

## **Relevant**

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Summaries by Corry den Ouden-Smit**

*The best would be not to wake up anymore*

### **'I HAVE HAD A FANTASTIC LIFE'**

**Bob van Dam thinks he has lived long enough. 'But making an end to your life is very difficult.' He would like to get help with this. A conversation with Bob and his good friend Harm.**

*By Anja Krabben*

Bob van Dam (88) receives Harm (78) and me in his house in Alkmaar. He wants Harm to be with this conversation since his memory fails him once in while.

Bob has some faithful friends. His wife died in 2003. He sees his daughter regularly and Harm comes often. Shortly he has 'home care'. But most of the time he is alone. This winter was severe and he could not go outdoors. He tried once, but fell down and could not walk for weeks. Besides walking problems he has a weak heart, suffers from incontinence and his short memory fails him.

Those are not life threatening ailments but, including his being alone, it is enough to say he does not want to live anymore.

Bob has tried to end his life several times. In 2004 he refused a pacemaker initially, but when he was told he was not allowed to drive a car anymore, he changed his mind.

After that he contacted a foundation who claims to help with suicide. But getting pills by internet was more difficult than thought of.

In 2006 he decided to stop with eating and drinking. But after a week a friend discouraged him to go on with it. 'It will become awful' he said 'I have seen that with someone in my family.'

In 2008 he tried to make an end to his life by taking pills and pulling a plastic bag over his head. But someone of the personnel of the care centre, where he was at that time, found him.

Bob says 'I can't succeed, and jumping in front of the train or hanging my self is too gruesome to all.'

Even drowning my self in the sea did not work since I am a good swimmer.

He let the general practitioner know he wanted euthanasia, but she refused 'because it is punishable'.

### **Generation**

Bob talks openly about his death wish with his friends and his daughter. 'My daughter goes along with this idea, but she does not encourage me.' We are of the generation of emancipation, and deciding about your life's end belongs to that.

Bob and Harm support the citizen's initiative *Uit Vrije Wil* (Off Free Will) They would like to see that the euthanasia law would be changed. In stead of asking the doctor to help, it should be possible to ask someone else like the pharmacist or special educated nursing personnel or other special educate people. If there should be a pill available, 'the Drion pill', many people would not use the pill, but would get peace by the thought they could end their life decently.

### **Tree tops**

Bob: 'My life is fulfilled. I have had a fantastic live, and I will never get that back.' Harm: 'Bob has had a busy social life. He and his wife were fighters for community living units. They have lived in one of those units, but since his wife became ill, they had to move out. He has lived in a senior house connected with a care centre, but over there he was very lonely.

Bob: 'The most important thing is that I will never get my wife back. We have been 41 years together. She was very special. I miss her every day.'

Harm: 'Bob likes social contacts but he does not have the energy. Even if friends invite him to pick him up and drive him home it is too much for him. He does not want to participate in the eating club he and his wife participated in for years, because he can't follow the conversation. At the moment he can't drive a car and he stopped playing the billiards, he loved so much.

Bob: 'I look to the television and read books, but that does not help. I am not depressed, but I don't see any future. And I do not fear death. I think there is nothing beyond this life. I do see death as a release: it is all over. I would like to go to bed to night and never wake up anymore.'

## **TO STOP WITH EATING AND DRINKING IS NOT AN ALTERNATIVE**

**The self wanted end with help of a doctor can only if it refers to euthanasia or help in suicide, both are strictly regulated. If you can't find the aid of a doctor you have to resort to pills you have gathered or deliberate stop with eating and drinking.**

*By Hans van Dam*

Deliberately stopping with eating and drinking does happen more often than thought of. Psychiatrist Boudewijn Chabot has told about it in his book *Auto-euthanasie (Auto-euthanasia)* Out of his research among 144 people he concluded that 4400 lives are being ended without the aid of a doctor, about 2800 by deliberately stopping with eating and drinking.

Deliberately stopping with eating and drinking is often described as mortifying the flesh. It is important to point out the difference. Mortifying the flesh is by no means a deliberate choice, but a natural process. It happens at the end of life in the view of death. The most known example is the last stage of dementia. The consciousness diminishes and the urge to eat and drink is gone. The body does not need food in the view of death.

It is unethical to thwart this natural dying process with artificial feeding. Mortifying the flesh is a natural end of life and should be respected.

## **Stress**

Mortifying the flesh does not involve suffering, as far as we know. In this phase of dying the stress hormone cortisol is high, but the conscious is gone. So there is stress but no death-struggle. Deliberately stopping with eating and drinking is of another order. The body does need food and the person is conscious and will feel stress.

Chabot concludes that deliberately stopping with eating and drinking does not result in suffering. But he has his information from 'reporters', mostly the nearest of the person who has died in this way. It is possible that they want to support the choice of this person, or don't want the dying of their loved ones to be indecent.

Apart from Chabot's mentions there are many, indeed many, reports of nurses, caretakers and mentions to the NVVE who declare they have seen grave suffering.

Personal I have seen people dying in this way -too smarting for words. Most cases I have seen were awful, in spite of good care.

## **Choice out of difficulty**

Deliberately stopping with eating and drinking is often a choice out of difficulty. Often euthanasia has been refused (in half of the cases in the investigation of Chabot) or was not asked for because one did not want to burden the doctor.

Nearly always points deliberately stopping with eating and drinking to failing help of the doctor. Most people would prefer another way.

There are other ways, a literally eu-thanasia, a good death. Those should be open to more people, as a gesture of love and last consolation.

Conclusion: mortifying the flesh in the sense of not disturbing the dying process initiated by the body with a declining need for eating and drinking is, when accompanied by good care, an easy death.

Deliberately stopping with eating and drinking is by no means a guarantee for absence of suffering, fear, stress and struggle. Most people have chosen this way only after euthanasia has been withhold or was not under discussion. In short, deliberately stopping with eating and drinking seems especially an alternative for doctors who don't want to go on with euthanasia under the mask of 'leaving the autonomy to the patient.'

*Coma, vegetating state and brain death.*

## **DO I EXIST, IF I DON'T THINK?**

**Dic Swaab, professor in neurobiology of the University of Amsterdam clarifies the notions of 'coma' and the 'locked-in-syndrome'.**

*By Dick Swaab*

Coma is a situation in which a patient does not react to stimuli from the outside world. It may be caused by an injury of the brain cortex, the thalamus (a connection centre in the brain), the connection between the two brain structures, or the brain stem. But also, it can be caused by a disturbance of metabolism, alcohol or drugs. The coma can be reversed, but the chance to die is great.

Coma can become a vegetating state. The brain stem is functioning but not the brain cortex. This cortex is necessarily for thinking, talking, feeling emotions, and moving legs and arms. The brain stem regulates functions, crucial to live, like breathing, heart beat,

temperature and the sleep-wake rhythm. It also houses the centres for the reflexes of coughing, sneezing and vomiting. People, in a vegetating state, can open their eyes, but may live on 'like a plant'. This situation is the same as the last stadium of Alzheimer disease. The patient lies in foetal posture in bed and does not react to the outside world.

### **'Living'**

Most people will improve after some weeks, but some will come into a 'permanent vegetating state'. They breathe spontaneously and have a normal heart beat. They may have their eyes wide open make sounds of weeping or laughing-without having the belonging emotions. They don't have any consciousness and are 'brain death'. For the family it is hard to accept that.

Those patients can stay alive for years with artificial feeding. The American Terri Schiavo came into a vegetating state in 1998. Her husband did not want to go on with this vegetative life, but her parents succeeded in bringing to a halt the stopping of the treatment. It has been a juridical fight with demonstrations in which the husband has been made out for murderer. After seven years the court ruled the artificial feeding should be ended. The autopsy showed that there was hardly anything left from the brain cortex and a dignified life would never have been possible.

### **Englaro**

In Italy Eluana Englaro has been in coma since 1992. After seven years her father started a juridical fight to get permission to bring the artificial feeding to an end, also because his daughter had said she never wanted to live on like a plant. Nine years later he got permission from the highest court to let the probe feeding being stopped. But the Vatican and the government came in between. They came too late, the probe feeding had been stopped and Eluana could die.

In The Netherlands a permanent vegetating state is seen as humanly unworthy. To go on with life-prolonging-action is seen as medical useless intervention, and the decision is made -together with the family- to bring intervention to a halt. This is not called euthanasia, because it regards medical useless intervention.

Yet, also in the Netherlands, many patients are in a vegetating state.

It is a shame that abuse is being made via internet, by the Coma Wake Up Brain Stimulations. They offer a 'therapy'. But even for 100.000 euro you can't get patients, whose brain cortex has been damaged irreversibly, out of a vegetating coma.

### **Bauby**

The opposite of the vegetative state is the 'locked-in-syndrome'. This is a complete division of the brain and the spinal marrow by damage in the brain stem. The patient is complete alert, but he can't communicate because he is completely paralysed. He can see, hear and understand everything, but he can't move or talk. He only can open and close his eyelids.

A French journalist Jean Dominique Bauby has been twenty days in coma after a cerebral haemorrhage. In order to communicate the alphabet was being read. He could blink with his eyes. And in this way the book *The Diving Bell and the Butterfly* came to being -see also the intriguing filming of this book.

Another story is about Nick Chisholm from New-Zealand, who became unconscious on the rugby field, in 2000. He was diagnosed as 'coma', but his mother and girl friend insisted he could follow consciously what was going on. They were right. He had the locked-in-syndrome, and he did recuperate later on. Family often know there is contact, long before the doctor sees it. Otherwise often the family thinks wrongly there is contact with an unconscious patient.

Until the transplantation era the diagnosis 'dead' was simple: no heart beat and no breathing. Only after extremely cold situations, the heart beating and breathing can return after a while.

Nowadays, since the patients with severe brain damage are being applied artificially respiration, the classic diagnosis 'death' is not valid any more. Heart beat and breathing can be continued endlessly, while the patient is out of consciousness or 'brain death'. The definition for death became irretrievable absentness of *all* brain functions. But 25 % of brain dead patients do produce vasopressin. This is a brain function for the kidney with regard to the water re-uptake. In that case, some brain cells are intact, but they don't contribute to the recovery of the consciousness.

Nowadays the criteria for brain death are the 'Harvard criteria': the pupils don't react to light irreversibly, the brain stem reflexes are absent and a permanent absence of the 'higher brain functions' like thinking and consciousness. In fact this is a logical reversal of the known credo of Descartes 'I think, so I exist'. If you can't think because your brain does not work, you don't exist as a person.

## **'OFF FREE WILL' CAUSES STORM OF REACTIONS AND DISCUSSION**

**The citizen's initiative Uit Vrije Wil (Off Free Will) that came into publicity in February unchained a flood of reactions. Within four days the needed signatures came in, to get the issue 'completed life' on the political agenda of the Second Chamber.**

*By Janneke Vonkeman*

The initiative group Uit Vrije Wil, with among others Hedy d'Ancona, Frits Bolkestein, Paul van Vliet and Jan Terlouw, strive for legalisation of help for suicide to old people who find their life has been completed. The wish should be explicit and out of free will, and the process should be strictly regulated and controllable.

In the beginning of February the initiative group held a press conference and the NVVE organised the Week of the Completed Life. All the media responded: the issue came in talk shows, journals, magazines, television and on the radio. Interviews were held, commentaries were given. Two documentaries were shown: *De laatste wens van Moek* (The last wish of Moek) and *Ongeneeslijk oud* (Incurably old). 'De laatste wens van Moek' describes the way Moek died. She took pills in order to die. Her son, after frequently being urged to do so, had organised the pills. Moek (99 years) died peacefully after falling asleep.

On television a program was broadcasted about the more than 400 elderly who yearly make an end to their life, on a gruesome manner. This was in strong contrast with the way Moek died.

The number of adhesions to 'Uit Vrije Will' has been overwhelming. After four days more than 40.000 signatures came in, culminating to more than 120.000 after a month.

The plans to put this topic on the agenda of the Second Chamber will have to wait till the new Administration has been formed. Some political parties have put this topic on their program in their election campaign.

There are also other sounds. The Medical Association KNMG opposes the 'second route' in helping old people to end their life. The 'second route' means that other people specialised in care could be qualified to help –under strict conditions. The KNMG finds a

doctor should have the monopoly. Another argument came up in the discussion: the fear that elderly, who don't find their life as being completed, feel themselves 'too much' for their surroundings.

NVVE-director Petra de Jong, responded again and again that controllability and carefulness are of utmost importance. She emphasised that 'nursing people and other caretakers are the ones who are confronted with this problem.' They are in between their involvement and the law, but are not allowed to help in the way old people ask them. She emphasised the importance of training specialised and certificated companions 'because it is very delicate to accompany such a process. One has to have empathy, be able to listen in between the lines and hear their fear.'

The comparison with Nazi-practices came from a churchman, referent L.P. Dorenbos. He even had sent fake last-will-pills to five hundred political persons and pressmen. The reaction of the NVVE was that with this comparison 'he disqualified himself and a large group older people to make their own, well-considered decision.'

## **INVESTIGATION: GENERAL PRACTITIONERS ADMINISTER LESS OFTEN A DEADLY DRINK**

*By Janneke Vonkeman*

Suicide assisted by general practitioners, often comes to pass by drinking a deadly cocktail. Ten years ago it happened in 25% of the cases. This percentage has dropped last year to 15. Researcher Annemieke Horikx of the KNMP, the pharmacist association, mentioned this in *Medisch Contact*, the periodical for general practitioners.

A general practitioner explained this decline is being caused by pharmacists, who have to make the cocktail themselves. Often they don't have the basic ingredients in stock, because the keeping date expires, due to the minimal demand. So it is a vicious circle.

The manufacturers do have the ingredients, but it takes a day to deliver and the general practitioner often needs it directly. Another problem is the taste of the drink, and the time it takes to do its work. 'If a doctor uses the oral route, he always has to be prepared to give a muscle relaxant via an infusion to end a coma' is said in the publication. The KNMP will give new recommendations.

## **ASSISTED SUICIDE AFTER AN INTERVIEW IN EINDHOVENS DAGBLAD**

*By Janneke Vonkeman*

Nita Wildbergh has received assisted suicide by a doctor, after an interview in the local paper the *Eindhovens Dagblad*. In November 2009 she told her story to the paper.

The woman endured twelve diseases, took more than twenty drugs a day, but still suffered extremely. She had asked various doctors to help her to die, but nobody was willing to do so. Shortly after the publication of the interview a doctor was willing to help her. Nita Wildbergh became 75 years.

## **DUTCH EUTHANASIA LAW DOES NOT LEAD TO MORE REQUESTS**

*By Janneke Vonkeman*

Researchers from the Dutch Research institute for Health Care, Nivel, write in the general practitioners periodical *The British Journal of General Practice* that the number of requests for euthanasia have not increased since the euthanasia law came into existence. The number of reports did increase, but not the requests to general practitioners. 'It means that euthanasia does not happen more often, but that it is reported more frequently' says epidemiologist Gé Donker on the Nivel-website 'and this is good for the quality: better means are being use in the correct dose.'

Donker says: 'The euthanasia regulation has been very strict, that is why euthanasia has not expanded. You can train your doctors, you can give after-courses. Hospitals and nursing homes can implement euthanasia in their regulations. Patients can choose a certain institution on this ground. One can be open about it, putting on the website how euthanasia requests are being handled. That one can be open about it has to do with the euthanasia law.'

Donker, who is also general practitioner, adds that he finds it very difficult to render euthanasia. 'It is an emotional burden. But you want to give optimal care and euthanasia can be part of that. A general practitioner only renders euthanasia out of empathy with the patient who asks for it.'

## **MEMBERSHIP RISES TO 111,000**

**The NVVE has now more than 111,000 members. The association is financial healthy, as was emphasised on the General Members Meeting, in which the new chairman mr.dr. M.F. Andriessen had been appointed.**

*By Leo Enthoven*

Director Petra de Jong told the General Members Meeting, on the 24e April, that early this year the 111,000<sup>e</sup> member has been checked in. The Association has been active to the outside world since the memorial 'Perspectives on Dignified Dying' (2008). The Week of the Completed Life gave rise to a lot of publicity and increase of the membership, as did the web page about the medication for life's end.

The finances are more than healthy, thanks to the growth of the membership and to a restricted financial policy, through which the financial crisis did not influence the NVVE.

### **Investigation**

In the afternoon director De Jong explained the results of the NVVE report 'Onderzoek naar (hulp bij) zelfdoding op basis van voltooid leven in verzorgings-huizen'.

'Investigation into (assisted) suicide on the basis of completed life in nursing homes.' A representative investigation has been carried out among the 1,000 nursing homes. The following was found:

- 'Completed life' is an extensive problem in nursing homes.
- Many residents do suffer greatly.
- In 48 of the homes suicides, or efforts in that respect, have taken place the last three years; in 29 of the cases it had to do with 'completed life' one assumes.

### **New management**

The NVVE has a new management. After an internal crisis, the chairman and two members decided to step down. The new chairman is mr. dr. M.F. (Margo) Andriessen.

The other new members are drs. C.M.J.C. Pauw-van Doormalen and dr.ir. R.D. Woittiez. Pauw was political adviser of D66 (a liberal party) and was involved in the policy of the euthanasia law in 2002. Woittiez is director of the Rijksinstituut voor Volksgezondheid en Milieu (RIVM), the National Institute of Health. He is active in the VVD (a liberal party to the right).

### **Week of the Completed Life: a very successful campaign**

*By Janneke Vonkeman*

The Week of the Completed Life, from 8 till 13 February has been a great success. Attention has been asked for the problem of old people who have completed their life. The campaign had been prepared for during months.

The NVVE wants to put this issue on the political agenda, and wants to know the extent of this problem.

An important investigation has shown that 75% of the Dutch people can imagine that old people see their life as being completed. To the question 'should a mortal expedient then be deliverable' the answer was yes in 48%. An investigation in nursing homes shows that 55% of the residents find their life as being completed.

The many reactions both from advocates and adversaries show that we can't ignore this problem anymore. Even the political parties have seen this and some political parties have put the issue of the self chosen end of old people on their election program.