General practitioner Van den Muijsenbergh about accompanying migrants in the process of dying.

For most non-western migrants euthanasia is not an option. They rather do not talk about the forthcoming death. General practitioner Maria van den Muijsenbergh tells about the differences in culture and a way to handle it. ‘I may say: “my medicines cannot help you anymore.”’

Inge Klijn

Thirty years Van den Muijsenbergh has worked as general practitioner in Nijmegen, in a practice with many immigrants. Lately she works as street doctor for homeless people and illegal persons. She gives training to general practitioners and does research in care for vulnerable people and immigrants at the expertise centre Pharos and the Radboud University Medical Centre Nijmegen.

Exception

Van den Muijsenbergh says ‘The Netherlands is a country with liberal opinions about euthanasia and a country where it is not taken for granted to be religious. Nearly all non-western migrants are religious. Not only Muslims but also orthodox–Christian Armenians and others coming from Africa. On the deathbed religion plays a major role. God or Allah decides when you have to go. Euthanasia is therefore wicked. The problem with migrants is they do not even want palliative sedation. For a Dutch doctor that can be difficult’
She tells about the deathbed of an Iraqi a patient. ‘A Muslim who wanted to stay lucid for Allah. I gave him a little morphine but that did not work. He stayed tight in the chest. It was very hard to look at for the children and for me. And very hard to do nothing. The man took it very well though. As doctor you have to ask yourself is it heavy for the patient or for me?’

Too confronting

Talking about the nearing end is tricky. Migrants find it too confronting and think it is God who decides. ‘You have to formulate very carefully. I use to say: “my medicines cannot help you anymore” or: “if you want to arrange things or want to see people you should do it now, when you are still strong. It is feasible you will become weaker.” The patient usually feels he is dying. You do not have to say that explicitly,’

Migrants find they have to look for recovering, that also has to do with their religion. ‘God has given you this body and you have to look after it’ is the thought behind. So they will not stop eating or drinking. ‘And that is difficult to a doctor’, says Maria van den Muijsenbergh. She tells about the deathbed of an Armenian patient.
FIVE POINTERS FOR DOCTORS

1. Most non-western migrants do not want euthanasia or palliative sedation, but always check with your individual patient if this is the case.
2. Recognize the role of the family. Ask the patient who he will take along to the talks with his doctor.
3. If the family does not want the patient to know he is incurably ill, take your time, ask about their worries and explain you will be careful in your formulation.
4. Explain in due time the effect of morphine and other sedative medication. Patients often refuse morphine because they think the doctor may kill them then.
5. Call in an imam (or clergyman) if you think a patient refuses pain control for religious reasons. That helps often, there is no religion that says you are not allowed to control pain.

‘He could not swallow his food and could hardly drink. His family wanted me to insert a drip. The patient wanted it also. For me it was hard, in my eyes inserting a drip in a dying person is not good care. But the role of the family is big.’

Interpreter telephone
Van den Muijsenbergh thinks she only can do her work properly if she can talk with the patient. Therefore she calls in the interpreter telephone in crucial talks with people who are not fluent in the Dutch language. ‘Quite a few older people take their children with them to translate, but I am not sure the right interpretation is given by them, because death is not a topic. I go along with their worries and tell them I have to call in the interpreter telephone. If I am convinced the patient does not want to talk about death, I leave the topic, but usually people do have questions.’

Dreary and lonely
The Dutch openness is relatively new. Nowadays 98% of the Dutch doctors think they should tell the patient he is incurably ill. But in the sixties most doctors found it wise not to tell. The patient would be harmed too much. From research in the seventies it became clear that those people became extremely lonely. From that time the conviction prevails the doctor should tell what is going on.

Maria van den Muijsenbergh hopes there will be a movement in the same direction of openness by migrants. She will start at Pharos a project for migrants about the last phase of life. ‘I want to take away the fear that you will die sooner if you talk about it. And explain how lonely you will feel if everybody, except you, knows that you are going to die. That it can be nice to share.’

Not only patients get information, also doctors and nursing people will get extra training in how to talk about death in a respectful way with patients from another culture.

Do-gooder and manager-director Robert Schurink new CEO NVVE

‘ALL LINES COME TOGETHER IN THIS FUNCTION’

With the arrival of Robert Schurink the NVVE has a CEO who is a do-gooder and a realist, a man of the barricades and a diplomat strategist, physician and manager-director, a man behind the stage and on the stage. A first acquaintance.

By Els Wiegant

His first encounter with euthanasia for Schurink (58) was when his terminal ill father died, in 1994, on a self-chosen moment helped by the general practitioner. ‘He was 63, declined visibly and suffered
intense pain. My mother and brothers, none of us had problems with it. As of that moment I thought: who can be against this? Who can deny my father to die so peacefully?"

Do-gooder
Schurink has been trained as doctor, but when his study was finished he had to compete with 2500 unemployed colleagues. ‘I had loved to be doctor, especially a paediatrician or gynaecologist, but it could not be.’ Instead he decided to go on with his political- social career. He became chairman of a youth organization and was president/ publisher of De Waarheid, a general daily. ‘Since my fourteenth I was a do-gooder. I come from a workers family, the Vietnam War was going on, and things were not evenly divided. I saw it as my duty to do my share.’ His experiences with campaigning taught him you have to have allies to attain your end. ‘In my early days I yelled: “Yankees go home!” and then? To realise things you have to hatch coalitions and link up the parliamentary to the extra parliamentary. I have brought that in practice as acting medical director of the Amsterdam Medical Centre and as independent entrepreneur in health care.’

Out of criminal law
His training as doctor, his experiences as manager and director of an association, his knowledge of the care and the euthanasia of his father all those things he can use in his new function at the NVVE, expects Schurink. ‘I have the feeling all lines come together.’

Schurink has made an analysis of 13 year euthanasia law and has drawn some lines and contours to shape his course for the future of the NVVE. First of all there should be support within the NVVE and a social basis. ‘I will talk with all sorts of parties.’

Euthanasia has to go out of criminal law. ‘In general doctors handle euthanasia carefully and professionally. What entitles us to say criminal law should apply?’ Schurink finds the right of self - determination of every individual should be the point of departure and not the medical suffering. ‘There are people who do not want to become hundred years, who have lived their lives and want to decide for themselves when to step out. The coming years there will be only more of them. Those people we leave out in the cold.’

A last will pill - like the NVVE advocates already for years - should definitively come, thinks Schurink, but it should be linked up with requirements. ‘The realist in me comes around the corner. Abuse of confidence is brought up for discussion: aunt says grandma wants to die, but aunt is also heiress. If you want this pill, maybe you should accept a route has to be gone through on which a third person, as for me a doctor, scrutinises the death wish. About the requirements which should be posed we have to go into discussion. I will contribute to the discussion with pleasure.’

19 year old Milou hangs herself after her general practitioner thwarted euthanasia
‘SHE WALKED STEADILY INTO THE ORCHARD, HER LITTLE GOATS BEHIND HER’

Three days before her twentieth birthday, on April 30, deadly ill Milou hangs herself in the orchard behind her parental home. The euthanasia her doctor in hospital would implement, has been thwarted by her general practitioner. That has made Milou so anxious that she took her life. A reconstruction.

By Marijke Hilhorst

In Zaamslag, Zeeland-Flanders mother Nicolle de Moor-Hertogh (51), father Diedrich (54) and Milou’s twin sister Janiek (20) talk about it. Behind the orchard of the house Milou has hanged herself with a silken shawl. ‘Sorrow is here always’ says mother Nicolle, and Janiek adds ‘we had arranged I would
sleep with her in the hospital the night before the euthanasia. Thereafter we would let her go. That is the way she wanted it.’ Father Diedrich shakes his head: ‘However it did not happen, by the inexplicable intervention of the general practitioner.’

Vain hope
After her eleventh birthday it became clear something was wrong with Milou. She loses weight, her growth stays behind and she becomes slow in understanding. After many years the diagnosis is made in the University Hospital (UZ) Gent (Belgium): NPLSE neuropsychiatric systemic Lupus erythematosus, an autoimmune disease. She has cognitive problems, insults, mood disturbances and headache. In 2010 she gets a treatment with prednisone, which seemed to help. But it turned out to be vain hope. Many treatments followed: chemotherapy, plasmapheresis and in 2012 bone marrow transplantation. ‘After the bone marrow transplantation Milou felt much better, she hoped to be able to go to school, bought herself high heeled shoes. But before Christmas her health went downhill. She had sensed life for a moment, before all hope vanished.’

Untreatable
Many hospital admissions follow but end 2012 Milou comes home, untreatable. She is often oppressed in her chest, has headache and tantrums for which she feels ashamed. In 2014 an experimental treatment is given with mesenchymal stem cells. But it does not help. Milou wants euthanasia. She fills in a living will and talks it over with the general practitioner, who says she can understand Milou’s request but cannot perform euthanasia because that is against her principles.
The attending doctors in the UZ Gent are willing to go through the procedure. Nicolle: ‘Many talks followed with psychiatrists, ethical commission, doctors and with the three of us. They were not very eager for Milou was only nineteen, had a rare disease and the doctors hoped to find a treatment after all.’

Releasing telephone call
In the midst of April 2015 comes the releasing telephone call from the UZ-Gent. The team agrees to the euthanasia, and the paediatrician will perform it. But then the general practitioner talks with the UZ-Gent team that she does not agree and will do everything to prevent the implementation of the euthanasia. Permission of the general practitioner is not required but the team wants to convince her of their point of view. Milou’s situation becomes more and more precarious. The talking goes on, time flies and Milou’s mind deteriorates more and more. She is afraid she will not be capable to express her will to say, at the crucial moment, that she wants to die. And that she will be doomed to live on. Nicolle says to the general practitioner: ‘what if Milou will commit suicide?’ The doctor replays: ‘Then I will call in a psychiatrist and see to it that Milou will be taken into a psychiatric hospital.’ So she does, she calls in a psychiatrist, but he reproves her. He has seen the electronic dossier, talks to Milou and says; ‘You have an awful disease’ and asks the doctor why she prevents the euthanasia while so many specialists have scrutinized the case. He advises her to let the hospital know, in writing, that she will not anymore object to the decision. So she does. But she also wants to be heard by the ethical commission and visits family De Moor asking Milou if she really wants euthanasia and if she is not being influenced by her parents and her sister. Nicolle says that the doctor talks to Milou as if she is a small child: ‘Shall the doctor call the UZ to tell it is alright? Shall the doctor just do this?’

Pink coffin
But Milou did not have any confidence in a ‘happy ending’ anymore. She said she was going to look to the blossoms of the trees. She walked into the orchard her little goats behind her. After a while we saw the goats coming back, agitated and without Milou. Then panic strikes. We did not see her in the orchard. We called family and neighbours. At last she was found by an uncle. She had hanged herself under the spruces with a silken shawl. Nicolle: ‘we knew she would die untimely but not in this
manner.’ Her funeral passed of the way Milou had desired: in a pink coffin with a white mourning car. Many people from UZ Gent attended the funeral, the general practitioner came after some days. The De Moors did not accept her condolences. ‘She has stabbed a knife in our back’ says Nicolle. The doctor said she has underestimated the situation, had thought Milou imagined everything. She will send a letter to the UZ Gent and tell them she regrets her threats to the UZ team. But the letter does not contain a word of regret. Diedrich, Nicolle and Janiek are baffled. And sorrowful. Extremely sorrowful.

NVVE-volunteer Leo Aretz gives information to groups and schools

‘THIS WORK FITS ME LIKE A GLOVE’
The NVVE cannot exist without the effort of many tens of volunteers. Relevant paints portraits of some of them. In this issue Leo Aretz (69), fellow worker of the presentation service. He gives information to groups and schools.

By Marijke Hilhorst

The biggest part of his life Leo Aretz has worked in nursing, in the education sector of health care. He made a switch to the regular secondary education when he was 54 years old. He has liked teaching very much.

Twinkling eyes
After retirement Leo looked around to see which volunteer work he wanted to do. By coincidence it became the presentation service of the NVVE. ‘This work fits me like a glove’ he says. Not that he is heavy, on the contrary. He is a cheerful man with twinkling eyes. He is enthusiast about the ‘excellent’ information material the NVVE volunteers receive: Power point presentations about living wills, instruction films about Life’s end and the recently launched lesson package Euthanasia Deadly normal in which the NVVE connects to the way of thinking of pupils. Euthanasia is one of the most often chosen topics for the obligatory profile paper in secondary school. Leo hopes to be invited by secondary schools. ‘Death is not an obvious subject for young people, but we have to realise not only old people die. Some songs and TV programs can be a starting point for discussion.’ Leo has also given information on vocational training schools. ‘Often they have practice experience. You can see by the type of questions they ask. More probing, they have seen something or other.’

Hardly taboos
Leo is very surprised half of the Dutch people who lose a near person do not know the wishes of the deceased person, and 80 percent does not know how their death should be ‘arranged’. ‘There are hardly taboos anymore. Why do we not talk about death? It is not only important for you, but also for them who have to make decisions over you. I nearly preach: make from it an ordinary topic of conversation.’ The presentation service of the NVVE gives yearly around two hundred presentations to the most varying groups like women of the country side or domiciliary home care. Leo likes it very much. ‘Those are nearly living room talks. In groups of ten, twelve persons we talk about a subject like reanimation. That brings about interaction and makes the meeting lively.’

Information box
Being a volunteer is not free of obligation, realises Leo. It takes him one and a half day a month. ‘Once I had a nasty experience, a person who gave vent to his anger about euthanasia. But I say the NVVE does not preach euthanasia, it gives information. I always explain the difficult role of the doctor, and emphasize euthanasia is not a right. Everyone should realise that.’ Leo has noticed people overestimate the number of euthanasia cases. ‘In not even three percent of the deceases
euthanasia is implemented. There is much ignorance. Therefore those meetings are so important.’ In the field of euthanasia there is much to gain, thinks Leo. ‘Usually the euthanasia requests of terminal cancer patients are complied with, but if a person has a severe psychiatric disease it is much harder. Most psychiatrist rather conjure up the nth time therapy. But if the patient thinks it won’t work and suffers unbearably? When is it enough? Who has the right to deny someone his own death?’ Leo has done what he ‘preaches’. ‘My wife and I have made an information box with our living wills, a small last will and some notes with our points of view. And we have discussed it with the general practitioner and our children.’