Relevant

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Summaries by Corry den Ouden-Smit

Wieke Koster about the agony of her mother

'IF ONLY WE HAD KNOWN HOW ALERT WE SHOULD HAVE BEEN.'

The 85-years old mother of Wieke Kosters was very clear in her wishes: if more suffering would come, she did not want treatment but euthanasia. But when she had fallen down and had many broken bones, the general practitioner called for an ambulance and she ended up on the operating table.

Teus Lebbing

To the best of her knowledge Wieke Kosters (61) thought her mother had spoken to her physician about life's end. Mrs. s'Jacob, her mother suffered from fibromyalgia and had chronically pain, but she managed to live on herself.

Since 1998 Mrs. s'Jacob was member of the NVVE. 'At home we talked it over, also with my father who was general practitioner. Death belongs to life is what my sisters and I learned early in life.'

Without consultation
Wieke was stupefied when the physician called her to say her mother was on her way to hospital. 'So many things do happen in such a short time, I saw my mother lying with pain, how sharp are you then?! If only I had asked ''Mam, you are going to hospital, is that what you want?'' If only I had known I should have pointed out to the prohibitive regulation, there and then.'

Also the urgent help began treatment without consultation. 'My mother said she did not want this, but nobody reacted. It is wisdom afterwards, but I should have named her prohibitive regulation loud and clear,'

Her greatest nightmare
'A physiotherapist wanted to revalidate her, but she could not stand on her feet. My mother was not able to live on herself anymore. Besides her broken hip and fibromyalgia she had worn out shoulder, a broken wrist and elbow. The pain could not be taken away. This was unbearable suffering, her greatest nightmare.'

Nobody listened to Wieke, who expressed het mothers' euthanasia wish. Not the general practitioner, nor the ward physician, nor the hospital. And the Life's end clinic could not help out, since it was an acute suffering. 'Í told my mother how distressed I was I could not help out. Dying in dignity, as she had in mind, was no option anymore.'

It was over
At last a spiritual assistant, contacted by the hospital, helped out. She listened to Wieke and offered to look for a place in a palliative home. 'The caregivers startled on seeing my mother. So skinny, so much pain, so sorrowful. My mother accepted the palliative care. It was over, she did not want to go on anymore. After five days she died.'

Wieke will not be embittered. But the last weeks of her mothers' life gnaw on her. 'I see how needless has been trifled with her. No caregiver has asked her if she wanted this. While my mother thought she had laid down her wishes efficiently – euthanasia request and prohibitive regulation. And by talking it over with her general practitioner.'

Shortly she will go to her physician and talk about her prohibitive regulation. Now she knows how important it is 'to hear what her physician exactly thinks, and if he is willing to fulfill her wishes. And how important it is to continue talking about the agreements around life's end. Time and again, and with all to whom it my concern.'

COMPELLING REGULATION
According to the Law on medical treatment every physician has to know that a written prohibitive regulation request is a compelled regulation, not a mere request. Yet the practice may be different. How do you increase the likelihood your prohibitive regulation will be respected?

***Three pointers of Wieke**:*
- Make at forehand known your prohibitive regulation to your nearest and caretakers, and go on in repeating it.
- Take someone along for the talk with your physician, as a kind of witness or check: are the reciprocal expectations clear?
- Stay on alert for the prohibitive regulation. Keep tuned in to expectations and do not take the view others will take it for granted and/or will fulfill it..

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SCEN-physicians want to be a support to colleagues and patients

'I HAVE THE FEELING DOING WELL'

What are the motivations for a physician to take up the task of SCEN-physician? For Ronald van Nordennen and Ellen Nijland the support they give to their colleagues is an important motivation. Besides both experience it as a nice task. 'You do well', says Van Nordennen.

Martien Versteegh

Starting as hospice physician Ronald van Nordennen saw many SCEN physicians who came for the residents asking for euthanasia. 'The emphasis was on consultation, but I found the support at least as important. Some cases are so intricate, it is nice to spar with an expert. Now I take this role on my turn, to support others.'

SCEN: SUPPORT AND CONSULTATION
SCEN stands for Steun en Consultatie bij Euthanasie in Nederland (Support and Consultation by Euthanasia in the Netherlands). General practitioners, specialists geriatrics and medical specialists who are working more than five years in their field can apply for
SCEN-physician. After a two days training they can go to work. They perform this task apart from their regular work. First with a buddy, later on alone. It averages five weeks a year. It depends on the number of available SCEN-physicians in the region.

Van Nordennen is specialist geriatrics and works in hospice Roosdonck in Roosendaal. He also assists general practitioners in the region in their care for older patients who live at home. He is SCEN-physician and also member of the regional testing committee.

Although a SCEN-physician has to see the legal requirements for euthanasia have been obeyed, also Ellen Nijland, general practitioner in Groningen, finds the support an important aspect. 'I have seen that with my father, the talks of the SCEN-physician with the general practitioner. I was still in training, but I realized how important it was to have a sounding board. I wanted to this myself.'

Support for the patient
Many patients are nervous for the visit of the SCEN-physician, so I start with setting them at ease. In fact we come for the doctor to give our expertise, assist in his or her choice or to advice. Our judgement is not binding, but only a few doctors will disregard our advice.'

If the advice is negative, some people will ask a second SCEN-physician. Nijland throws doubts on that. 'It feels as if people are shopping for euthanasia. I would love to see a good deliberation between doctor and SCEN-physician, exchange arguments, comparing ideas. Then a doctor can come to a weighed choice. Mostly it goes this way. Only three times in the six years I practice this, I found the requirements of care were not satisfied. More and more people are asking an early consultation. They are not ready yet for euthanasia, but want to be reassured.'

Van Nordennen has the same experience with an ALS patient. 'You know speech can fall out. It is good to know the exact wishes of the patient, so you can anticipate on his wishes when speech has fallen out. Communication can with blinking of the eye, or nodding.'

Not till the end
Van Nordennen only gave twice a negative advice in eight years. 'Legal frames give more room than doctors think sometimes. In the beginning of euthanasia legalization in 80 till 90 percent of the cases it concerned cancer patients. Mrs. Els Borst of the ministry of Health, and Mr. Benk Korthals of the ministry of Justice have taken care the euthanasia law is for *all* patients who suffer unbearably and without perspective. Also it concerns a piling up of symptoms of the old age, if they provide for unbearable suffering.'
As specialist geriatrics he has to do with this when doctors of the region ask him to take a 'second look'. An example: a doctor asked him to look at a 52 years old patient who became the diagnosis Alzheimer. 'The man had declared not to go on till the end. So with the doctor I visited the man, and we watched out for the course of the illness. Once every three months. When he came into the grey zone we told him that, and he chose for euthanasia. He did not want to come into the black zone. These are difficult cases. Of course I was not asked as SCEN-physician in this case.'

Sympathize
The crux is if you can sympathize with unbearable suffering.' Unbearable suffering has a lot to do with the patient' explains Van Nordennen. 'The one can bear more than the other. The one finds bedridden and becoming dependent unbearable, the other after eight weeks when he became incontinent.' Not always you have to tell in words what you find unbearable. Nijland came to a man with cancer of the jaw. 'The pus was dripping down. When I asked the patient if he could tell me about his suffering he said in Gronning's dialect ''you can see this doctor, don't you?'' And he was right. If I am not sure I come back, as in cases of psychic suffering. In my SCEN group are three psychiatrists. It is nice to talk it over with them. It must be clear to me, before I pass to advice.'

Life stories
As SCEN-physician you hear a lot of life stories. Often Van Nordennen is one and a half hour at the home of a patient. 'Consultations I do with utmost pleasure. It sounds awkward but it is beautiful

work, I can mean something to the other. People tell me about their choice and often about their life and their choices.'

To check if the choice is voluntary the patient should be seen face to face. Nijland recalls a case with many family in the room. After I had asked them to draw back into the kitchen, a complete peace came over the patient. So much takes place between people. You have to be sure someone does not choose for euthanasia for his family. Of course it plays a role if one feels to be a burden to his family, but that may not be the only reason.' Nijland often sees patients who are not able to tell their story. 'Of course I read his file, and have contact with the attending doctor. If someone is critically ill a short conversation will do.' Yet even those short visits sticks in her mind. 'Life and death belong to each other. It is good we have an outlet if life becomes without perspective. I am glad the way it is regulated in The Netherlands and that I can do my share. Still there is a lot of ignorance about euthanasia. Also among doctors. Lately a doctor called me, he had his doubts about the euthanasia request because the patient was still walking around. But you do not have to be bedridden to be considered for euthanasia.'

Mercy
During his study Van Nordennen was amazed so much attention went to the birth of babies, and that people die in the middle of nowhere. 'As much attention should go to the dying process as to birth. A death bed that passes off awkwardly, can be very traumatic to the next of kin. In that period my personal mission to provide people an as good as possible life's end came into being. For me being a good caregiver means: assisting people till the end. Euthanasia is a matter of mercy.'

Nijland endorses this: 'The choice asking for euthanasia is always far-reaching. It feels good if you can help a patient with his last wish. If it is as doctor or as SCEN-physician,'

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French coma patient Lambert died this summer after a legal struggle

WHEN ARE YOU 'ALLOWED' ATO DIE WHEN YOU ARE IN COMA?

This summer the French coma patient Vincent Lambert died. The 42-years Lambert was subject of a many years legal struggle about the question if it was allowed to stop catheter feeding so he could die.
How is this in The Netherlands?

Els Wiegant

What had happened with Lambert again?
After a motor accident in 2008 he became in a 'vegetative state': only his eyes moved, his consciousness was minimal. The doctors ascertained his situation was chronical and irreversible. In 2003 they decided, in consultation with Lamberts' wife to stop with food and drink. Lamberts' parents, traditional Catholics, went to court. Five times the court judged it was approved to stop, every time the parents appealed to a higher court. On 28 June 2019 the court of justice passed the Judgement of Solomon: the feeding can be ceased.

Coma, vegetative state: confusing these terms
Yes, there are more: longtime consciousness disorders or not-responsive wake syndromes. Wrongly the locked-in-syndrome is mentioned in this context, since these patients, who only can move their eyes, are completely conscious

Previous the term coma was used for a person with a lowered consciousness who was unable to do anything, not even breathing.
Nowadays 'coma' is a container concept for all types of 'lowered consciousness'. In the 2010 directions of the physician's organization KNMG the term coma includes all types of lowered consciousness.

***Wat is meant by* 'consciousness' ?**
The KNMG says consciousness has two aspects: being awake, and aware. Someone can be awake without knowing that – moving and looking round- without being able to make contact and communicate. That was the case with Lambert. A lowered consciousness has various levels. This can be measured by the Glasgow Coma Scale. Doctors look if patients can open their eyes, answer questions and can move

***What are the prognoses in lowered* consciousness?**
That is tricky. In reanimation it depends if the patient has been reanimated fast and shortly, or after a while and during a longtime.
It also depends from the brain injury. But the one person may recover more or less, the other not at all. Sometimes you hear from miraculous recoveries, but these are very, very exceptional.

The situation of Lambert was 'irreversible'. Till when is a chance of recovery?
Also here applies we cannot say. We can measure the brain activity by functional magnetic resonance imaging or electroencephalogram, but they don't tell enough how the brain really functions. There are new developments but not yet operational.

If I come in a state like Lambert's I would like the doctors would let me die. Is that possible?
Firstly you should have a negative living will. It is like a prohibitive regulation in which you register what you do *not* want. Caretakers have to observe such a regulation, unless there are well founded reasons like the authenticity, the signature or the interpretation of what is meant. A sentence 'living as a hothouse plant' does not mean that much to a doctor. It is better to say you do not want to be dependent on a resuscitation machine. Also for this kind of situations the NVVE advice applies: see to a 'clean as a whistle' living will, and in time, and talk it over with your nearest and your doctor.

Any other factors?
A doctor can, in fact has to, cease the therapy if this is 'medical senseless'. Giving food and drink is also therapy. A therapy is medical senseless if the therapy does not (anymore) contribute to maintain the state of the patient or brings about a betterment. Also medical senseless is if the means are out of all proportion to the objective or if a minimal level of quality of life cannot be reached. The notion quality of life differs from person to person. For the one if only he can listen to music will do, another will not go on if he cannot move anymore. A doctor can find out by talking to the patient (if that is possible) or with the nearest.

Something went terribly wrong in the case of Lambert?
Yes. If there is no, or a not sufficient, written living will a patient, incapable to express his will, has to be represented. The relevant law handles this as follows. If there is a curator or mentor he comes first, thereafter the written authorized deputy, if there is no written authorized deputy, the partner may decide. Parents, children, brothers or sisters follow in that order. In France the parents have a stronger legal position than in The Netherlands.

What happens if I have a written euthanasia request?
If you are not incapable to express your will such a request can substitute for a verbal request. But the demands of carefulness has to be fulfilled in order to be eligible for euthanasia, like unbearable suffering. And that is not always so in cases of lowered consciousness. In 2010 a guideline of the

physician's association states if the patient is not awake nor aware euthanasia is absolutely impossible since the patient cannot experience suffering. If the patient is not awake but once in a while aware and there are signs of suffering like anxiety the doctor may, but does not have to, give euthanasia. But all other demands of carefulness should be met.

Thanks to Jeroen Verwiel, internist and intensivist in Radboudumc in Nijmegen

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Stopping with food and drink asks for a painstaking preparation and support

'LAY DOWN WHICH CARE YOU DO NOT WANT'

With the aging of the population and the need for self-determination more and more elderly people will resort to stopping with eating and drinking in order to die. The following story of Fien shows how difficult that can be. In italics the story the informal care has sent to the NVVE.

Marleen Peters

LAY DOWN YOUR WISHES
If you have decided to stop eating and drinking register that in a prohibitive regulation:
- why you want this;
- that you do not give permission to offer you food and drink, nor to apply artificial feeding or drinking;
- how to act if you ask in a disturbed state for food or drink;
- that you do not want to be take-up in hospital or nursing home;
- that you do not want life-prolonging therapy (no reanimation);
- who will be the legal deputy in case you become incapable to express your will.

For more information on stopping with food and drink:
- Boudewijn Chabot, Uitweg, via bol.com
- Zorg voor mensen die bewust afzien van eten en drinken, van KNMG en V&VN, - website knmg.nl/afzien-etendrinken

'I am at the end of my life. It is very good. I do not want anymore' says Fien one day to her nephew and niece. Up till then she was satisfied with her life, but now her body and mind let her down. Walking becomes difficult, she hears badly and beginning dementia has been diagnosed. She cannot go out of her house anymore. She asks her doctor for euthanasia but she refuses. Fien decides to stop eating and drinking, because 'then I will die on my own.'

'For aged people or people in delicate condition stopping with eating and drinking is a reliable option for dying in dignity', says coordinator
Herman Speerstra of the Advice center of the NVVE. 'But you will not die ''automatically''. A painstaking preparation and support is needed for a good course of the process. A right medical and palliative care is needed to die in dignity. If stopping with eating and drinking is not the first choice, like with Fien, it is more difficult to go on with it. Eating and drinking, like breathing are life's first needs. If the need for eating and drinking is minimal, the process will pass easier.'
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Fien stops eating and drinking but takes the deserts the district nurse gives her. After two weeks she refuses all food. Her nephew and niece, her informal care takers, ask the district nurse not to give her food anymore, so Fien will not be tempted. But the nurse finds this is not good care. Nephew and niece find they are worked against.

‘Working against is a heavy word’, says Speerstra. ‘I think it is ignorance. Giving food is such a basic thing to caretakers. It is important the doctor explains to the district nurse and the informal care what can be expected, and about the course of the process. A combined care plan should be made. I think this has not been done. Because Fien ate deserts the dying process did not set going. On three deserts a day, often with a lot of sugar and protein, aged people can go on living. And if one drinks more than 50 mg a day, needed for mouth care, the dying process can go on for day’s even weeks.’

The doctor gives instructions to the nurse not to give food to Fien.
Her health is getting worse, she loses weight. Her dementia grows worse. She needs care three times a day now. During the evening and the night Fien is alone. One morning the niece finds her laying on the ground. Because the doctor could not come the nurse wanted to call 112. The nephew prevents this. Fien wanted to die at home, not going to hospital or nursing home.

Speerstra: ‘This happened although Fien had a prohibitive regulation which she had discussed with her doctor. Such a document is important. You register which therapies and care you do not want (any more) – see framework. Caretakers are obliged to follow up this prohibitive regulation and take decisions in line with the wishes of the patient. The story of Fien shows this does not happen always.’

Fien’s health deteriorates. She becomes bedridden and hallucinates. She gets 24-hours care. Often she is very agitated, she loses her dignity and experiences her suffering. The nephew asks the doctor if she can give her palliative sedation, so Fien can die in peace. The answer is no. Fien does not have pain, so she would not suffer. Only after six weeks Fien becomes palliative sedated. One and a half day later Fien dies.

‘Palliative sedation is possible at an earlier stage’ knows Speerstra. ‘Doctors are not always knowledgeable about this. Sedation is a reversible process, it could have been done during the night. In any case this had lightened her suffering. The dying process of Fien has taken too much time. In the mean older people die within two weeks when they stop eating an drinking deliberately. But, like earlier has been said, a painstaking preparation and support is needed.’