

Relevant

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Summaries by Corry den Ouden-Smit**

Two general practitioners and the practice

'THE PATIENT DECIDES WHAT IS UNBEARABLE'

Constance de Vries is 25 years physician in a village in Limburg; Dick Arentz has been physician in Haarlem, during 35 years. How do they think about the self chosen death? What do they learn from their experiences? Arentz pleads for a pool of experts; De Vries thinks there lies a task for 'buddy-physicians'.

By Leo Enthoven

Constance de Vries, physician and SCEN-physician (Support and Consultation for Euthanasia in the Netherlands) does not hesitate: 'Dementia can be unbearable and hopeless suffering. You know everything becomes worse. Some people find this spectre futureless, to them it is unbearable.' Within the law euthanasia and assisted suicide in dementia are permitted: in 2009 twelve cases of termination of live have been judged as careful.

In October 2010 Constance de Vries was 25 year physician in Limburg. She has 5.200 patients in a group practice with two colleagues.

Pastor

She comes from Den Helder, but was raised Catholic. So she can understand the 'Catholic south' and the role of the pastor. She does not see much difference in the quality of village- or town physicians. And the patients are not different either. Chlamydia occurs regular here, abortion and euthanasia too.

Fourteen times she has administered euthanasia, once to a mother of a family with three children of 9, 11 and 13 years old. One of the girls screamed out of rage and distress. Constance de Vries has written a letter in which she explained why their mother did not want to go on and had asked for euthanasia. How much their mother had suffered 'The mother had fought against cancer for twelve years, I have written the children that their mother did not want to go on, that euthanasia was her own choice. And I have tried to describe her suffering had become unbearable.

I have written this letter also to take away the burden of guilt from their father's shoulders. I said to him: 'You read this letter and, if you want, you give it to your children. You can do it now, the next year or never. This letter may make it more easily to talk about it. The next day he has read the letter together with his children.'

The effect was touching. The nine year old son wrote back, a long letter in which he asked: 'Doctor De Vries, please come to see how mama is lying in the front room. She wears a beautiful white dress and there are many white flowers and I am not at all angry because I know that she was very ill, and what was unforgettable to me was that during that eve we made tea together.

Dogs

After the euthanasia of a lonely old man she did what she had promised to him: informing the forensic physician, calling his brother, the notary, the veterinary to pick up

the dogs, giving a thank-you letter to the neighbours, notifying the undertaker and the pastor. The pastor was not willing to help with fore mentioned activities -most of them were far beyond my duty. He was only interested in the money for the requiem mass. 'Patients are afraid to talk about euthanasia with the pastor, afraid not to being buried out of the church. As long as the pastor does not hear the word euthanasia he does not know about it. Of course he does know, but if we don't talk about it, it does not exist.'

She has seen the deterioration of her mother when she was demented. Within four years her mind and body came down. Constance de Vries, her sister and four brothers have visited her regularly. They wrote down their findings for each other in a booklet. Those findings and experiences have resulted in a book in 2005: 'Een tijd van komen, een tijd van gaan' (A time to come a time to go). This compelling and personal experience has contributed largely to the making up of her mind.

She can't understand colleagues saying they don't find the suffering unbearable. 'The patient determines what is unbearable, the doctor may think there are possibilities but if the patient says 'I can't anymore'' it is over.' She is concerned about the fact there are liberal and conservative SCEN-physicians. If a person with a severe lung disease has half a year to live or a MS patient maybe five years .. if he can't or won't endure that he may hope to end up with a liberal physician. The requirements of due care don't state that one should die within three weeks.'

It is not complicated

Many a physician including SCEN-physicians don't know the space. It is not necessary to reshape the law. 'Just make physicians aware of the possibilities for euthanasia.' Providing of the medicines she sees as a task for the physician. 'If not enough physicians are willing to participate, we should look for a solution. For example buddy-physicians who are willing to help out in cases of beginning dementia, who have regularly contact with the person about this subject and act according to their wish if possible. She sees another role for the physician when the diagnosis dementia has been made: 'Euthanasia should not be a taboo. The physician should talk about it at a time the patient is still clear of mind. If the physician does not take the initiative the request for euthanasia comes often in a too late stage, not only with dementia but also with other illnesses. The request should be well considered – one of the euthanasia criteria- and that takes time. Where one does not talk about stays unsaid. We should not give away death from our task parcels. It belongs to our profession.'

PATIENS MOVE OVER THEIR BORDERLINES, IS THE EXPERIENCE OF DICK ARENTZ

If everything stays the same emancipated baby boomers will, within years, go searching for Vesparax-like medicines to end their life. That can't be the objective, finds Dick Arentz, former general practitioner in Haarlem.

The first step should be getting assisted suicide out of the Penal Code. The quality of the asked help will improve. He supports the movement 'Uit Vrije Wil' who recently asked for such a regulation as the euthanasia law for people who find their life has been fulfilled.

Dick Arentz will stay active as SCEN-physician he stopped working as general practitioner, after 35 years. 'As a student I was convinced of the right of self determination. I have given euthanasia fifteen times. An interview with me in the local paper, about euthanasia has been kept by many people and they showed it me many years later when they considered euthanasia for themselves.

Injection

Arentz: 'In our medical centre the rule was: if people want it, they should do it, if possible, themselves. In that way the free will is most clearly expressed.' In his SCEN-

group not everyone shared this opinion. He finds giving a deadly drink less burdensome than a deadly injection. 'But if people can't swallow I will give the injection.'

Being incurably old can be unbearable, is the opinion of Arentz. The regulation the initiative group 'Uit Vrije Wil' supports, shall not lead to a tsunami of suicides. 'There are people who want to keep the direction of their life in their own hands and there are people who are hesitating. Physicians can give advice but the people have to decide for themselves.

The last year of his practice he received two requests for euthanasia. One wanted to go on with it, the other did not. His catholic past came back. He got palliative sedation instead.' Mostly, patients move on their borders, is the experience of Arentz. The urge to live is basic to the human.

Artificial difference

The KNMG (Royal Dutch Medical Association) had initiated a research to questions about assisted suicide in cases of 'suffering of life', after the case Brongersma. But the KNMG had done nothing with the outcome for six years! Dick Arentz is a little angry about that. He thinks more discussion should be entered about using the juridical possibilities and space. Physicians should agree about the meaning of 'quality of life'. That is important and usable. If that has been settled, the issue is not so difficult anymore. After the verdict in the case Brongersma we have differentiated between the medical domain and what's outside of it. This is an artificial difference because people with severe functional complaints, not terminally ill, can suffer unbearable and hopeless.

The KNMG does not direct enough discussion, is his statement. 'The KNMG should form a pool of experts in this field like nursing home physicians, general practitioners, oncologists, revalidation physicians in order to ponder on this issue. They are the ones who encounter the notion quality of life. If we can make a valid definition of this notion we can go on.' If 'ready with life' leads to suffering of life, the doctors could bring this suffering within their medical domain* If this should not belong to the medical domain, there should come additional but comparable legislation and also organisation.

* The KNMG has entered this discussion in the meantime.

Frits Hage (71) stays cool about Alzheimer

I SAY NO TO A BITTER END.

Frits Hage (71) does not want to go on living when his illness impairs him too much. He goes often to the Alzheimer-café.

By Anja Krabben

Frits Hage stays cool. He has Alzheimer but takes the disease as it is. He does not deny it, in contrast to his brother.

'I go once a month to the Alzheimer-café. Roughly twenty do come, including their partners. A pity no more people are coming. I find it interesting and comforting to talk with other people and to get information from experts how to handle my illness.'

War

He does not reflect on his future too much, nor does he ponder about his past. He was born in the province Zeeland and grew up in Indonesia. 'My father was in the army, we

have been locked up in Japanese camps. I was six when the war was over. I weighed only 11 pounds. We went for a short time to The Netherlands, just to recuperate. When I was 11 years old we returned definitively. I did not like it in The Netherlands.' But he did not go back to Indonesia. 'I did not have the money and not the urge to go. And going now is no option. I don't know anybody, and everything has changed.'

The past is not pressing on him, although that often is the case with Alzheimer. His daughter has asked him to write his life story. His memories came back easily, resulting in a nice booklet with photo's and written memories.

As of ten years Hage has Alzheimer but the disease seems to be in an early stage. He looks o.k. but sometimes he repeats himself, he forgets years and especially has difficulty to recall where his keys are. But those things go also along with the 'infirmity of old age'.

He drives a car, even asked for a test at the CBR, the driver licence office. His medication is Reminyl which seems to postpone the effects of Alzheimer. He does not have side effects.

Frits Hage lives with his friend Victorina (85) in Zandvoort. 'She is my second memory.' They both love travelling and have made long journeys. Now they make trips in the neighbourhood and nearby countries.

Ten years ago he asked for a brain scan because his mother suffered from Alzheimer. He was diagnosed with Alzheimer, the hereditary form. He stays cool, knows what can come but tries to enjoy every day, as long as that is possible. When asked 'to what stage you will go along?' is the answer 'not to the bitter end'. He has seen his mother in a nursing home. 'She has been there for years, rocking in a chair. She did not understand anything, was not able to do anything. I said to myself that never.'

Agreements

He has made clear agreements with his physician, the general practitioner. Hage wants above all to have control over his situation, with a lucid mind. 'That's why I have made agreements with my physician. If I say I don't want anymore, he will help me.' Hage has completed all NVVE forms, also the non-resuscitation statement.

Twice a year he makes an appointment with his physician and twice a year with the specialist. Both look if the disease has been progressed.

With his physician he talks about his life's end and his living will. But what is the limit? 'That is difficult to say. Anyway I don't want to go to a nursing home. I have seen my mother deteriorate, becoming a hothouse plant and I don't want that to happen with me'.

If Hage will over live Victoria, he will move to a home for the elderly close to his brother, or close to his daughter. He has made arrangements to that.

He knows his future is full of uncertainties. 'But one thing I know: never into a nursing home and never going on to the bitter end.' And if the physician will not help him after all, he will make an end to his life.

Determined

'Yes, even if Victorina is still alive. If the physician doesn't want to do it, I will'. His reaction is sure and certain. 'I cannot get the pills I won't jump from a high building, so there are few possibilities left.' And he points to his wrists. Victorina does not like to think about it, but she knows how important it is to him. Hage denies he wants to press his physician 'it is no thread, I but I don't want to walk the Via Dolorosa to the bitter end.'

At the moment the issue is not at stake. Life is well and his agenda is filled with dates and short trips. It will be a drawback if he won't be able to drive a car anymore. 'But we will see. At this moment life is worth living.'

PSYCHIATRIST STAYS HESITANT IN ASSISTED SUICIDE

Less than 2 percent of the requests for assisted suicide are attended to by psychiatrists, according to research on the assignment of the NVVE. The percentage in 1996 and today is comparable. The research was done at the Radboud University Nijmegen with the cooperation of the University of Amsterdam, The Erasmus University and the Dutch Association of Psychiatrists (Nederlandse Vereniging voor Psychiatrie -NVvP).

As of 2002 the Dutch Euthanasia Law offers space for assisted suicide in unbearable and hopeless suffering –also mental. In 1995 the number of requests to psychiatrist for assisted suicide was 320, in 1981 520. Asked if assisted suicide was acceptable, 75% of all psychiatrists agreed; 45% could imagine to actually help– yet only 2% of the requests is implemented. An estimate of 55 persons yearly, commit suicide after rejection of their request.

The directives about assisted suicide, since 1993 provided by the NVvP are only known by 56 % of the psychiatrists. In the meantime the latest, renewed version dating back to 2009 has been put on the public part of the NVvP –website.

PETRA DE JONG ON LIST OF PROMINENT WOMEN IN OPZIJ

NVVE-CEO Petra de Jong was named in Opzij, a known women monthly magazine, in their list of top 100 prominent women of the Netherlands. Ten categories were chosen and she was listed tenth in the category Health Care. Overall she was named as the one with the most talked of items.

Petra de Jong, is CEO of the NVVE as of 2008. She, a former lung specialist, likes to engage in the public debate especially since she looks after the interests of so many people.

Physician finds it 'very complicated'

EUTHANASIA AND DEMENTIA: THE DISCUSSION GOES ON

Three quart of the NVVE-members has stated in their living will they want euthanasia in case of dementia. In stinging contrast is the number of physicians who encounter this problem with 'critical doubt'.

By Leo Enthoven

An investigation among their members and general practitioners about the way of thinking concerning euthanasia in (beginning) dementia was explored by the NVVE. The results were presented October 4 during a nationwide debating session in Utrecht with physicians about 'Dementia and the self determination of life's end'.

The facts in the Netherlands: 230.000 patients with diagnosis dementia. In 2050 the number will be around 500.000. According to the Regional Euthanasia Review Committees euthanasia has been granted to 12 persons of the 2.636 requests in 2009. That is 0,46 %. The legal space for euthanasia and assisted suicide in beginning dementia is much higher than thought of by patients and physicians.

Uneasy

The subject is uneasy, even to those NVVE members. It is hard to formulate your wishes, to choose the moment when, and to enter into a dialogue with your physician. The most important reason to ask for euthanasia in dementia is loss of personal dignity (84%), fear to become dependent (81%) and loss of direction (78%).

Physicians mention the 'complexity of the requests' and the 'dilemma'. Nearly half of the physicians (42%) aren't aware of the space which is granted in the law for euthanasia or assisted suicide in beginning dementia.

Busily engaged sessions

The conclusion was made that it is very important to discuss nationwide the problem of euthanasia and dementia. Nine –busily engaged- sessions have been held by the NVVE with the public and with specialists. The session with physicians has been the closing debate.

The forum member Bert Keizer, nursing home physician and author, pointed out to the physicians that refusing those patients euthanasia or assisted suicide, sentences them and their nearest to a lasting *Via Dolorosa*. The attending physicians declared that it is 'incredibly complicated' for the physician as well as for the patient: 'the requirements of due care, the living will in writing, the way of implementation, the time for decision making and the correct timing.' It happens that the patient and his environment are convinced that it concerns dementia but the physician has another interpretation saying 'well, everyone forgets once in a while'.

Impact

At the one hand people can change their view after completing their living will. At the other hand the living will is not a guarantee to get what is aimed at. To persuade a physician is hard working, since euthanasia has an enormous impact on physicians. They have their feelings and find it hard to implement euthanasia or assisted suicide, especially to demented people. Intuitively they don't want to do it, although they know they can do it legally.

NON-RESUSCITATION TOKEN, GOOD NEWS IN TWOFOLD

When the non-reanimation token had been introduced, there was doubt if the bearers would realise what reanimation really means. The NVVE has made an information brochure in cooperation with the organizations concerned. The other good news story is that the non-resuscitation token has the same legal status as the living will in writing.

By Walburg de Jong

In the brochure are mentioned the considerations for not wanting to be reanimated. Some people have a certain age and wish that nature will have its course. Others are afraid of the risks. Reanimation, what is that?

The Dutch Reanimation Council gives the following definition: resuscitation is the total of actions to restore the spontaneous circulation and/or respiration, e.g. in loss of consciousness in cardiac arrest, drowning, an accident or severe haemorrhage.

What is the succession rate? We can distinguish the chance to survive from the way we survive. The chance to leave hospital alive is 20%. Half of the reanimation efforts don't succeed at the location of the cardiac arrest. It is an average. The most important factor to succeed is the time span in which the defibrillation has been administered. The survival rate can be 50% or 2 to 3%.

Another question 'How big is the chance I will become a hothouse plant?' The above mentioned situation is an exemption, but most of the survivors will have unfavourable, even detrimental outcomes. Important is one's personal weighing of 'quality of life' and the acceptance of the risks that go along with resuscitation.

Legal status

As of September 2010 the non-resuscitation token got officially the legal status after an answer to this point, by the Minister of Health Affairs Ab Klink. The token has now the same legal status as the living will in writing. Everyone has to respect that. It is a relief to those who wear the non-resuscitation token, and to those who want to do so in the future.

CONGRES WORLD FEDERATION IN MELBOURNE BUSILY ENGAGED

The congress of the World Federation of Right to Die Societies is being held once every two years. In October many interested people from over the world came to Melbourne. Ans Baars has represented the NVVE.

The theme of the congress of the World federation (WF) was 'Dying With Dignity: Bridging Principles and Practice'. Assisted suicide was the central issue. Another point was 'more money'.

The NVVE had contributed at an earlier stage and suggested to contribute structurally if other countries would go along. Most other countries did not want to go through with it. A part-time manager has been appointed though, to keep the WF web up-to-date.

Europeans

Deputies from over the world came to Melbourne. Of course many Australians came and people from the USA, Canada, Japan and Europe. Germany and England are not joined up to the WF. France did not show up. Belgium, Luxembourg, Norway, Scotland, Sweden and Switzerland were represented, and The Netherlands with deputies from De Einder and the NVVE.

Ans Baars says 'We are the example. We have legalized those issues, there is no *slippery slope*. Only fervent adversaries have the hardcore idea of 'euthanasia tourism' in spite of arguments, reports and withstanding figures.'

The Netherlands has more to bring to the congress than to receive. 'We are in the frontline. It is a pity we have not been invited to talk about the latest developments in our country. But I had a presentation about euthanasia and dementia in The Netherlands and could talk to many people from all over the world. I found the presentation on euthanasia by a new Australian society of Christians, the Christians Supporting Choice for Voluntary for Euthanasia very interesting'

The atmosphere was good, the interest great. Four hundred people have visited the public part. Radio, television and the journals were very interested and a covering Australian organization has been established. That means a stronger political weapon!