

Relevant

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Summaries by Corry den Ouden-Smit**

Marc Cosyns about law and practice in Belgium

'NOTHING MORE NATURALLY AS DYING'

The Belgian physician Marc Cosyns (54) stands in the frontline when euthanasia is at stake. His intention is to open up the discussion about the dying process, to show this is a very naturally process. He even performs on stage about this theme.

By Fred Verbakel

Cosyns compares the situation in the Netherlands with Belgium. 'Dying is the end of a continuum we call life'. The Netherlands acquired her euthanasia law thanks to more than thirty years discussion and juridical procedures. Before the euthanasia law in Belgium became effective we followed the more natural way of palliative sedation. Cosyns is acquainted with the situation in the Netherlands where he has followed schooling for abortion physician.

Great pressure

Euthanasia legislation would have been unthinkable without the French-speaking Belgians. They are mainly liberal and they are the advocates for euthanasia. Flemish Belgians are mainly Catholic and against euthanasia. In 2002 the Belgian government came up with legislation. At that time Guy Verhofstadt, a liberal, was premier. Shortly after, euthanasia has been regulated by law. The conditions correspond with the Dutch conditions. A national committee (the Dutch have regional committees) checks if the physician has acted correctly. Prosecution can follow. This is a burden to the physician and his patient. Euthanasia is a great taboo.

Up till now Cosyns has not been prosecuted 'although questions have been asked. But they have accepted my responses'.

To Cosyns it does not seem right that euthanasia resorts under criminal law, and palliative sedation or guidance with withering (stopping with eating and drinking) not. He works for another law which broadens the right to a dignified death. 'The patient should decide after consultation with the physician and the family. The physician has also the right of his opinion. If he can't go along he has the duty to refer, that's my view. I am for equality of decisions and treatments concerning life's end'.

Nazi-physician

Cosyns is part-time physician and teaches Ethics at the Gent University. He also makes documentaries about terminal care. He followed theatre workshops to expand his view on important issues. 'The power a physician has over patients is one of the most fascinating themes in ethics. One has to handle this power wisely'. In a theatre play 'The judge and the hangman' Cosyns plays a Nazi-physician who kills sever handicapped persons and mental patients, but comes after the war into moral conflict when his sever handicapped friend asks for euthanasia. 'Such a role brings me to the heart of the matter'.

From the beginning of his medical practice Cosyns had talks with patients about life's end and after a while he found himself at the Patient's Association, and the Organization Right to Die in Dignity. 'I saw my patients struggle with the vision of a painful life's end for themselves and their dearest. You can keep to the law or you can listen to their sighs.'

I have helped patients even though that was not allowed. As physician I wanted to change the conduct in which medical science is being practised.’
Cosyns will not be labelled as euthanasia physician. He will help people in distress, who are not his patients, with listening and talking. ‘But I will not help them directly. I will refer them to a colleague or a *LEIF*-physician, comparable with SCEN in the Netherlands’. (Leif: Life’s End Information. SCEN: Support and Consultation for Euthanasia in the Netherlands)

Paternalism

The organization Recht op Waardig Sterven (Right to Die in Dignity) with 6000 members the little sister of the NVVE, is working hard ‘to stop the therapeutic stubbornness’. Physicians tend to go on with treatment even when the situation is hopeless. ‘In ninety percent of the cases the word of the physician was law. This paternalism is changing. I try to get to know what the patient really wants. Is this his decision? Was there any pressure from outside? The patient has to demonstrate me his death wish is lasting. He has to know there is no way back.’

Cosyns differentiates between groups of patients. In cases of cancer he finds the implementation of euthanasia easier than with psychiatric patients. In cancer the deadline is predictable. And the patient can have the choice: treatment or no treatment, and how far to go with therapy. With psychiatric patients that’s different. A physician can help with medicines but the prognosis of many psychiatric illnesses is poor after ten or twenty years. I find it hard, if not impossible to implement euthanasia when a young person who knows his long-term prognosis is poor, asks for euthanasia. In Belgium psychiatrist are as averse of euthanasia as in the Netherlands.

If someone comes to me, who suffers say thirty years from a psychiatric illness, and most of the time is admitted to a clinic ... and if the periods he feels better become shorter and shorter, in that case I could say yes. One has to admit that some patients can’t be cured, can’t be relieved. Most psychiatrist would refuse, scared to be prosecuted. They even say they won’t bring their profession in discredit.

Cosyns does not have problems with the elderly people who have completed their life. ‘It asks for empathy to feel and to know what it means to those who always have been independent to have to go to an old people’s home. It is like emigrating: to another place, without your mate, without knowing exactly where you go and how long it will last. If they really desire euthanasia, I will help them so they don’t have to jump in front of the train. A perfect healthy person who says ‘it has been enough, my life is fulfilled’ will not get euthanasia, neither in Belgium. But that question has not been asked.’

In personal contacts Cosyns does not set value on a written document, he sees the advantages, though. ‘One writes something down, talks about it with his dearest and with the physician. It shows it’s the patients will and it’s well considered. And it prevents problems afterwards with family and justice’. Cosyns tries to motivate physicians in training to make euthanasia a discussion point. ‘A formulary provided by the organization Recht op Waardig Leven (Right to Live in Dignity), like the NVVE, will also help. It makes people assertive so they will go to their physician saying ‘I like to have a chat with you’.

Concern

‘The process of terminal care preceding the euthanasia I find very emotionally. It requires quite a lot from you. The patient has the right to concern and attention. The act itself I find not burdensome. When it is done, it’s done. Otherwise you will go to pieces. And of course I stay in contact with the next of kin’. Asked about his preferences about him giving an injection or the patient taking a deadly dose Cosyns answers ‘In principle I let the patient decide. But if the patient takes the dose it is clear to all persons being involved and they won’t have to feel guilty. And in case of prosecution I can say it is a case of assisted suicide’.

Hugo Claus

Cosyns himself does not feel dementia is unworthy living, but if people are motivated and don't want to go on, he respects that and is willing to help with euthanasia. The death of Hugo Claus illustrates that. In that aspect we are ahead of the Netherlands.

In Italy the death of coma patient Eluana Englaro caused much commotion. The Roman-Catholic church raised an outcry, just like in the case of Hugo Claus. In Belgium it came from cardinal Danneels and in Italy from the Vatican, supported by premier Berlusconi. Cosyns is not dissatisfied with it. 'The commotion around Claus and Englaro has made euthanasia discussable. Danneels and the Vatican led to a contrarily effect. In both cases nothing wrong had been done, according to Belgian law. For patients in coma who have made a living will, euthanasia is possible. The reaction of the Catholic Church and other adversaries made more Belgians wonder: what do I want with the end of my life? Now they know they have a choice.'

A daughter about her father's dementia and euthanasia

IT CAN BE DONE IN THIS WAY!

January 2009 Maks van der Mast died, nearly 79. He suffered from Alzheimer and was allowed euthanasia. His daughter likes to tell about it. 'Normally you only hear the bad experiences.'

By Anja Krabben

A picture, taken in 2007, shows a laughing greying man. The diagnosis Alzheimer had been made a year before, but the disease had not come yet to a progressed stage with tarnish, a stage he did not want to live in. A year later his death wish became more urgent. In 1997 Maks van der Mast had made a living will and had talked about it with his physician. He had seen the process of dementia with his mother and sister and did not want to die in this way. He was an active person. After his working life he started hobbies, he became a silversmith. He became active in society as well. He liked discussions, had an open ear for new insights. He was brought up Gereformeerd (a protestant denomination) and had raised his children in this religion. Later on he let go his belief but the day before his death he said 'you never know'. Though, he did not expect anything.

In 2006, before the diagnosis Alzheimer was made he did already suspect something was wrong. He did forget a lot and could not understand what was being said. After a visit to the memory clinic the diagnosis was made.

Controller

After a while he thought about euthanasia as a possibility. His discussion partner, apart from his wife, was his daughter Inge. She was the one who would organise his interests around euthanasia. Van der Mast might forget his way home, he never forgot that Inge was the one he could count on in matters of euthanasia. His situation aggravated after a cataract operation in 2008. A melanoma was discovered and one eye had to be removed. He could not see in depth anymore and had to quit his hobby welding silver. He lost interest in life since there was no perspective anymore.

'The physician, a general practitioner, was positive about the euthanasia request. He came to our home and explained explicitly the euthanasia. He was going to consult a SCEN-physician –a requirement by law. He explained to us in which way euthanasia can be performed. He advocated the intravenous injection 'because that is the best and the most clear'. He also suggested to my father to have a talk with his brothers and sisters, to tell them why he had chosen for euthanasia. It was difficult for my father to do, but after all it has been very important that those talks had been taken place'.

Too early

The encounter with the SCEN-physician was emotionally. My father told him in tears that he could not weld anymore and how he did suffer from that. Apart from that he was not able to have conversations or discussions, which he enjoyed so much. The SCEN-arts said to us that it was clear to him: this was futureless suffering.

The way to euthanasia was free. When? What would be the right moment? That is very difficult. Not too early. But if you should wait too long it could be too late. You should still be able to express your will. In September 2008 the parents of Inge had visited the memory clinic. 'Until now my father had participated in trials with medicaments and therapies. But he did not feel well taking this medicaments and he wanted to stop.

"That's fine" the specialist replied "but then you don't have to come back anymore. I will write a letter to your physician that you are treated out". To our consternation the specialist had written the physician that mister Van der Mast would not receive treatment anymore and that euthanasia did not come up for discussion. My father had told the memory clinic that he had a living will, but they did not give any notice to that'.

This unasked advice was a burden to the physician. Something else was at stake: he was going to retire in October. But he was going to talk to his successor. She agreed to the euthanasia, although she wanted some time to get acquainted with my parents. That was no problem, since we, the family, wanted also more time. Our former physician promised to be with us at the moment of euthanasia.

Nice day

First our physician wanted to talk to the specialist about his rejection of euthanasia. The specialist reconsidered his opinion and did not object anymore. 'When the last confirmation was there my father was very much relieved. Of course he was sad. It is hard to part from your beloved ones. My father decided to go on with the holidays around Christmas and to choose the date January 5, some days before his birthday. The last two weeks my father was very lucid. He made calls to his old friends to say goodbye. You are inclined to think: is it not too early, after all? But at the same time another thought came across: this way is the right way, it is a beautiful way!"

The last day was a nice frosty day with a clear blue sky and a radiant sun. Early that morning Inge went to the woods with her father. At twelve o'clock the physician came to insert the infusion needle. At three o'clock the brothers and sister arrived. At four o'clock the parents entered the bedroom. The children said goodbye one after the other. Only his wife and the physician stayed behind. First a soporific was given followed by a muscle relaxant. 'Fortunately it happened fast. After ten minutes he was dead.'

The inspection physician came after two hours. 'That was not a burden to us, since we were prepared'. Two months later we received the message that the controlling committee had given the green light. After my fathers dead we came together as family for a farewell session. That was good.

Rode Hoed

Half November 2008 Inge and her father had participated in a debating session about the self chosen end in beginning dementia, in the 'Rode Hoed'. 'My father had the intention to say something, but it did not work out'. From the stories told, and the documentary 'Voor ik het vergeet' (Before I forget) we learned that it often can go wrong –mostly by miscommunication. To other people Inge would like to say: do talk openly. Don't shield away from it. Of course it is not necessary, but it is very important for the peace of mind of all persons being involved. As for us we respect his choice and we can accept it'.

PSYCHIATRIC CASES JUDGED AS 'VERY ACCURATE'

In 2008 two psychiatrists reported having assisted in suicide to their chronic psychiatric patient. Psychiatrist Johan Huisman, member of the board of the NVVE, revealed the two cases in a symposium, in March 2009.

Both patients were women and aged between 60 and 70. Ever since 1994 one woman was suffering from depression and attempts to commit suicide. Many therapies were given among others electroshocks and light therapy. Since 2007 she has asked time and again for help with suicide. Her psychiatrist consulted a colleague who stated her suffering was substantial. A third psychiatrist was consulted and more electroshock therapy seemed useless, besides, the woman rejected it. His report stated 'Every perspective was lacking'.

At the end of 2007 her psychiatrist consulted an independent psychiatrist who ascertained 'Agony, no tranquillity of mind and melancholy'. He noticed that the woman could not get through the day without tranquilizing medication. The report goes on with 'The wish to die is not primarily the result of a vital depression but a resultant of her decision-making not to go on with this dreadful disease'. Also the second consultant, an independent physician as well as SCEN* physician came to the conclusion that the suffering endured by the woman had become unbearable. He communicated with her eight days before her termination of life. The controlling committee has judged the case: The path that has ended in assisted suicide had been long. The parties involved had proceeded extremely accurate and with due care. And the request was made voluntary and well-considered.

In the second case, a woman who was being treated psychiatrically since her fourteenth and whose suffering was characterized by the specialists as 'not treatable', the predicate 'extremely accurate and with due care' was given by the controlling committee -with the mentioning that in special cases a request for termination of life demands 'extra cautiousness'.

* SCEN Support and Consultation for Euthanasia in the Netherlands

Chairman Rob van der Heijden

'THE NVVE CAN'T BE MISSED IN THIS TIME'

'The NVVE has achieved a lot in its existence, especially in legal aspects. Now the focus is on new target groups, the demented people, the psychiatric patients and those whose life has been fulfilled'.

By Leo Enthoven

M.R. (Rob) van der Heijden was chosen chairman of the NVVE at the General Assembly, April 25, in succeeding Eugène Sutorius. He started his carrier in business later on he became active in politics. He has been mayor of Leens, and Zandvoort (until 2007). He has been active in the organization of elderly people, and in many non-profit projects. About the future of the NVVE Van der Heijden is clear: "We have to work diligently to reach our goal: to get the new issues accepted by society and politics. To give room to those who are so desperate they want to end their life. The important thing is the quality of life, the quality of dying and the quality of law." 'The NVVE has accomplished a lot already, but we have to go on with full strength focussing on the new target groups. In this era the NVVE can't be missed.'