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Summaries by Corry den Ouden-Smit

NVVE-CEO Petra de Jong believes in a clinic for termination of one's life

'IT STAYS A VERY PRECARIOUS SUBJECT'

On the question if a 'clinic for termination of one's life' will be feasible her answer is YES. The NVVE-CEO Petra de Jong has made circumstantial research to see if such a clinic is possible for those who ask for help to die. For those, whose wish is legally correct but is not honoured.

By Anja Krabben

Petra de Jong, as of 2008 CEO of the NVVE, has a dream. She hopes that in the Netherlands it will be possible for everyone to die in a humanly way at the moment they find their time has come. She talked to many organisations to look if such a clinic is feasible.

Euthanasia is organized well in the Netherlands. Why such a clinic?
'Every year about ten thousand real requests for euthanasia are made, a third is honoured: in 2009 there have been 2636 reports. Some of them have died before the request could be fulfilled, but a third got the answer NO, even though they fulfilled the euthanasia criteria. Some of those refused have chosen for an awful suicide, some for a less gruesome suicide, but their death was in bitter loneliness. Others are forced to wait for a natural course. There are 1500 persons a year who commit suicide, among those are four hundred elder than 65 year. Those who are refused euthanasia or assisted suicide, about 3000 people a year, could be candidate for 'the clinic for termination of one's life'.

Who are those people whose request is not being honoured?
'Those are persons in the beginning of dementia and patients with psychiatric illnesses, but also people with cancer.'

The existing hospices will not accommodate them?
'All hospices in the Netherlands, over two hundred, have been interviewed in 2009. Eighty percent say euthanasia is possible in their hospice, but under the condition that the person should be at the point of death, dying within three months. This is not the case for the groups we are talking about.
Part of the problem is the compensation, for the stay in the hospice, by a general fund for costs of illness. Another argument is that there would be a conflict in giving optimal palliative care for one group, and euthanasia or assisted suicide for the other, in the same hospice.

Safe
'Moreover a clinic for termination of one's life should be open to all kinds of the self willed end' says De Jong. 'People gather deathly medicines but would like to take them in a safe surrounding, not alone. This gathering of medicines is called suicide, not assisted suicide. In a clinic a physician can give information. According to the law a physician can give this information in order to prevent them from an awful death.'

And people who decide to stop eating and drinking?
'The clinic should be open for that too. Psychiatric patients could be helped in this clinic by their psychiatrist who cannot help them within the context of their own institution because of certain protocols.

Will it not become too easy for physicians to let others do the job?
'Euthanasia is not something new, it is part of the medical thinking for years, jurisprudence since 1984, legalisation in 2002. If you stick to the criteria you are not being sued. And yet many physicians won't do it and often it is then too late to change to another general practitioner.
More and more I see that psychiatrist find they have to do something to a persistent wish to die. In the fore mentioned clinic the psychiatrist could get moral support but also practical support. Psychiatrists are not used to medical interventions outside their profession. In such a clinic they would feel safer.

In the end stage of life, referring to another physician is often not possible because physicians in general practice want to build up a relationship with their patients. Isn't that at stake with such a clinic?

'As physician you see a lot of suffering and if the suffering is extremely, and the person meets the criteria for carefulness many a physician grants him his choice for not having to go on with living. Those people have been rejected by other physicians. In a clinic it is possible to help people within a short period of time. I talked to physicians and nursing people and all said yes to the question if they were willing to work in such a clinic. Of course it will not be a fulltime job, but say one day a week. There is a parallel with the abortion clinics. In 1981 abortion have been legalised, and still the clinics do exist because many women are refused in the regular care. It was said that hardly any physician would be willing to work over there, but they would, because they find this is good work, and merciful. Always there will be physicians who refuse to perform euthanasia although it is legal. So a special clinic can be a solution.

Three days?
'The admission in the clinic will be about three days. This time is needed for the patient and physician to get acquainted with each other and to talk everything over. In such a clinic the nearest of the patient can be close by. It may be possible for them to stay overnight. In the period before the admission all what is necessarily has taken place, like if the requirements of carefulness have been met. Like in hospices the clinic will have about eight places. The ambiance will be informally.

Can an unwanted effect resort from such a clinic? Could elderly feel pressed by their surroundings?
'I find it of utmost importance to say that nobody should feel forced or influenced to make this choice, a choice for a voluntary death. Everyone should make his own choice. The people who will turn to such a clinic are mostly those who have made steps to this end already. Besides, the clinic will be professional and look if unwanted pressure has been laid.'

Will there be a financial problem?
'If the Medical Care Insurances won't reimburse, there is the possibility of a subsidy as is the case in abortion. Moreover 90% of the population could finance it themselves. And for those who can't we could make a special fund. I can imagine that the NVVE will help out in such cases.

The media have taken comprehensive notice. There are opposite opinions, but they have been very mild. How come?
'The taboo on death is diminishing, and even so on the self-willed end. I have never seen a person, completely healthy who wanted to stop living. Human beings hang on to life. The moment you say 'it has been enough' whatever the reason, it is a genuine reason. I see, more and more, that society is respecting this view.'

Could you tell something more about the conclusions of your research?
'The conclusion is that a clinic for termination of one's life is feasible. The demand is there and the personnel will be there. It is legal correct so politics should not interfere: the law does not have to be changed. So, yes we can!'

There is nothing in its way?
'The NVVE will not set up such a clinic. If a financer could be found, a clinic could be set up easily. The business case has been made! The first clinic will be important for all kind of experiences. We need them because the subject is very precariously. Emotions are important. A positive connotation will help. Thanks to the discussion around euthanasia, going on since 1973, the Netherlands knows a culture in which we all have decided it is unnecessarily to suffer unbearably and endlessly. If a society thinks this way, it has to organise the possibilities. One of them is a clinic for termination of one's life.

'WE USUALLY HAVE THE MOST INTENSE CONTACT

Nursing personnel and care givers are important at the terminal care. However their role is not always clear. SCEN-nurses and –care takers will be of help.

By Anja Krabben

SCEN means Support and Consultation for Euthanasia in the Netherlands. In the Netherlands we have SCEN-physicians, specialized in giving information about euthanasia and assisted suicide. They also have a legal duty to give consultation in requests for euthanasia and assisted suicide.

In the profession of nursing there seemed to be a shortage of knowledge about what is going on in the last phase of life concerning euthanasia or assisted suicide.

Twenty people

The Dutch Association for Physicians (KNMG) and the Association for Nursing and Care Taking persons (V&VN) organized a pilot 'SCEN Nursing & Care taking people.' Schooling has been given and a Helpdesk will be in action as of the end of February. Two regions have been chosen in different parts of the country. Fifty persons responded to the demand for special training and twenty have been selected. Motivation and experience was considered important, as was the level of knowledge. The twenty came from different regions and work environment: hospital, hospice, home care, nursing homes. Eric van Wijlick, project leader SCEN at the KNMG, is involved in this project.

'De SCEN-nursing and -caretaking people will get and give their advice by telephone, they will not go visiting, like the physicians.

'Not only euthanasia or assisted suicide is the issue, all decisions around the end of life are included' says Joke de Witte, of the Ethic committee of the V&VN. 'All the decisions around life's end are included like palliative sedation, stopping with eating and drinking, refusing of treatment and especially what is the difference between them and euthanasia.'

Motives
Mireille Nijssen (40) talks about her motives. 'I work more then ten years with patients in the last phase of their life. There lays my passion.' Since two years she works in a hospice, the years before in a nursing home for palliative care. 'I like it in the hospice. You can give more care then in a nursing home. Death is not always in your mind in fact you focus on what life does mean, and how you can give quality to life. You get to know people in a short period of time. The living is intensely'

Moral considerations
Nijssen applied for this project because she wants to help colleagues. 'In our hospice the policy has been changed. Euthanasia was not possible in our hospice, but after long deliberations it is possible now. We had the moral consideration that we were excluding patients if they wanted euthanasia and we would not allow that. This whole process of thinking will help me to help others'

José Boots (49), home nurse oncology in palliative care, sees a lot of ignorance with colleagues. 'If you know what is possible and how it works and how decisions are made you can prevent stress in the patient. And you can give him back the direction of his life. If you can explain to him what the possibilities are he can make his own decisions.

The role of a nurse or care taker in euthanasia or assisted suicide is: calling attention, getting to know what the patient really means. They can point out complaints and suggest a discussion with the physician. They can see if the wish for euthanasia is constantly, and even if the family puts pressure on the patient.

Get to the bottom
The nurse is not allowed to have discussions about euthanasia. She has to make sure a physician will take this discussion up. Sometimes patients are not transparent in their demands. Often they don't dare to request for euthanasia. Nijssen: 'But you can ask and go to the bottom of their remarks. If someone says 'My life has no meaning anymore. I wish I were dead' Then I ask: 'What do you mean by that?'
'The contact physician-nurse is important especially in the end of life questions. It is important that physician communicates to the nursing staff what has been said in the euthanasia discussion between the patient and the physician. That is not always the case. So the subject euthanasia may stay mysteriously between the patient and me. And we, the nursing people are most near to the patient. We have to work on this field too' says Nijssen.

Vu-research about the meaning of a living will

EXPECTATIONS ARE OFTEN TO HIGH

Patients and their nearest often have very high expectations of the meaning of a living will. As of 2005 the Free University of Amsterdam is doing research on this topic. An intermediate score

By Fred Verbakel

Physicians see a living will as a tool for discussion on medical decisions in life's end.
In case of incapability to express one's will, they stay at the sideline. They will consider euthanasia only if suffering is clearly visible and if communication is more or less possible. A more detailed work-out of the existing rules is desired. That is necessarily to take away fear and discontent in patients and their next of kin.

Those are results of the research on a living will, done since 2005, at the Medical Centre of the Free University Amsterdam by Professor Bregje Onwuteaka-Philipsen. She published in a Dutch Medical Journal, the *Nederlands Tijdschrift voor Geneeskunde*, about the living will given on demand to members of the NVVE and the Christian Patients Society.

Not clear

In the group tested for this query of the living will 72 percent answered 'yes' to the question if they wanted euthanasia in case of dementia. But it stays questionable if the living will is of help in dementia. The law says that a written statement can be considered as an oral request. The physician has to be convinced by his own judgement, consultation with other helpers and with the next of kin.
Most persons completed their living will, because they had seen dementia of family and friends close by.
General practitioners don't believe it makes sense to talk about it, when the person is healthy, since one can change his opinion. At the other side talking about a euthanasia declaration when the person is demented can bring him in utter despair – as was the experience of a SCEN-physician.

Many physicians hardly remembered the discussions about euthanasia with their patients. Most found the living will in their dossier. Some said they should have talked about the living will more openly. Nursing home physicians have a better understanding about it. They have talks with the patients at intake.

Literal sentences

All patients had high expectations about the feasibility of euthanasia in dementia after talking to their physician. Some could see the objections the physician has with euthanasia in dementia, but thought he would help them nevertheless.
Few of the patients could literally recall the words the physician had said, which gave them rest. Others know better. They had seen in their surroundings that physicians not always keep their word concerning the euthanasia declaration.
It stays hard for a physician to tell that the chance to get euthanasia in dementia is very small, because he does not see that the suffering is unbearable. 'Maybe you can talk about unbearable suffering if the patient himself realises his memory is deteriorating.'
Nursing home physicians see other signals of unbearable suffering in the end-stage of dementia: They look unhappy, are sad, restless, confused or aggressive and medication is not a solution. Nursing home physicians find euthanasia in dementia is more a task for the general practitioner because he sees the demented patient when communication is still possible, besides in a nursing home too many persons are around. The general practitioner finds that treatment of restlessness or anxiety can best be tried out in a nursing home so the decision about euthanasia is should then take place in a nursing home.

Effective rules

More effective rules are needed, find many a physician. They want to know what their right is. They are afraid for juridical consequences. Worked-out rules also will give better patient information.
Earlier research from Onwuteaka- Philipsen showed that 60 per of the physicians does not know that a written living will for euthanasia can be granted if the patient is incapable to express his will, and all requirements of due care have been fulfilled. Even more astounding is this same percentage of ignorance in SCEN*-physicians. Physicians consult the SCEN-physicians and ask them for a second opinion!
The researchers plead for working out of the rules for the use of euthanasia declarations in dementia. That will give transparency for physicians, patients and their nearest. Also it will give a realistic view over the feasibility of the euthanasia declarations and at the same time guarantee the due care and legal security.

They suggest that the Royal Dutch Medical Association and the Association for Geriatric Specialists could install a commission to look if such rules are desirable and feasible.

* SCEN Support and Consultation for Euthanasia in the Netherlands.