

Relevant

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Summaries by Corry den Ouden-Smit

Trying out laying in a coffin, to tempt talking about death.

'WHAT STARTED JOLLY ENDED UP SERIOUSLY'

How to talk with youngsters about death? This query was put on the music festival Lowlands. This festival attracts about 60.000 visitors, mostly young, and always there is room for science.

Martien Versteegh

Bucketlist-wishes

In The Deathly corner, the name of this festival part, people can fill up their wishes on the 'Before I Die Wall' of bureau Morbidee, the so called Bucket-list wishes. Questions about the music to be played on your funeral, about what to be done with your digital legacy.

Witkamp: 'Many a person had never thought about that. Remarkable since so many people use social media, and the number is growing, just like the number of digital apparatuses. What is happening with your account? And the pictures on your phone? Are they accessible to others? These and other questions were put to 540 persons who took part in this investigation.

Virtual clone

It happens frequently a person, long ago deceased, passes by on Facebook or LinkedIn. Faced up with this can be awful for the next of kin. Witkamp sees there is hardly anything sorted out in this field. We, as researchers on care and decision making at life's end, were curious to know if this is a topic lives under Lowland visitors.'

Although these people are not representative for the average Dutchman – their mean age is 28 and their education is high school and above – the reactions and answers were interesting.

Van der Smissen: 'One of the questions is if one should wish to live on as avatar or chatbot (an automated conversation partner). In the near future it will be possible to talk with a chatbot of a person who does not live anymore. This question raised interest. The science-fiction-Netflix series Black Mirror came up, in which there is talk of a clone of a deceased one, a living doll. But most of them did not like the idea.'

Van der Smissen himself is curious. What are the possibilities? 'I am curious if you really recognize your beloved one. And if it gives comfort.' Both researchers are definitively these possibilities will come. Van der Smissen: 'Twenty years ago hardly anyone wished – when asked about it- to possess a mobile telephone and be always reachable. Nowadays nearly everyone has a mobile. Often we do not know what we want, till it is there.' Witkamp adds: 'but the researcher in me is curious. What can this mean to the mourning process? If a child loses a parent, can an avatar play a role in his life?'

Music in a coffin

Most special was the coffin on the science field. People could lay in the coffin and experience what that means. Their preferred music was played and friends could say a word. Often people grew still. Sometimes a jolly atmosphere brook out, but mostly people became convinced of the possibility of death. Witkamp: 'We got many positive reactions. People realized it is a good idea to say to your beloved ones what they mean to you, and not to wait with it.

We also have heard youngster have talked to their parents about this topic. So you see, we can talk with people about death, even with youngsters on a festival. People look up extremes. With a glass beer in their hand talking about death.'

Opinion

IN DEMENTIA RREGULATE WELL

September 11, the court of justice The Hague sentenced in the first euthanasia case since the euthanasia law came into operation in 2002. A specialist geriatrics was charged with murder since she should have acted carelessly in giving euthanasia to a person in an advanced stage of dementia on basis of her living will. Differently to all other controlling instances the court found the physician had acted correctly. It is high time to make euthanasia better possible in advanced dementia.

Hans van Dam

The law permits euthanasia on the basis of a written living will. If a person is not able anymore to ask for euthanasia a written living will passes for an oral request. The execution is bound to demands of carefulness, laid down by law, but as a matter of course as far as they apply. Like the demand a person should affirm his request. That would be odd, for a living will is for these circumstances in which a person cannot look over his situation and cannot judge adequate over himself. Complying with a request would then be bound to an inaccessible demand, and precisely that the legislator wanted to prevent.

Contrary effect

Trying a conversation about life's end can be good, but also it can have a contrary effect: if someone does not understand, all kinds of contrary effects can occur. That assessment made the physician against whom charges were made. The Regional euthanasia review committees (RERC), the Inspection and the Public Prosecutor sadly did not catch sight of this aspect of dementia, with all its consequences.

Another error was made by these instances, to condemn giving a sleeping pill in the patient's coffee beforehand. The physician had done this to prevent anticipated disruption, like resisting when giving euthanasia. This would have been awful to the patient and to the nearest. The rules of the law had not been infringed since the law does not forbid this. A carefully executed euthanasia aims at dignity, and exactly that was achieved by giving a sleeping pill. In the meantime the RERC has changed her policy. Luckily the court has rectified the errors made by the controlling committees. With this the way lies open to the following step: how to regulate euthanasia in dementia in a good way. Here are some fundamental thoughts that could be used as starting point.



Peter de Wit

(About the cartoon: Doctor: I'd like to start with a sedative in the coffee. Daughter: mama always takes decaf otherwise she cannot sleep)

- Appreciation of the good right one has to set limits in illnesses, which, like dementia, bring increasingly a deterioration of personality.
- The heart of the matter in dementia is losing your spirit. The person diminishes slowly but definitively into a Nobody. The personality fades away. This is biology, the harsh reality. Denying this is possible, but it is senseless and even a deception.
- An inevitable consequence is the thinking brain get lost so expressions and reactions stem from the emotional brain. That emotional brain is in its turn dependable from outward stimuli or stimuli from the body.
- Utterances of this person often are not in keeping with the person he was. It is one's good right to lay down he does not want to be bound to these utterances but to his laid down wish.
- 'Friendly' dementia is, unless to those who find this acceptable, no reason to refuse euthanasia. For those who do not want to go all the way of dementia the breaking point is the illness itself. To make it concrete: the state of dementia. Searching endlessly for your keys, caressing the nurse you mistook for your deceased wife? It is conceivable you lay down this in time.
- Everyone has the freedom to draw his own limit. A number of people want to go before the inability to express their will sets in. This sounds good, but reality is different, because many fade away without knowing it. The living will serves as safety net for those who willy-nilly get lost in inability to express their will. Other people want to go when they do not know anymore who they are. They find an earlier state untimely.
- A careful living will is of the utmost importance. Talking it over with the general practitioner is necessary and it would be good if he shouldered the responsibility for the lucidity of the

text by also putting his signature under the text with the words 'seen' and by making appointments on regular base.

- In the living will the physician can be authorized not to ask anymore and to give a sedative beforehand when the moment is there.
- Tie role of a dear person must get a place in the procedure. When you are lost in your thinking only a dear person can say which moment you had in mind. A clause of that kind would be good.
- In extension of this lies assisted suicide in which a nearest will assist. But then the relevant law should be adapted to this specific situation.

These fundamental thoughts are meant to safeguard the freedom from life and death: everyone has the good right to go on till the end in dementia, and everyone has the same good right not to go on, and to draw limits. Every physician has the right to give help in dying, if asked for.

In the column Opinion authors contribute to the discussion on euthanasia and the end of life. They do this private. Hans van Dam is teacher and consultant bran damage, specialized male nurse and publicist.

Liza Jansen about dementia and the euthanasia of her father:

'HE DEFINITELY DID NOT WANT TO BE TOO LATE'

March 2019 architect and widower Laurent Jansen (65) received the diagnosis dementia. He and his four children had seen this coming. Shortly thereafter he said loud and clear he wanted euthanasia. Thanks to his drive and openness - and of his children, caretakers and NVVE- his wish could be fulfilled half a year later. September 4 he died, on his favorite place in his house he designed himself.

Teus Lebbing

Two and a half weeks later daughter Liza (29) looks back in resignation. 'This was exactly how he had wished it. My brother, two sisters and I are resigned to it and are relieved. If we could not have rounded this off so nicely, for sure I was sitting here differently.'

'Last months have been enervating, we did not know if it would succeed. The walk to the diagnosis dementia had been long, because this got entangled with his brain infarction in 2008, in which forgetfulness is one of the symptoms. Therefore we could not place his sudden anger and loss of flexibility. This was not the person we knew.'

Great fear

Thanks to a fragment of a dementia dairy Liza was listening to the penny dropped. 'It was about the character change of a young person with dementia. I thought 'this person is my father.' After a family consideration followed contact with his physician. 'He confirmed our assumption and volunteered to test him. Father denied at first but later on we knew why. Both his parents had suffered Alzheimer. It was his great fear to end up like them.'

The diagnosis, in March this year, was the turning point. 'Since then we could talk about it with my father.' He told us he could not read well, how much he forgot, how difficult apparatuses were to

him. 'He disciplined himself to a tight schedule. That was his hold.' At first he seemed to manage but later on it became more and more difficult. 'In panic he called my sister saying: "I do not want to go through this. I want euthanasia".'

Hurry

For the children Jansen this was the moment to start talking with him about life's end. 'Our mother has died early from cancer so we are used to talk about death.' Father was consistent in his euthanasia wish so we decided to start the procedure. We were told not to wait too long, to hurry, since deterioration in dementia goes fast. And also that the NVVE could be of help in this.'

Liza was told the same thing by the Base for Life's end and Dementia of the NVVE (see cadre). 'I was told to look at the documentary "Before it is too late" and that spoke volumes.' After a consultation by phone a home visit was made by a consultant of the Base. She explained how you make a euthanasia request. 'How concrete it must be, how do you see this? Of course this is very personal.' Also the consultant showed us the way to go, the complexity of the process and no guarantee in succeeding. 'Especially the capability to express one's will is a tricky point. A bladder infection can deteriorate one's mind. We children felt the urgency, we were willing to do everything, but we did not expect anything.'

Liza's father took this message at heart. 'He did not want to be too late. Since that time his life was circling around euthanasia. The family gathered around the table, together with a friend, to make the expression of his will. It took four sessions, because it is hard to tell all the things you do not want to take place. My father made a long list with concrete points varying from "I want euthanasia if I cannot see the difference between night and day" to "I want euthanasia if I am not able to take care of myself anymore". Especially the last remark was important to him.'

The general practitioner did not want to go on with the euthanasia, so we sought contact, in July with the Life's end clinic (now renamed Assessment center Euthanasia). 'A very nice nurse and physician came to our home. We had a good conversation in which they explained what was going to happen and why. They saw my father was determined to receive euthanasia, and was able to express his will. After that they took over the route.'

'My father was very obsessive about the euthanasia and he called the nurse frequently. The nurse saw his condition deteriorated fast, and that he wanted euthanasia badly.' The Life's end clinic speeded up the route, taking care of all the requirements of carefulness. Talks followed, also alone with my father, and with a SCEN-physician, tests were done, and every time my father was consistent in his will.

Relieve

'Though, when in August the decision was made and the date September 4 was determined, it was hard to swallow. So fast! But it was also relieve. At once all insecurity falls down and you can arrange everything: with each other, with your work and your family.

The last weeks his four children came to live with their father. The day before his passing away the whole family including the in laws and grandchildren, went with him to the zoo. As a farewell. 'That was the only thing he really wanted before passing away. He has enjoyed that tremendously, knowing everything was arranged.'

Also the morning of the euthanasia happened peacefully. 'He started as usual, with his fixed ritual: switching on the washing machine, breakfast and douching. Till the last minute he could do what he always was able to do. Then he set down in his favorite chair, where he passed away peacefully.' So Liza's father has had the direction over his life till the end, like he always has had. Liza ends up: 'That this could happen, makes it easier for us. But you have to act boldly and stay open for it. And

surround yourself with people who know the ropes, take you seriously and want to assist. And who dare to catch on, if necessary.'

PEOPLE AND ANIMALS

At the NVVE work around 140 volunteers. Hans van Amstel-Jonker en Jaap van Riemsdijk are two volunteers who tell in turn about their experiences. This time: Jaap van Riemsdijk

A man in front of me is sobbing. I ask: 'Can I help you?' It is the first Saturday in October which the NVVE has proclaimed Day of the Declaration of one's Will. All over the country one can get information on this subject from the NVVE.

His wife tells recently they have let their dog Boris pass away, and this gathering reminds her husband of this event. I think the choice at life's end of a dog may get attention in this week in which falls Pet's day, so I start a conversation. The death of a beloved animal may arouse more emotions than the passing away of a human. Boris was found in the woods, tied up to a tree. After talks with the police they decided to keep the dog. It was a pug dog and soon they found out what was wrong. His pug-nose made he could not breath well. Sophie and Ferdinand spend a lot of money to operations but Boris kept breathlessness. The veterinary insisted to let him go, to end his suffering. The decision to end Boris life was difficult, especially since they believed the Creator goes over life and death. But as the suffering of Boris became harrowing they asked themselves why it would be necessary to suffer so badly. And after some sleepless nights they decided to let him pass away. After that the thought came up: would they want to go on tilt the end? To suffer unbearably waiting for a natural death? The announcement of the NVVE in the paper won them over. The lecture made many things clear to the couple, Sophie was determined, Ferdinand was hesitating. 'If you have a written will, can you renounce that?' I answered 'Absolutely, just tear it down, and also the copies you gave to your doctor and nearest.'

'I see a parallel with the legislation concerning animals and humans. Our euthanasia law has brought us a lot, but some people stay behind. In 2020 a new bill will be brought to Parliament by Pia Dijkstra concerning those who find their life has been fulfilled. According to Gandhi our civilization can be judged by the way we mix with animals. Isn't it a way of civilization elderly may die when they find it timely?'

Politics want more clarity

GENERL PRACTITIONER SHOULD MAKE CLEAR IF HE WANTS TO GIVE EUTHANASIA

Every Dutchman should know if his doctor is willing to give euthanasia or not, before he has to do with this issue. Minister Hugo de Jonge of the Department of Health should stimulate this. But the doctors, are they waiting for it?

Marleen Peters

Liberal party VVD, seconded by D66 proposed a motion concerning life's end. They want clarity in the issue if a doctor is willing to give euthanasia. Since euthanasia is not a right, and a patient can come in a situation he rather would have prevented, the doctor should speak plainly. Euthanasia is a tricky issue. If it is not talked about timely, it can be too late.

A lot of 'fog'

The VVD and D66 find the practice can be better, now there is a lot of fog around this issue. According to an investigation of the Humanistic League only 6 percent of the general practitioners indicate on their website how they think about euthanasia.

The liberals find doctors have to state on their website if they are willing or not, to give euthanasia, and should start talking about euthanasia with their patients. One of them says: 'The Assessment center Euthanasia has developed models that can be the base for starting a discussion on the topic of voluntary ending one's life.' What do general practitioners and the NVVE find from this view?

General practitioners.

Asked about this some of them spoke out and said they understood the appeal, but it is too simple to state you can tell on your website yes or no. Euthanasia is so tricky. Every case is different and if I state I give euthanasia patients think they can get euthanasia, and they become frustrated if they do not get it because they do not fit into the picture. If a euthanasia request is not relevant you do not talk about it. And when it becomes topical you have to talk it over anew. It is not to politics to decide. The possibility exists if doctors have to choose between yes or no on the website many will state no, just to be safe.

National society of General Practitioners

'We do understand the request of politics to give clarity. It looks simple show your hand on your website and the patient knows what he can expect. But if one thing is clear you cannot catch the issue euthanasia with a yes/no sticker.

The euthanasia request should be sensed by the doctor, and that depends from the exact request. Every patient, every situation, every illness process, every request, every life's end is different. A yes/no sticker on the website goes beyond this nuance and makes a discussion about euthanasia even more difficult.

When a yes-sticker is on the website it is more difficult for a patient to accept the no of the doctor. The doctor should talk with the patient about life's end, what is important to the patient, what are the possibilities. The doctor wants to know what the wishes of the patient are, will give the possibilities and help to find the best route together.'

NVVE

'We don't believe in obliging physicians to state they are willing to give euthanasia. We think physicians, who first say "yes provided that", or "no, unless" will shrink from giving euthanasia. Besides physicians who are willing, do not want to be known as "euthanasia doctor" from fear they raise the wrong expectations. Doubtless this explains the reservation in the investigation of the Humanistic League.

The NVVE does not support the idea of a black book of unwilling physicians, but sees rather a good discussion between doctor and patient. If physicians are principally against giving euthanasia, they should have the plight to refer to physicians who are willing to enter into the euthanasia talk.'

LIFE'S END CLINIC WILL BE RENAMED ASSESSMENT CENTER EUTHANASIA

Since September 4 the new name of the Life's end clinic is 'Assessment Center Euthanasia'. With the name change the organization wants to give more clarity to what they do, and to make an end to the confusion.

Marleen Peters

March 2012 the Life's end clinic opened their doors. The aim was to help patients who got no to their request by their own doctor but fulfilled the requirements of carefulness.

'Soon it became clear people did want to die in their own home, and not in a clinic in The Hague', tells director Steven Pleiter. 'So there has never been a clinic and our business concerns not the questions around life's end, but we judge the euthanasia requests. We wanted to make an end this confusion.'

Is 'not it a pity a name, so well established disappears?'

'Indeed the name was well established. We took no risks. Already in 2014 we thought about it. We were bothered by this, the name did not cover the overtone. We chose to make our aims higher than in the beginning. Besides dealing with requests for help, we want to support the professional group even more. The new name corresponds with that.'

In the beginning there was talk about helping people, who had collected medicines themselves, to be assisted to die in the clinic. The new name suggests this plan will not be continued.

'At that time we have chosen deliberately to start with euthanasia, there was a great need to that. And from the beginning we have stated to work within the cadres of the law. Collecting medicines is not illegal, but with helping we would not stay within these cadres.'

The number of requests have stabilized last years. Does this trend persevere in 2019?

In 2017 and 2018 we got 200 till 210 requests a month. This year around 250 a month, a growth of 15 percent. That is quite an increase. The expectation is to get this year well over 3000 requests for help and about 850 or 900 euthanasia requests will be honored.'

Has this growth of the number of requests to do with the increasing attention for euthanasia of the Public Prosecutor?

'Firstly I am a supporter of the euthanasia law. In this is stated a controlling committee has to make mention of unartful actions and send this to the Public Prosecutor. But if you have done your utmost best to help someone in a vulnerable state and you are charged with murder, like a geriatric physician lately, the balance is lost, in my opinion. We see, by the conversations with physicians who refer patients to us, the fright sits deep. The insecurity is great. Also physicians, experienced in giving euthanasia, come to us for guidance. They do not feel secure anymore.'

Till relief of many the case against the geriatric physician has been dismissed.

'In this case probably a "notice of appeal in interest of the law" will follow. That means the High Council could give her opinion about the questions this case evokes, without consequences to the physician. This way to come to a sentence – notice of appeal in interest of the law- has to be picked up further. I will make an effort to that.'

Since 2012 came in 12.000 requests for help at the Assessment center Euthanasia. 30 percent of them have been honored. Isn't that few?

'No, I can explain that. 16 till 17 of the requests do not fulfill the requirements of carefulness, The same percentage does not has an authorization to look into their medical dossier, and 10 till 15 percent die before we could have given euthanasia. In about 5 percent of the requests the personal physician gives the euthanasia at the long run, with or without our guidance. So 30 percent is not few.'

The Assessment center Euthanasia has been established as a 'temporarily solution'. After some time it would dissolve itself, was the assumption. Is that still the case?

'The idea after the foundation was to start a movement among doctors. If the problem was laid open we hoped more doctors, supported by their organization, would handle the euthanasia requests. And that doctors, who refused to give euthanasia, could refer to a network of doctors who were willing to do this. Seen this way it was a temporarily solution. Through the years we saw a need for a specialized organ that supported doctors in more complex cases. Nowadays we have a network of 140 doctors and nurses. Apart from giving euthanasia, we give information and advice to doctors, and concrete support and refreshing courses. Especially the more complex requests, like in psychiatry or dementia, the Assessment center Euthanasia is a safety net. In this we have unique knowledge. There is no talk of closing anymore.'