for all patients in the terminal phase of their life. 'Openness has a good influence on the mourning process' knows Smid from his own practice. 'The reactions on the call in *Relevant* confirm how talking about it, speaking out your wishes can contribute in having peace with a decease.'

Cultural aspect

The opposite, being secretive and secrecy, can hamper the mourning process. A Swiss study showed psychic problems occurred when people in Switzerland, where euthanasia is forbidden, had to hide euthanasia had taken place. A cultural aspect sticks to this: is euthanasia or assisted suicide accepted in your environment? Can you be open about it? Or are you afraid for lack of understanding and disapproval? Having to be secret about something can lead to loneliness. Swarte and colleagues named also the possibility of saying good-bye as an explanation for a milder form of mourning by next of kin of someone who had died by euthanasia.

Smid: 'In euthanasia the surrounding is often taken in in the process to euthanasia. They are aware they have to say good- bye. If you could not say good-bye, like with in an accident that can pursue you for a long time.' Some readers said what pursued them, sometimes for decades, was not lack of openness, but anger and 'helpless rage'. In all cases it concerned euthanasia was not granted, or the non-cooperation of doctors.

'Complicated mourning often goes hand in hand with longstanding anger and rage. When people see their dearest has suffered long and unnecessary, thoughts come up like: why did the doctor do nothing, which brings about emotions like rage' says Smid.

'In fact it are the "what-if"-scenarios": what should have happened if the doctor had cooperated? Or: what if I had done this or that? This can lead to self-reproach, guilt and shame feelings. Those thoughts distract from the sorrow the loved person is gone. This is the core of complicated morning: the reality of the loss seems unacceptable, or is not seen, out of fear for the accompanying grief. At the other side, the majority of the reactions was positive about the euthanasia of a loved one. Someone says 'a deliverance', another 'a special experience which makes thankful', a third 'a special experience and rewarding closing of a very difficult period'. About the euthanasia of his wife says a man he 'has become a richer and more conscious living man'. Another man says 'After 56 years of marriage it was a source of strength it could happen this way.'

Making an impression

Smid: 'The autonomic way people give form to their suffering and life's end can make great impression on the nearest. A severely ill patient in your surrounding is also a confrontation with your own limited existence. If someone goes in peace, that can be an example for you. It can give you hope you may go that way.'

'I HAVE EXPERIENCED THE CONVERSATIONS ABOUT EUTHANASIA AS EXTREMELY HEAVY'

Kees Doets (77) has experienced euthanasia in his surrounding more often. Last time was this year when his second wife Liesbeth, whom he had met in 1975, got euthanasia. 'The biggest problem was she felt doubt and hoped for an alternative. Maybe by her mental retardation, which I played down. The children were more negative about it.'

Marijke Hilhorst

'Last year the nerve pains, my wife suffered from, started. No cause was detected and the medication was heavy. The pain stayed in all its violence, coming and going. Also her mind deteriorated. I thought she was better off dead. I saw we should not be able to care for her at home, especially since my physical condition was bad.'

Conclusion

Liesbeth Doets hoped to die in her sleep, but the prospect was dying in a nursing home, dementing with heavy pains. 'We started talks about euthanasia. Because of her forgetfulness we had to talk things over, again and again. Till we reached the conclusion it could not go on anymore. I have experienced these conversations as extremely heavy. Till the end my wife looked for not existing options. That must have drained her energy. Anyway it drained mine, aside it was heartbreaking, for me and for our children.'

Two years ago my wife had renewed her living will, but when she contacted now her doctor he refused to cooperate, since 'she was not capable to express her will'. The Life's end Clinic helped out, with a nice team that could make good contact with my wife. Till our surprise she could tell her story facing doctors and the SCEN-doctor. She expressed crystal-clear her wishes. Then it was quickly done.'

Top evening

'The afternoon before the euthanasia should take place our children and grandchildren came to our home, and in the evening we had dinner at our daughter's house. 'It was a top evening for her. She did not have pain. She was sitting on the couch and on tour everyone came to her to talk and to look at pictures. There was a lot of laughter.' Now Kees Doets has doubts and is uncertain. The thought haunts him he has pushed his wife to her decision. 'It was not always easy to separate her interest from mine. I was concerned in all ways. Her death wish was vivid when she had pain, and flawed when the pain was gone. I wanted certainty. Didn't I push her when asking to cut the knot?' He is silent for a while and continues 'but I was at the end of my tether.'

Afterwards Doets realizes how limited the meaning of a living will is. 'Euthanasia seems a right but you have to stand up for it yourself. To explain in crystal-clear words how unbeatable you suffering is may be possible, but that your suffering is without perspective may become a problem. Doctors want to try everything out. I find it absurd a grown-up has to persuade doctors about his death wish, doctors who are curtailed by law in their actions. I am looking for a more autonomic route.'

'WE WERE POWERLESS.'

Jacques, the man of Liesje van Baal (82), has always been afraid of becoming demented. And he became demented. For euthanasia it was too late. 'So where he was afraid of happened and we were powerless' says his wife.

Marijke Hilhorst

Liesje and her husband have known each other since their training for teacher physical education. She worked as a teacher, he became director of the Student Sport Centre of the Technical University Eindhoven, which he helped to set up. They have been married for 56 years and got three children.

She tells dementia occurs frequently in Jacques family. He did not want to go through the tarnish process he had seen with his father. 'He was 63 when the first signals came. He could not get the essence of a conversation anymore. Things became worse. He could not find things, had to stop

driving the car. Sport was important to him but after an injury of his Achilles tendon he could not play for nine months, and lost his social contacts. Thereafter he got complaints of his back which needed an operation. The three hours during narcosis has deteriorated his brain, thinks Liesje. 'He has not been the same since.'

Heavy years

In 2013 Jacques was being diagnosed with vascular dementia and Alzheimer. 'Three days thereafter we went to the general practitioner to talk about the possibilities of euthanasia. He said he would cooperate. After that we did not see him often, but when I visited him I always reminded him of the living will and his promise.'

In the meantime the geriatrist came every five weeks, a case manager put Liesje wise in the world of dementia. Jacques went to day care, at last four times a week. Those were heavy years for both of us, in spite of the efforts of our daughters.

December 2013, Jacques said he could not go on anymore and wanted to put on the euthanasia procedure.

'When the general practitioner made the house visit Jacques greeted him with "Hello Father." They talked together and Jacques made clear the time for euthanasia had come. The doctor said he would help. He would send a SCEN-physician and after his holidays a date for the euthanasia would be made. I was afraid it would be too late, but the doctor said it would be just in time.'

Delirium

Christmas was celebrated with the daughters. Jacques repeated he did not want go further downhill. In January came the SCEN-physician. Her first question was: 'Do you know where I come for? Jacques answered: "Yes, but I do not know if you are the right person to take over my job."' Afterwards Liesje is very happy she was present at this conversation. 'Otherwise I would not have believed what he had said, Not one answer matched, he even did not know how many children he had. The SCEN-physician did her best to set him at ease. On the last question "Do you want dead?" Jacques reacted shocked. "Dead? Of course not. All my life I have been with Liesje. I will not leave her alone." When leaving the SCEN-physician wished me strength. She was not to blame. We were simply too late.'

Liesje had to be operated so Jacques had to go temporarily into a nursing home. Over there he got a delirium. He could not go back home so he had to go to a nursing home, which was away from his home town. Over there he lived still for eleven months. 'So it happened where he was always afraid of, and we were powerless. He died, 81 years old. I will be glad when at last a pill will come we can take when living becomes suffering.'

'WE WERE VERY HAPPY WITH TWO GENERAL PRACTITIONERS WHO DID NOT GIVE UP'

Leo Enthoven

Jeannette de Bruijne: 'My husband Sjors, a clever ICT'er, discovered, around his 50^e year, something was wrong. Our two sons did see it earlier than I. Dementia. This nice man started to react surly and angry, became confused and depressive. In 2006 the diagnose Alzheimer was made. Working did not go since 2003. Every month he went to the doctor and said: "I do not want to go to the end." The doctor told him: "Sjors, I will not desert you".'

Sjors noted down his wishes. We became member of the NVVE and of the Friends of the Life's end Clinic, we went to meetings and filled up all necessary documents. Sjors did not want to end up in a nursing home.

Our doctor left and a new doctor came. But the promise to help stayed up. Suddenly Sjors condition deteriorated and he had to go to a nursing home. That was a heavy blow.

As of that moment Sjors became under the jurisdiction of the nursing home doctor, and the general physician became side tracked. Sjors suffered severe pain and he reminded me what we had agreed on. The nursing home doctor did not want to talk about the subject. 'Your husband drinks and eats so well'

'The old and the new doctor have never left Sjors, even if he was not their patient anymore. At a certain moment they said: "Sjors, this we did not have promised you." They contacted the Life's end Clinic The deputy nursing home physician, also SCEN-physician, took pity on my husband, resulting in a meeting between the two general practitioners, the nursing home doctor, the SCEN-physician and the co-workers on the unit. They also knew my husband did not want this kind of life. Fall 2015 I took my husband home. The same day a doctor of the Life's end Clinic came to give him euthanasia. Sjors died in my arms. His death was for him a deliverance. Even if you have sorted out everything with your doctor, it can go wrong. One person, like this nursing home doctor, can block euthanasia. How happy we were with those warm two general practitioners who did not give up, with the empathizing team of the Life's end Clinic, and the warm male nurse who inserted the infusion. These nice moments will carry us into the future.'

'THE ONLY THING I COULD THINK OFF WAS: SOON THIS WILL GO WRONG ALSO'

For Ninke van Keulen (66) death belongs to life. The dying process of her husband Ted did not go as she had thought off. 'Nearly eight years I have been consultant for the NVVE. Now I have experienced euthanasia to my husband I do not think I will go on with this work, or find myself able to do it anymore.'

Martien Versteegh

Not that she is against euthanasia. Self-determination is essential to Ninke van Keulen. She is also member of the Cooperation Last Will and would choose for the autonomic route if possible. 'My father has chosen for dying by lack of food and drink. In a way that was good. Ted wanted euthanasia and was dependent on the doctor. Most doctors are working part-time nowadays. That makes things complicated. My father was also general practitioner. He gave euthanasia far before it was regulated. He said he was schooled to help people, not only to cure, like many a doctor nowadays states. And he was always accessible.

'If you are in the dying process it is not convenient if your doctor is on holidays and his deputy is not willing to give euthanasia.' No, if the end is there I do not want to wait. Not for public holidays neither for part-timers or whatever.'

Panick

'Ted became worse and panicked because it was the Pentecost weekend and we could not reach our doctor.' Tuesday our doctor came, and Wednesday the SCEN-physician. 'He was friendly but Ted had the impression he had to do an examination, while in cases of terminal cancer it is obvious.'

Friday May 25 was the date. The euthanasia did not feel like a deliverance which it should have been in Ninke's eyes. 'Not everything went all right. As consultant we advise an ambulance nurse to give

the infusion. Our doctor wanted to do it himself.' Unfortunately it did not go right. After all an ambulance nurse had to come. Ninke became so upset she did not remember the hour afterwards. She had to ask her daughter if she had properly said good-bye to her husband. They could set her mind at ease. 'The children found it had been nice and good. I was happy about that. But for me the minutes between the administration of the barbiturate and the moment of Ted's death seemed like hours. The only thing I could think about was: soon this will go wrong also.'

Revise

For her this is part of the reason to stop with her freelance work for the NVVE. 'After a year of seven I usually stop with something. I have been active seven years in Palliative Care and eight years in politics. So I need something else. Besides I think I will not be able to do my work as consultant, my experience with the euthanasia of my husband will come in between.'

Fortunately Ninke has good memories of the days thereafter. Ted lied in state in his study between his beloved books, the funeral was wonderful with all children and grandchildren taking part. And she is happy they had six weeks to say good-bye and to be able to say what had to be said. But she wished it had been different that Friday. That she also could have said: 'How nice was it all!'

New NVVE-chairman Job Cohen:

'ABOUT THE SELF-CHOSEN END OF LIFE WE WILL NEVER GET CONTRIVED'

'The self-chosen end of life is a very difficult subject. We will never get contrived about it. I back completely the NVVE standpoint that people do have the right to decide themselves about their own death. Thereafter comes the interpretation and that is a lot more difficult.'

Leo Enthoven

Job Cohen wants to say he cannot give a cut and dried solution to all the questions around the self-chosen life's end. He names the pill of Drion. The plea of jurist Drion for such a means is more than 25 years old. It still is not there. Many elderly people who well-considered choose for ending their life would benefit from this. 'The possession of such a pill would give me a feeling of rest. Not that I need it now, but the moment may come and then I should be very happy to be able to execute my decision without juridical problems.' Apart from this lucid plea for the autonomic route Cohen subscribes the youngest policy paper of the NVVE, with the same attention for the doctors route (the classic euthanasia) and the social workers route (the D66-initiative bill 'Completed life')

'This well-considered policy paper forms an important contribution to the public debate. In that debate the NVVE has to keep on playing a major role. The NVVE has to its disposal a lot of know-how and competence in this field. For the euthanasia law is a good regulation which has made further thinking possible. That means we have to go on talking in its continuation and think deeply to come to acceptable and careful regulations for these other terrains also.'

Looking away

Job Cohen (71) did not have experience with euthanasia, not privately nor professionally. He tells about his first wife Lidie, who was diagnosed with multiple sclerosis (ms) when she was 30 years old. 'Of course we have talked about it, but we decided to look away since ms has such a capricious course. What I had not seen is that by the ms her intellectual faculties became affected. Then we were too late to talk with a doctor about euthanasia.'

Final she choked in a piece of kiwi. Brain death followed and we decided in mutual agreement to stop further treatment. I was there with my son and daughter when she died. Her kidneys were all right for transplantation, Lidie had given us the choice and donating her kidneys made the day of her decease easier. His second wife and he have talked extensively about their life's end.

A little bit war

Job Cohen, chairman since June 2, has no doubt whatsoever that doctors give, 'with the most possible carefulness' within the frame of the law, euthanasia to their patients who suffer unbearable in a situation without perspective.

'That is why I do not understand the Public Prosecutor (PP) all at once prosecutes five cases. Does the PP act with the required prudence in this delicate terrain? I find this of utmost importance. After all doctors find giving euthanasia difficult and if they have to be afraid that makes it even more stressful. And that goes at the expense of the patient. The least doctors want to face is juridical intervention. Cohen wants to talk, as soon as possible, with the PP.

Society changes. The NVEE sees it with their members. 'The mean age of our members is 71, ten years ago it was 80. More and more people belong to the after-war generation who has learned to fight for themselves. Also, they will do that for their own life's end. The autonomy route will become more and more important, so reason enough to enter the debate on this subject.'

Cohen told the members meeting: 'I do not walk away from a little bit war.' But do not expect him on the barricades. 'I do understand the activists like those of the Cooperation Last Will, who wanted to force a breakthrough with the deadly powder. For the NVVE it is sensible to work within the juridical frame. The NVVE has to stay thinking, discussing, lobbying, striving for acceptable, juridical regulations in completed life, dementia and other categories. And yes, we have to go on the road. As chairman I will put this into action together with the other members of the board, the CEO, co-workers, freelancers and members. We have tot do that with respect. People differ. Ideal solutions in which everyone finds himself do not exist. We have to respect the opinion of those who think otherwise. Then we can demand they respect our opinion. Our most important instrument to reach this is to keep talking with all parties.'