

Relevant

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Summaries by Corry den Ouden-Smit

Wishes of life's end and dementia

'TALK ABOUT IT BEFORE IT IS TOO LATE'

Talking about life's end is important, but not easy. Especially if someone is demented. The moment is important, emphasizes Saskia Danen to family and caretakers. In the care for her father she reaped the fruits.

Saskia Danen is advisor in dementing care.

Teus Lebbing

As head of a nursery home Saskia has seen many despairing children who had to take decisions for a just deceased mother or father and asked themselves had father or mother wanted this, and in this way? 'I was startled by their ignorance. Important is to know their wishes, which can differ from one to the other. Make appointments and document it, not only for the last days but also for the last phase of their life. Palliative care is linked to cancer. Since dementia is not curable it is a deadly disease so life's end care starts when the diagnosis dementia is made.'

No misunderstandings

Danen has worked in geriatrics and psychogeriatrics as a nurse and later as manager. Now she is consultant in dementia care –also to the NVVE- about Advanced Care Planning (ACP); a structured method of the palliative care which is usable in dementia. Anticipating the moment the client cannot take his own decisions anymore he talks his wishes over with his doctor, nearest and caretakers. 'But', emphasizes Saskia Danen, 'ACP is more than a living will, it is about communication on the consequences of the agreements.' Who has to take the initiative for the conversation? 'The caretakers are together responsible, the doctor medical, the case manager and home caretakers moral. Together with the family the right moment should be chosen to tackle this issue. Dementia has many faces, and there are moments of brightness and of absent-mindedness. And the wishes can change. So it is important to check regularly.'

Crystal clear

Saskia Danen has experience with her father, who has vascular dementia and lives in a nursing home. He has lucid moments and in these moments he enjoys looking TV and drinking coffee. He also has bad moments with pain and suffering, saying he wants to die. 'I could not see him suffering so badly and have said he could get euthanasia. But he does not want that. "I also have my good days." In an earlier conversation with his wife and caretaker, he had said crystal clear, he does not want euthanasia. But neither does he want curative therapy or interventions, only palliative care. And if he cannot express his will anymore my mother has to decide for him. It is all written down.'

Knotty

The question is when is a person not capable to express his will? This is a knotty point. 'The KNMG provides guidelines, but it stays tricky. I have seen a mother with dementia who wanted to stay at home but she neglected herself. The daughter went along, knowing how much her mother valued her independence. It took many conversations but her mother could stay at home till her death.'

In all stadia it is important to stay alert, says Danen. Check the wishes, look closely, non-verbal reactions say a lot. 'Offering resistance to pills as far as retching speaks volumes. Or refusing to eat. Look at it and take these signals seriously.'

TIPS FOR TALKS WITH DEMENTED PEOPLE ABOUT LIFE'S END

The conversation about life's end with a demented person, how do you do that? Saskia Danen gives the following tips:

- Do not postpone the talk, look for the right moment and if heavy emotions come up, take a break.
- Come with a clear introduction, explain the purpose of the talk.
- Give an opening to talk about it. So they know they are welcome to talk about it with you, another time. It works, also with demented people.
- What may help is to talk about other persons and later on focusing on the person himself. That is less threatening.
- In case of denial, accept this and come back another time. ® Do you think the person is afraid to record the agreements? Explain he can always change it.
- Develop your own vision on dying. What is important to you? What is your borderline? If you find it difficult to talk about life's end, it will be even more difficult to have a conversation with someone about this topic.
- Specific for caretakers; the client and his nearest go through an important and difficult period. That can affect also you as caretaker.
- If euthanasia comes up as concrete subject? Pass it on to the doctor. He can give information, see if it is possible and assess if the person is capable to express his will.

Five die types

'Not everyone can talk about dying. Reports show people postpone talking about life's end. One report says there are five die types: the "pro-active ones" who want to have the direction and indicate that; the "trusting ones" who let go because you do not know what is going to happen; the "following ones" who do what the doctor says and are inclined to let be over treated; the "social ones" who are inclined to denial; the "rational ones" for whom death is taboo, you do not talk about it, not even at the end of life. When all this dawned on me I thought: there is a lot of work to do on information. For caretakers like me. And for the NVVE.'

The dissertation of Katja ten Cate shows:

PERSONAL IDEAS OF DOCTORS PLAY A ROLE IN LIFE'S END CARE

Doctors are often not aware which role there personal ideas plays in the care for their patients in life's end. To this conclusion came Katja ten Cate (33) after conversations with more than sixty doctors on behalf of her thesis Doctors and dying. Ten Cate is teacher medical ethics and philosophy of Health care at the Radboud University.

Marijke Hilhorst

What did strike you most in your research?

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'A Doctor told children their father was dying, while the father did not want to see his children. The doctor found you had to say goodbye. Another found you had to patch up a quarrel before dying; or the patient had to acquiesce to death; or euthanasia came not up for discussion because the patient had still conflicts; or being dependent of others was not a form of suffering. They found dependency and decay were part of life, and patients should learn to cope.'

What differed from your expectations?

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'What stroke me most was doctors had problems with the unnatural character of euthanasia, while the difference between euthanasia and stop with treatment is not that big. In fact you can ask yourself in which way dying is natural in The Netherlands, at present, because before nearly every decease decisions have to be made: therapy or no therapy. Secondly a natural death, is by doctors depicted as a better death, because of a - in my eyes- false romantic image of dying. The nature is often not beautiful, but cruel.'

Personal views, do they hamper a euthanasia request often?

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'Hardly anyone looks exclusively to the legal requirements. Many a doctor does not know the bandwidth of the law, and there is room for interpretation. A tricky point is unbearable suffering. A doctor may think the suffering is not unbearable if the person walks around. In my eyes the patient may determine what unbearable is, but the doctor must be able to feel the suffering. And the patient cannot say I want it, so you have to do it. But if personal views, having nothing to do with the legal requirements or its interpretation, predominate I am critical.'

What if views on a good dying process between doctor and patient do not match?

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'A doctor should not start in a judging manner a conversation with his patient about quality of life, suffering, decay, dependency and dying. He should bring his view but have an open mind to the view of the patient and willing to learn from him. The patient should start the conversations at an early stage and, if possible, with an open mind for the view of the doctor. But the doctor should make himself sub servable to the patient, for it concerns him. If there are too many differences in the conversation I would advise the patient to look for another doctor. '

What can be done with the results of your investigations in the medical world, for patients, politics and legislators?

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'I do an appeal to doctors for awakening and more reflection. I hope my conclusions may reach education. And I hope for a wide social debate for re-evaluation on the exclusive status of life ending actions (which presently can lead to prosecution contrary to regular medical action- ed.) From my point of view the moral differences stopping with lifesaving treatment on demand of the patient, are not that big to justify that status.'

Do you have experience with euthanasia?

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'I only have seen a refused euthanasia request. The death wish of my grandfather has not been taken seriously by his doctor. A clear example the view of the doctor is leading. By this experience I have seen the impact on the family and nearest by the acting of the doctor at life's end.'

Place in hospice gave artist the possibility to let go his life

'NOW FRANS COULD GO ON SOUL HOLIDAYS '

'Daily you should be able to step out life, which many people love so much.' This citation of Seneca has Frans Jan Peters taken to heart. Katrien de Zeeuw tells about the last weeks of her friend. 'Hospice IJsselOever gave Frans the possibility to let go his life in all peace.'

Martien Versteegh

Frans Jan Peters (73) was a born artist, says Katrien de Zeeuw (71) his friend and former spouse. They have two sons. 'He played the piano, song the opera, did cabaret. He liked people and was always in the centre of attention.

'The first brain haemorrhage came in 2010, and in 2017 Frans became half sided paralyzed by a third brain haemorrhage. He had to be taken in a nursing home. He suffered from shingles, the pain was heavy. He did not like the nursing home and wanted to spend his last time with me. So we looked for a place we could be together.'

The subject euthanasia had been brought up often, Frans did not want to live anymore when he could not talk anymore. In the nursery home euthanasia was not possible, but they arranged contact with the Life's end clinic. At last contact was made with hospice IJsselOever in Capelle aan den IJssel.

Strong body

The hospice takes people in terminal phase of life. You cannot stay longer than three months. Frans was deadbeat bodily and mentally, but he had a strong body so he could live longer than three months. Frans did not want that, absolutely not. After talks with the family doctor and caretakers the hospice agreed to take Frans in. The hospice had made the following conditions: Frans had to leave the hospice after three month, if he did not want euthanasia any more. And the whole process with the Life's end clinic had to be fulfilled. In the meantime the SCEN-physician had given the green light.

Very difficult

'Although Frans was certain about his euthanasia wish he found it very difficult to choose the moment. Every time he got worse, he found something to brighten his life. But after he got again shingles and suffered an epileptic insult it was enough. Simultaneously I had the same idea. There was no hope, no perspective and we had the conviction this was no life.'

Two occupants

The doctor of the Life's end clinic gave Frans January 15 euthanasia. Katrien and their sons Jeroen en Ernstjan were present. With respect they look back to the careful procedures. Frans was a special man, and in the hospice he was a beloved person. That Katrien was with him and also occupant of the room in the hospice was new for everyone. But it had been a nice process to all.

'The coordinator promised to make room for people like Frans, so they could say goodbye to life. This was for Frans a nice statement. Now could he go on soul holidays', as he said.'

Prof. dr. Jan van den Bout warns for 'mourning veils'

'MOURNING IS DIFFERENT FOR EVERYONE'

'If your loved one has died, you may not laugh. After one and a half year mourning you recover your balance. That are the views in coping with mourning, while it is a personal process, says professor doctor Jan van den Bout. He was the first professor coping with mourning, trains people and is now emeritus. 'Mourning is different for everybody. We should accept that.'

Teus Lebbing

About what good mourning is, even the scholars differ. How come? 'Sigmund Freud said mourning is "necessary hard working" and the American Elisabeth Kübler-Ross developed a widespread model with the various phases of mourning: from denial and anger till acceptance. But this counts for special groups, like those of Kübler-Ross in hospital. There are the next of kin who do not talk about it

and are functioning well. And where some people go on after several weeks, for others it takes years. Mourning has so many faces.'

You call the usual views mourning veils. Why?

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'Because they conceal the real, personal manner of mourning and make this problematic. If you do not fit into the normal pattern of mourning, doubt and feelings of guilt come on top of the pain of the loss. Then they ask themselves 'did I love him enough, or am I going too fast?' Those feelings can lead to depression and fear. And going with these complaints to caretakers, they can make the wrong diagnose. The mourning symptoms are veiled! Mourning is not a disorder, but the loss of a dearest can cause it.'

Since your thirstiest you started specialising in mourning. Did you see changes?

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'More and more attention is paid to the mourning process. The overturn came in the '90 years. Till that time one did not talk about mourning. I know that out of experience. My mother died when I was fourteen. My father knew she was terminal ill but the doctor had told him to conceal that for everyone, including my mother. When she had passed away nobody talked about her death. Six years later, when my father died, the same happened. It was the time spirit. The doctor could not express himself, nor my parents, nor the environment. It was awkwardness, surely with me.'

How is the situation at the moment?

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'One talks about it now. And all these personal stories tell the many different emotions and thoughts around the mourning process. This leads to better guidance by professionals, although death stays a difficult theme. But an open conversation about the feelings and thoughts, even if these are difficult and negative, relieves. It prevents the person stays wresting with things of himself, he does not understand. If always hurt when the ties with a beloved one are broken. Knowing that this is normal may lead to acceptance. This is mourning, and even after years those feelings of sorrow and grief may stay.'

In 2003 you and some colleagues of the Utrecht University did research on mourning after euthanasia. What was the result?

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'Usually family and friends of patients who had died after euthanasia had less symptoms of mourning than those after a natural death. That was surprising. But in euthanasia people get acquainted with death and can say farewell intentionally. Together with the guidance that goes with euthanasia, it helps coping with loss. But there is no guarantee. What if you do not agree with euthanasia? What if you cannot say goodbye? What if you have resentments against the person? Also after euthanasia applies: mourning is for everyone different.'