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Summaries by Corry den Ouden-Smit

Starvation in a hospice: it is possible

'I DO'NT WANT LEAVING YOU IN DISTRESS'

The mother of Mirjam Rooseboom had a general practitioner who didn't want to give assisted suicide but he arranged a hospice where she could stop with eating and drinking.

By *Anja Krabben*

Her own mother died being demented and she has seen this as a horror scenario. 'If I am going to be demented I do not want to go on with living', she said. And later on ''I don't want to become 90 years old.' Her health became very bad and she found it had been enough. She was member of the NVVE since her 80th year and had given her living will to the general practitioner. She knew he could not give her euthanasia because his faith prevented him from doing so.

Her health came down, she did fall often, she had spells of dizziness and her memory became worse. After the death of my father, in 1999, she nourished the many contacts he had. She had many hobbies, enjoyed being outside, made walks, played bridge and did catch up with the actualities. All these became things of the past when her health became worse and she hardly could see or hear. Her big fear that her mind would decline came close to reality.

Urgency

She talked to me, the eldest, about not wanting to go on with living. I talked it over with my sister and two brothers but my brothers did not see the urgency of her wish. We had contact with Inge de Lange of the NVVE. She advised us to talk again with the general practitioner. He persisted in not wanting to get actively involved, but was willing to think with us. We asked several other general practitioners to take my mother as patient, but no one was willing, for they want to establish a relationship with a patient before starting the euthanasia procedure. It became clear my mother had to do it herself. At first she did not want starvation, thought it was awful. No, she was going to save medicines. She even had fixed the date it should happen. But I got nightmares about prosecution. And also: what if the medicines did not work as expected? My brothers had spoken to their juridical friends and they warned us that a forensic physician would certainly come and justice would be informed.

Everyone was open and clear

Inge de Lange is a volunteer of the member support service of NVVE. She assisted Mirjam Rooseboom and her family. To her it was a special case because hardly ever a hospice will take in a person who is not terminal ill.
'This case was very instructive for me and became more and more difficult, but the end was beautiful. The strength of this story is the openness and clarity of all people involved: the physician, the mother, Mirjam and her brothers and sister.
The physician gave several options and was willing to help when the choice of starvation had been made. The whole procedure took half a year but after all that may have helped the children in accepting. The role of the hospice was important. That has opened my eyes: starvation in a hospice. For not everybody is capable, or in the situation to accompany a starvation process at home.'

We talked with my mother about our fears and she did understand. 'I don't want to leave you in distress' she said, but she hoped we would not leave her alone. I had the book of Boudewijn Chabot about starvation and recited: 'you want to die, so you have to do things yourself.'
My mother lived in a house with support of a nursing home. Every day many people came by. My mother did not want to confront other people with her way of dying. Especially since the house had a Christian signature.
For us it was not possible to give the intensive support needed for a human starvation. The general practitioner has found a hospice willing to cooperate. It had also a Christian signature but they had an open mind. Those of the personal who had objections were put to work at other beds. The physician of the hospice said 'we give you food and beverage, but you may decline.'

Apple
'She lived on for three weeks. Not eating was not the problem. Once in a while she took a piece of apple. Not drinking was difficult. I gave her water, thinking I was the only one. After two weeks she was not weakened. She had asked everyone for water. I said 'if you have changed your mind, just tell us.' But she persisted in her wish to die and said 'I have to be strict.'
Two days afterwards she asked for palliative sedation. Her consciousness became less and less. When she became restless and said she did see awful things, a higher dose was given and after two more days she died peacefully. I feel grateful. Professional people have taken care of her and we had time for each other and could say goodbye.

Clinic for the end of life
I have thought about the plan for a clinic for the end of life, as lately was proposed by the NVVE. If this clinic would look like the hospice, with the professionally, the warmth, the possibility for the nearest to sleep I would applaud.

Alzheimer centre VUmc happy with money Eerde Award

PATIENT FEELS HE IS BEING VALUED

What are the possibilities for those who are looking for assisted suicide? The Alzheimer centre of the VU medical centre is not mysteriously. An interview with Freek Gillissen, nursing consultant dementia.

By Leo Enthoven

He is happy with the 5,000 euro's donation of the Van Eerde family. Freek Gillissen, nursing consultant dementia of the VU medical centre (VUmc) in Amsterdam, tells the money will be used for giving faster and better information with a web portal. General practitioners, physicians of the centre and patients will get entrée with a special code. Gillissen has been involved with the Alzheimer centre two years before its foundation in 2000 by Prof. dr. Philip Scheltens. Gillissen is a psychiatric nurse and has worked for years in a memory clinic.

EARLY DIAGNOSTICS IN THE VUmc ALZHEIMER CENTRE
The VUmc Alzheimer centre is active in patient care, scientific research and education. Diagnostics at an early stage, say before the age of 65, is a hallmark. Yearly about 2500 patients, 550 of them new, are being helped in this newly build centre and a 25 persons are being employed. Also the universities of Maastricht and Nijmegen have an Alzheimer centre

Quick diagnostics
In 2001 a one day screening has been introduced by the Alzheimer centre VUmc. Gillissen: 'It was revolutionary to do all the test in one day. Up till then it took four till six months before the diagnosis was communicated to the patient and now it takes a week. Because a whole day of screening may be stressfully, a hostess is in charge. For relaxing in between the tests there is a lounge or private alcoves. So you can talk with other patients or can go into solitude, just what you prefer.
All employees are aware of the anxiety of people with Alzheimer disease at such an early age –sometimes at the age of 45 or 50 years. To set patients at ease they wear ordinary clothing, except for the physicians.

Friends
Gillissen and a colleague are responsible the screening goes on as planned. He has to go in to problems like patients with a pacemaker not allowed in the MRI scan. Gillisen tries to talk to as many persons around the patient as possible in order to get an idea of the home situation. 'Sometimes I say to a patient: I do understand, you forget that you forget. Then they look gratefully at me and feel being understood.'

Paul van Eerde, main person in the documentary *Voor ik het vergeet...* (*Before I forget* ...), came to the centre a number of years ago, with his wife Marjan. Gillissen did accompany them intensive during their visits and also by telephone. 'Paul was special. He did know exactly how far he wanted to go. When he came to us with the query for euthanasia or assisted suicide it was new to us. Paul and Marian did know nothing about it, nor did we. For the Alzheimer centre it was the first time a demented patient did not want to go all the way but preferred to die.' Paul van Eerde has gathered lethal medicines abroad, because his general practitioner refused help.

'I tell patients they should not start tomorrow but yesterday'

Freek Gillissen did not reject the query of Van Eerde - neither today, when the query is expressed weekly. He tells what is possible and what not, and about the severe conditions. 'I tell them to start with the preparations not tomorrow, but yesterday. General practitioners often react with "it is not allowed, no way" and patients feel abandoned.'

Clear and visible
He wants to go on and make - on the web portal - clear and visible what is possible. 'Action 1, action 2, action 3 and so on, with emphasis on dementia and the self willed end of life. So patients and their nearest can go to their physician and say: "Doctor, what you say is not true" and show this information.'

EUTHANASIA IN THE OPEN
Yearly the NVVE will award the Paul van Eerde Award, named after the main person in the fore mentioned documentary. Van Eerde decided to make an end to his life before he should become severely demented. His family received the prize last year and donated the 5,000 euro's to the Alzheimer centre VUmc. Paul's widow Marjan: 'The centre is excellent. Paul and I have build up a personal relationship with Freek Gillissen. The web portal of the centre will be one of the few locations where the combination of dementia and euthanasia is discussed to show the opportunities for patients and their nearest, and for physicians. That money can be of help for this project.'

EXPLOSIVE GROWTH

Dementia is a term for more than fifty illnesses. Mostly known is the Alzheimer disease, named after a German physician.
In 1906 he had performed autopsy on the brains of patients who had been very confused and had loss of memory. He found plaques of protein and other irregularities in and around the brain cells. At the moment there are 250,000 people with dementia in the Netherlands. That will be 500,000 in 2050.
The process of loss of memory, disorientation, change of behaviour and personality, and diminishing reaction ability is irreversible in Alzheimer. Curing is not possible. Characteristic for the end phase is total dependency.

NVVE-workgroup did research into the 'autonomic route'

THE LAST WILL PILL IS REALISTIC

A majority of the NVVE-members have a preference for the possibility of a 'last will pill' with which one can end his life at a self chosen moment. A special task force looked if this could be realisable.

By Marleen Peters

Research has been done why - in nearly twenty years thinking and talking about 'fulfilled life' - the autonomic route has not been explored. All those reports concluded that physicians should give the means or non-physicians should give the means only in controlled conditions.

Yes, but

The discussion on the autonomic route has never started because the reasoning 'yes, but' prevented it: yes, but if one gives it to another; yes, but if a child finds it; yes, but if one becomes depressive and takes the pill in an impulse; yes, but if one has been forced to do so.
The task force started with the minimal conditions which should be satisfied. The method and means should be humane, ethical justified and safely in administering, also in the neighbourhood of the nearest. All should be within the law. Existing methods like stopping with eating and drinking, gathering deathly medicines and helium gas were first looked at.

Starvation

Who chooses to stop with eating and drinking will die of dehydration, in which the vital organs stop functioning. To palliate the starvation a physician is needed and home care of a nurse, family or friends. The physician to prescribe palliative medication and bring the patient in a deep sleep in case of incurable complaints as vomiting, pain and anxiety; the nurse to give injections and advice about mouth hygiene; and the surrounding people to give the daily care.
Starvation is an option for very old people, whose organs are failing. Younger persons and not-ill persons will get serious secondary effects like headaches, cramps and epileptic insults which may be so severe that a physician has to interfere with bringing the person into a deep sleep. Starvation as an autonomic route is not humane.

Gathering medication

Information is given - only for members - in a closed part of the NVVE website about medicines and combination of medicines which can be lethal. But one needs a

prescription, and physicians, aware of the lethal working, will not prescribe and certainly not in the huge quantities which are needed. Buying at pharmacies abroad or ordering via internet is hazardously and more difficult than thought of.

Helium method
Other methods were looked at, but all did not reach the benchmark of being ethical, humane, practically and safely in administering.
In the USA the organisation Final Exit Network (FEN) has experience with the helium method in terminal cancer patients and chronically ill patients. This method is technically difficult. One needs the help of others in preparing and administering. In The Netherlands it is a crime to help in this preparing, in the USA not. In both countries, active assistance by suicide is a crime
In using helium gas there may be spasms of an arm or leg, or deep breathing up till fifteen minutes afterwards. Although these are unconsciousness movements it looks as if the person becomes conscious. The FEN warns the surrounding people: it can be very shocking and emotionally to see it.

The disposition of a last will pill has the preference of the task force. Medicines to make an end to life are available, like the lethal drink made by the pharmacist. But the government does prohibit the sales of medicines as soon as their possible lethal action becomes known, like Vesperax and Depronal. The task force looks into possibilities to develop and produce a last will pill, and into the organisation of acquiring it. A cooperative could be formed to that end and members of the cooperative should be able to get information about producing the last will pill for themselves or acquire it from the cooperative.

FACTS AND FIGURES
In February 2010 the NVVE made an inquiry about 'fulfilled life' among 218 Dutch nursing homes. In 55 percent of the homes, in the last three years, one or more residents thought of their life as being fulfilled (1,257 persons). In 22 percent of the homes suicides have taken place, or suicide attempts. In 60 percent the reason of suicide (attempt) seemed to be 'fulfilled life'. Totally 156 queries for assisted suicide have been made. That means 12 percent of the residents who thought of their life as being fulfilled. In the same period the NVVE asked the opinion of the general Dutch population about fulfilled life. It was shown that 83 percent of the population thought it feasible for old people to think of their life as being fulfilled – even if they don't have a lethal illness. And 53 percent finds that a lethal means should be disposed of for persons who, in that case, don't want to go on with living.

Slippery slope
Fear exist that the last will pill will lead to lessening of care for especially older people, and to devaluation of the notion 'life'. The same fear has existed when euthanasia was legalised. However, that has not been the case. In fact people hang on to life. But for many it may be a reassurance to know there are means. And talking openly about those problems has ameliorated care. But good care is not always sufficient if one finds life has been fulfilled. Another objection was possible misuse of the 'pil of Drion'. The task group thinks that can be pared.

Information and support
Since making an end to one's life is irreversible it is important that there should be information and support for those who want to make an end to one's life. At the other hand should the cooperative know if the person is capable to express his will, and if he cannot be helped otherwise. Therefore a medical exam is feasible. Important is to write down the suicide is a free choice and fully autonomously prepared. And last but not least: to talk it over with your nearest.

AUTONOMIC ROUTE

In The Netherlands autonomy and auto determination is an essential part of our civilisation and anchored in our culture. Everyone has the freedom to live his life as he wants, and to make decisions about it; also about life's end. When help is needed from another, you cannot speak of autonomy. The ones who are supporters of the autonomic route don't want intervention from others (physician, social workers, family or friends). The autonomic route is the route of the individual and starts with auto determination and self realisation.