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Summaries by Corry den Ouden-Smit

THE NEW ROUTE OF THE NVVE

After the realisation of the Euthanasia Law in 2002 the core business of the NVVE has shifted from euthanasia and physician assisted suicide to áll possibilities of choosing how to die in a dignified way. To shape this new route the NVVE wrote the memorial *Perspectieven op waardig sterven (Perspectives on dying with dignity)*. Project manager Marleen Peters started with four teams, which will come with concrete plans of approach before November this year.

By Fred Verbakel

Four teams consisting of members of the Board, office employees, NVVE members, volunteers and extern experts will concentrate on this subject. They will especially focus on the problem of dying in a dignified way for patients with dementia (in an early stage, or at a later stage with a declaration of a living will, made when still healthy) for psychiatric patients who are still capable to express their will, for people who regard their life as fulfilled and want to end it, for understandable reasons.

Open conversation with psychiatrists

The Team Psychiatry is unanimous that assist in suicide should be provided more often. How to proceed? Discussion with patients about their death-wish and eventually helping them to commit suicide is the task for psychiatrist not for the NVVE. The team looks into the possibility of setting up a network of psychiatrists who are willing to help those patients. If there is a network, the NVVE could give names of a psychiatrist in the area of the patient instead of a psychiatrist who refers the patients to the NVVE. Many psychiatrists are not aware of the possibilities of the Euthanasia Law or of the house rules for *Assisted Suicide* of their professional group.

Shifting borders in dementia

The Team Dementia is confronted by the denying of dementia. Older people do not want to talk about it and physicians don't dare to confront their patients with it. People with a euthanasia declaration should have the courage to discuss euthanasia in an early stage of dementia. And a physician should face the problem openly by reminding the patient of his declaration and by asking if he still stands by this declaration. Diagnosis is very important, so one can decide when assisted suicide comes up for discussion at an early stage. For there is a line, physicians won't cross. If the patient is clear about his wishes, the moment of euthanasia could be postponed to a later stage of dementia.

Fulfilled Life

The Team Fulfilled Life tackles the problem of existential suffering of people who are not ill but 'ready with living'. Two routes are set out. The 'medical route': the

physician gives the lethal medicine. In that case assisted suicide for a fulfilled life has to become a part of the Euthanasia law. The 'auxiliary-route': ''the lastwillpill'' will be given by a certified not-medical auxiliary. In that case the law has to be amended. The Team will open a social debate about the criteria, and will think about ways of 'trying out the lastwillpill'.

Centre for End-of Life Problems
The Team End-of Life Problems has been assigned to draw attention to the new statement of the NVVE: all the choices there should be for dying with dignity. We don't have a culture of 'how to die' in The Netherlands. The Team will facilitate the 'Centres for End-of Life Problems', an independent organisation by several partners. It should be a place were people have admission to all requests about the ending of life, were the information is good and reliable and were autonomy and helping oneself stands central. The opinion of all the four teams is that physicians, nurses, providers of care and citizens should be better educated. An important reason why people don't get the desired help is lack of knowledge.

Ambassadors
Apart from schooling, the Team End-of Life wants to recruit ambassadors to propagate the message of the NVVE. They have to create a wide base in society so politics cannot disregard the problem.
Cooperation with other organisations is of the utmost importance. Contact has been made with the Dutch Alzheimer Society and with the Humanist Society. The Humanist Society has the same ideas about themes like fulfilled life, dementia and psychiatry as the NVVE. At the end of this year priorities will be set by the NVVE. 'We hope to have realised all the plans by 2015 says project manager Marleen Peters. As for the Teams: 'we are ready for it'.

Rein Zunderdorp, president of the Humanist Society:

'ALWAYS TAKE PEOPLE SERIOUSLY'

People with a chronic psychiatric disease seldom get help when they want to die. Psychiatrists are reluctant and see it as a defeat when they cannot cure their patients. Rein Zunderdorp, president of the Humanist Society thinks there should be an end to needless suffering. His organization cooperates with the NVVE to improve this situation

By Fred Verbakel

The NVVE and the Humanist Society (HS) join forces to effectuate the right to help for people who suffer psychically and want to end their life.
Hardly any of the over three hundred well-considered requests a year are honoured. The Euthanasia Law does not differentiate between physical and psychical suffering. In practice there is a difference. According to the NVVE and the HS this is an undesired situation and the profession of psychiatrists falls short. 'We humanists think that if life does no longer have an added value we may decide that life has come to an end.'

Does self-determination apply to everyone?
'In principle yes, but sometimes people are incapable to express their will and cannot see their life in perspective. When people panic or suffer from depression they should be helped. A request for euthanasia should be well- considered. One has to talk it over so misconceptions can be clarified. But the person himself should decide.'
Mag ik dood? (*May I die?*) the film about death-wish sponsored by the Humanist Society, demonstrates that psychiatrists do not react to requests from treated-out patients with suicide wishes. This leads to despair and often to horrible and aggressive ways of suicide. All next of kin, who have been interviewed in this film, are embittered that there was no other way. They have seen the despair of their nearest and talked to the medical staff to no avail.

Can a psychiatrist foresee that his patient will commit suicide?
'The psychiatrist has the means and methods to find out what impels his patient. He should share his knowledge with him, show the ways of recovery if any and draw attention to postponement. If the patient commits suicide it can be unforeseen. If suicide was foreseen the psychiatrist probably did not want to give the desired medication'.
The NVVE and the HS operate differently. We take the patients point of view, the NVVE is permanently in debate with the medical profession. We are less knowledgeable in that field.'
The government does not want to be involved with assisted suicide. The NVVE-CEO Rob Jonquière and Rein Zunderdorp wrote an article about this in the newspaper *De Volkskrant* saying that the legislator has the duty to guarantee this help to patients by summoning the professionals to co-operate loyally in the implementation of the euthanasia law.'

Is amendment of the law advocated by the Humanist Society?
'When the medical profession turns down 90-95 percent of the requests for medical assisted suicide on principle then the law may be amended. Certified consultants should have dialogues with the desperate patient and should have the key to the medicine cabinet. Those certified consultants may be nurses, psychologists, NVVE consultants, De Einder consultants or parties otherwise involved. Assisted suicide by non-physicians has been regulated in Switzerland. In The Netherlands help for suicide by non-physicians is punishable'. The taboo on death-wish in case of psychic suffering should be broken otherwise the list of violent suicides will grow endlessly.

If priorities are set, do psychiatric patients have priority over cases of dementia?
'That is not for the Humanist Society to decide. The principle of self-determination is at stake. The majority of the population believes that people should decide for themselves. However the 'pil of Drion' (lastwillpill) is more accepted by the population than assisted suicide for psychiatric patients.

Alzheimer
A member of the Humanist Society takes part in the dementia study group of the NVVE. Dementia and euthanasia are a delicate combination admits Zunderdorp. The starting point is that people must be capable to express their will. In the beginning of dementia people know what they want. If the dementia is progressive decisions should be made soon. If the person does not want

euthanasia anymore, that should be taken seriously. Euthanasia is not meant for the people around him. The person himself has to decide.

THE PSYCHIATRIST DELAYS

Help for the death wish of psychiatric patients has always been a difficult subject in the discussion about its legal aspects. The discussion has come to a halt.

By Hans van Dam

Helping people with a psychiatric illness to die has shifted from 'hardly' to 'never' –while the need of psychiatric patients did not decrease. New medication has helped some patients, but there are many patients left who can not be helped.

Apart from psychiatrist Detlev Petry in the psychiatric hospital Vijverdal in Maastricht who has realised homes for those untreatable patients, hardly any psychiatrist wants to talk about death wishes. The professional organization is looking away. The latest report about medical assisted suicide (2004) was published in the private part of the website of the Dutch Association for Psychiatry. In the meantime the Board DAP has decided to place the report on the open part of the website and to send it to all psychiatrists.

Years ago the scene was different. Psychiatrist D. van Tol published the book *De dood als keuze (1977) (Death by choice)* which focussed on the right to suicide. The NVVE followed in 1980, 1991 and 1993 with elaborate advices. Prof. Diekstra (psychologist) and Prof. Speijer wrote *Hulp bij zelfdoding* (1981) about help in suicide. The Health Counsel pleaded in 1982 for removal of the article that forbids help in suicide from the penal code. The theologian H.M. Kuitert wrote *Suicide. Wat is er tegen? (What is against it?)* (1983 revised in 1993). The book focussed on objections from Christians and refuted them.
A working paper by the Royal Dutch Medical Association on helping psychiatric patients with suicide was published in 1993. In 1997 this paper was included in the volume *Medisch handelen rond het levenseinde bij wilsonbekwame patiënten*, about medical treatment at the end of life for patients incapable to express their will.

Rapid

In the working paper, a first parting of the way appears. Attention is given to reasons psychiatrist may have to deny suicide; hardly any reason is given for assisted suicide. During those years, a lot of publicity was given to the prosecution of psychiatrist Boudewijn Chabot, who gave medication to a patient so she could die. In the second half of the nineties the legal aspects of ethical issues came in a rapid. The discussion about help for psychiatric patients stops. For example, the last article in the journal *Tijdschrift voor Psychiatrie* on this subject appeared in 2001.

Impossibility
Psychiatrist Chabot makes a plea for euthanasia without the assistance of a physician. In his book *Auto-euthanasia* (2007) he advises people to do it themselves by saving medication. The NVVE-reports emphasized the possibilities for help, the most recent report of the Dutch Psychiatry Association emphasizes the contra-indications and the limits of help. The legal aspects have become prominent. On the one hand many psychiatrists do agree to talk about suicide, but on the other hand, many patients have to sign a non-suicide contract. Thus the patient is placed in an isolated position.

Winning
Two third of the psychiatrists find medically assisted suicide acceptable and nearly half of them find it conceivable that they will ever do it themselves. In practice it is different. Help is refused systematically. There is much to gain: in recognizing the agony of psychiatric patients, in acknowledging that not all patients can be helped and in using the possibilities of the law to give the requested help for suicide.

2007: 10 PERCENT MORE CASES OF EUTHANASIA REPORTED

In 2007 the Regional Euthanasia Review Committees received a total of 2120 reports of assisted suicide and euthanasia. The year before 1923 cases were reported– about ten percent less. In most cases euthanasia took place at the patient's home and it concerned patients with cancer. The reports came from general practitioners and in only three cases the committee found that the physicians had not followed the requirements of due care. Those cases were reported to the Inspection of Health Care.
The forecast was that the number would decrease. Physicians were said to prefer palliative sedation in order to stay clear of the Euthanasia law. The review committee does not have an explanation for this increase. In the past ten years the number was between 1800 and 2100. Most reports in 2000 (2123), least in 2003 (1815).

Petra de Jong, the new CEO of the NVVE.

'Make optimal use of the legal space'

As of September 15, Petra de Jong (55), a lung specialist, will be CEO of the NVVE. She is, like the former director Rob Jonquière, a physician. She will focus on present day's practice and avoid risky political statements for the time being. 'Many physicians are afraid to be taken down by the law'.

By Hans van Dam.

'Treating patients endlessly has become standard. Even when the physician knows it leads to a dead end. The key word in therapy is trying. It often leads to longer suffering. Some years ago we did stop therapy in cases of aggressive lung

cancer as soon as brain metastases did occur. Nowadays we go on without change of perspective. It is a hard struggle to realise that death belongs to life.' For years Petra de Jong worked in the Zuwe Hofpoort Hospital in Woerden. She was the one who set up the Lung Department. Apart from her work with patients, she likes to organize. She looks forward to her new job.

Touchiness

'Euthanasia is a touchy topic, politically and socially. I like to set out sharp lines around the sore spots. Concerning the NVVE I want to look how the organisation can be even more professionalized and how its name can be better known.' Petra de Jong has experience with euthanasia. 'I know how difficult it can be, and how necessary. The farewell can be worthy. I am happy there is a legal arrangement. Since 2006 I am a SCEN* physician. As such, one is confronted with the definition of the problem: what is unbearable suffering? I say to my colleagues 'who am I to define what suffering is'. A physician has power over euthanasia: to give the green light or the red light. The questions is: how does he implement his power?'

* SCEN Support and Consultation for Euthanasia in the Netherlands

Dependence

The NVEE stands for autonomy, and objects to too much power of physicians. Petra de Jong: 'Indeed, patients are dependent on physicians, but the patient is expert of his life and death. In this society we have to use one another's expertise. But the patient should not be too dependent on the physician'. The NVVE asks attention for the 'forgotten groups': people with dementia, chronic psychiatric patients and people who find their life has been fulfilled. De Jong thinks there is room in the law to help those people. 'Many physicians stay well away from the margins, because they are afraid to be taken to court by the law. As NVVE-CEO she will try to facilitate optimal use of the room given by law. 'In that case, justice can be given to the patient. And as physician that is what you should want.'