Relevant
Magazine of Right to Die-NL (NVVE)
Volume 36, nr. 3, August 2010
Summaries by Corry den Ouden-Smit

Fatma Koser Kaya (D66) is a rational being

'I HAVE MY OWN WILL'

Fatma Koser Kaya (42), fifth on the list of political party D66, finds political persons can't decide for the voters, but they can facilitate the freedom of choices.

By Fred Verbakel

Fatma Koser Kaya thinks that euthanasia and assisted suicide are not in want of better regulation by law, but she hopes an inquiry will start about the possibility for old people, who find their life has been fulfilled, to get assisted suicide. A motion in that direction has been introduced by the political parties GroenLinks, VVD and D66. This motion has been declined.

Difficult discussion

In politics it is hard to talk rational on medical ethical questions. The demarcation line is often not only *between* but also *within* political parties.
Fatma, born in Turkey, was raised with the idea that everyone has to lead his own life. Her father came in Holland as migratory worker but she could study at the university.

After her law study she became member of D66. 'This party gives room to make your own decisions. I am Muslim and I don't understand that Christian parties define by their faith the way people should live. It is God, who has to decide. It is not their task.'

Koser Kaya is often invited as speaker for meetings of Muslim women. They are interested, and do respect other people's view. But the orthodox Muslims don't come to those meetings. They live in isolation, like the SGP, the orthodox Christians.

Did things change during the administration of CDA, PvdA and ChristenUnie in the last three years?
Koser Kaya: 'We had debates about euthanasia and evaluations about palliation care. Many people don't know palliation care is not the same as euthanasia. Even physicians don't know the difference –or don't want to see it.

Alert

In euthanasia the request from the patient is to end an unbearable and hopeless suffering. In palliation the demand for care is the important question, not the longing for death.

Koser Kaya: 'The patients should decide, not the political parties. Physicians should be alert. *What is the patient's wish*. The communication between physician and patient is of utmost importance. And not for nothing did we organise specialised people like SCEN-physicians. The controlling committee will see to it that the euthanasia has been performed carefully.'

Some people can't find a physician who will help them. Should a better regulation be provided for?
'That is for the professionals to decide, not for political persons. But I see the dilemma. It is an *ongoing* debate.'

Family
You have liberal views.
'D66 has been at the cradle of the euthanasia law. You can't regulate everything. But total freedom to make an end to your life is not where D66 stands for. Euthanasia is an option, but other ways are possible. I know of a lady of over the 90 years who did not want to live on. She had still all her faculties but said her life was being fulfilled. Family took her in and she blossomed. That can be too.'

Fatma Koser Kaya's model and adviser is Els Borst, D66 and minister of Health at the time euthanasia was legalized. 'Before you start anything, look carefully first. It makes you proceed slowly but effectively.'

Dutch citizens over the seventy years old should get professional help to make an end to their life. The group 'Uit Vrije Wil' has initiated a petition in that direction to influence politics. Will that work?
Koser Kaya is amazed that in a short time span so many signatures came in -120.000 at the moment. 'Surely politics should do something with it. But it is a very delicate subject. We have to study this problem in depth. I expect that this will lead to results.'
Asked about statements in the coalition agreement she answers: 'I am not involved in the negotiation and what we discuss intern is not public.'
She does not want to tie herself up with the text the NVVE has made about this subject. But in great lines she can agree.

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Volunteers of the Member's Support Service have life experience

'DREARY WORK? ON THE CONTRARY'

The work is not easy, but most of the volunteers of the Member's Support Service have a long state of service. What makes them tick? 'Their involvement is great' says one of the coordinators of the NVVE office.

By Anja Krabben

Ellen Rentema (56) and Yvon van Baalen (53) are both coordinator of the Ledenondersteuningsdienst (LOD), Member's Support Service.

The demands come in by telephone, mail and e-mail. Problems in which a personal contact is needed go directly to a LOD person and as soon as possible an appointment has been made. Many queries go into the actuality.
Till 2008 most questions came from older people with somatic illnesses; nowadays more and more questions about psychiatry and assisted suicide.

Life experience
At this moment there are 44 LOD persons (17 men and 27 women; the youngest is 45 years old) all over the country. They have life experience and are already members of the NVVE. They are volunteers and most of them have a background in healthcare or social work. They are being coached and trained by the coordinators. Twice a year refresher courses are given about subjects like psychiatry, medication, etc. And meetings are held to talk about cases in practice.

The requirements are high. The LOD person does represent the NVVE and should be acquainted with the rules and the new developments. The demands are emotionally heavy: depressed persons, euthanasia queries, unwilling physicians, difficult family relations. Moreover they should not let themselves being overpowered by physicians.

Ellen: 'It is nice work to guide the LOD persons. We also get feedback from them. They often are critic of the NVVE because they stand in the middle of the situation in practice.' Yvon underlines that the work can be lonesome and heavy. 'Yet the turnover is minimal. People doe have great involvement.'

Two LOD persons tell their story, Thea van Dam (65) and Els Huizinga (66). Thea is a nurse, Els has worked in Human Resources. Els had a bad experience with the death of her mother, and she hopes to help others preventing mistakes and omissions. 'A problem often seen is that many people think everything is o.k. if they have completed the form about their life's end. They forget to inform their physician, they don't have talks about it, neither with their physician nor with their family.'
Thea: 'It is of utmost importance to inform your physician. Take the time to explain your wishes and give the physician the time to react.' Els assents 'most NVVE people are autonomous. The may forget that the physician has his autonomy too.'
She tells about a case where an old lady has taken her own medication in the hope to die, it did not work. Afterwards it became clear her physician was not against euthanasia, but a real discussion had never taken place. She opened up a discussion between the patient, the physician and the family. And the lady got her euthanasia. 'LOD persons can play an important role. A patient may be confused, a physician should never be.'

Some people only need help in completing their form, but even so, long discussions may follow about life and death. Very confronting are the discussions about dementia: with persons with beginning dementia and their family. You can explain what is possible within the borders of the law and what not. Also that contact with your physician can be of great help.

Notifiction of death
Often you don't hear the end of your intervention. That is why Thea asks the family to send her a notification of death.
She is specialised in queries from people with a psychiatric background. 'They often think that the NVVE can help them to fulfil their death wish. But the NVVE does not do that. They haven't physicians on duty nor does the NVVE deliver medicines. The expectations are often unreal. Often the physician says treatment is possible, but the patient sees it differently. I had such a patient and offered to go with him to the psychiatrist, but he refused. I can't force him, but I am afraid he will commit suicide. For yourself it is I important not to take the problem home. That is part of your professional too.'

Three kisses
What makes you a good LOD person? Els: 'Knowledge about discussion techniques, knowledge of men and life-experience. And you have to keep to the point, you give information and you go. That is not always easy, especially when one gives you three kisses at the farewell. But the discussions are often very intense.' Thea: 'Yes, persons are very confidential. You talk with them about their life's end and how to die in dignity.'

Els and Thea want to continue this work for a long time, it really gives satisfaction. Els: 'Not everyone understands it, because you are confronted with death all the time. But I can really help. Often I come back from a visit happy and content.'

LOD GOT 1225 QUERIES IN 2009
The LOD is in existence since the end of 1970. The need for information came right from the foundation of the NVVE in 1973. In 2009 the LOD got 1225 queries. The number of somatic questions was 472, about dementia 99, about fulfilment of life 71, and 203 about psychiatry. General questions amounted to 380.

Complaint committee, refresher courses and evaluation

SCEN MORE PROFESSIONAL

The work of SCEN-physician becomes more professional. The aim is to give better support and consultation, and to meet the wants of physicians and patients.

SCEN means Support and Consultation on Euthanasia in The Netherlands. It is a network that started in 1999 in Amsterdam and has gone nationwide since 2002 under the auspices of the KNMG, the medical professional organisation. Every general practitioner can count on the support and consultation in matters of euthanasia and assisted suicide. The ± 600 SCEN-physicians do their work now even more professionally after the installation of a complaint committee last year. 'Complaint committee SCEN' consists out of three SCEN-physicians, a jurist and someone from the patient's interest group.

The aim is to learn from the practice, not to judge colleagues. So it became clear that patients and family are often anxious and uncertain and that a SCEN-physician, with his experience, has to communicate clearly and transparently to prevent misunderstanding.

The criteria for SCEN-physicians are heavy. Training and refreshing courses are a must. The Training and Registration Committee SCEN-physicians (CORS) controls if the physician is registered five years as a medical specialist, a general practitioner or a nursing home physician.
The appointment lasts for five years and can be extended if a certain number of consultations have been given and region meetings have been attended to.

SCEN is also topic in scientific research. In the beginning of 2010 the EMGO-institution for research in health and care has made a report Evaluation SCEN, in cooperation with medical researchers of the Free University and the University of Amsterdam.
They compare the difference between a 'good consultation' and a less good consultation. They give quality demands to meet the aims of SCEN in the home situation a well as in the hospitals.

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Sytske van der Meer hammers on frankness

NEVER GO AWAY FROM THE RULES.

Sytske van der Meer is physician, SCEN-physician and member of the Medical Advisory Committee of the NVVE. Police came to visit the first time she had assisted in euthanasia. She knows openness brings you farthest.

By Fred Verbakel

Sytske van de Meer is one of the brave physicians who made euthanasia general accepted in The Netherlands, and contributed to the fact that euthanasia has a legal ground since 2002. In 1999 she wrote an article about euthanasia, in psychiatry and in dementia with emphasis on carefulness, in a Dutch medical professional journal, the *Nederlands Tijdschrift voor Geneeskunde*. 'That article has changed my life. Since, they take me for an expert in that field.' She prefers to give the poisoned cup over the infusion, but the choice should be made in consult together. 'A poisoned cup is taken by the patient himself, so he can decide up till the last minute.' Van der Meer (1951) is physician in a psychiatric hospital in Enschede, SCEN-physician and, as member of the medical advisory committee, connected with the NVVE for nearly ten years. Since 1997 the KNMG, the medical association, trains physicians to become SCEN-physician. SCEN

means Support and Consultation on Euthanasia in The Netherlands. There are nearly 600 active SCEN-physicians among them 54 nursing home physicians and 80 medical specialists. With regularity they are being consulted, because one of the requirements of carefulness is consultation of an independent physician. The physician can call a nationwide number and a SCEN-physician on duty will come.

Fatigue
Van der Meer has given 80 times consultation to other physicians. Physicians can't relief all suffering, is her statement. 'Suffering is not only pain, but also fatigue, dependency and loss of dignity. One can't relief that with palliation. The patient himself indicates when he finds living is no more an option.'

Research indicates that in 20 percent of the cases SCEN-physicians advise not to go on with the euthanasia. Researcher Prof. Dick Willems says: 'There is room in the euthanasia law for psychic suffering, but some physicians are too strict. They argue that there must be physical suffering.' In the mean time the proof of carefulness has been given in eighteen cases of euthanasia and asisted suicide in dementia. It gives courage to Sytske van der Meer. 'We can advance now since physicians know they can give help without the fear for prosecution.'

She has given twice euthanasia to demented people, the first time in 1996. The fore-mentioned article acts about this case. Earlier she had helped cancer patients in terminal stage with euthanasia. 'The patient wanted her to leave when he took the poisoned cup. I gave my private number to call when the patient had died. I got a reprimand from the Public Prosecutor. I should have stayed at the death bed. With afterthought I think so too. It is now included in the law: the physician should be there. The euthanasia law came in 2002 *because* physicians, like me, did not work in the dark. Here in Twente we had the first euthanasia protocol. It stated how to work and how to register. Over here, nobody has ever been prosecuted.'

'Euthanasia in dementia is less a problem than thought of' says Sytske van der Meer. 'The possibilities are not being used though. Physicians stay shivery. It is good the NVVE has put it on the agenda. And in the field of 'ready with life' there is a whole lot to be done. The KNMG (Royal Dutch Medical Association) has put an important report, concerning this, in the cupboard. This report of the committee Dijkhuis was made on commission of the KNMG and I was a member of the committee. But the KNMG has put it out of sight.'

Not all of the psychiatric patients and demented people are eligible for euthanasia or assisted suicide. 'They are too far in their dementia or they don't ask for it. They have to fulfil the criteria of unbearable and hopeless suffering' emphasises Van der Meer and goes on: 'The shivering is much larger than with terminally ill cancer patients. Refusing colleagues say about the demented patients: he likes still things or he smiles so friendly.'

Van der Meer has seen that refusing physicians change their mind when confronted with patients they know for a very long time. 'He says then: I thought I would never do such a thing, but with this patient in beginning dementia I can imagine he wants to die in dignity, so I will do it.'

She understands how it works. You do talk for months to come on one line. It is not 'you ask we turn.' As a patient you do have to have courage, majority and intelligence to say: my life has to come to an end. Review committees find fear for future suffering also a form of unbearable suffering.'

Under pressure
If the physician is not willing to give euthanasia he seldom will ask for a SCEN-physician. 'Sometimes the family pressure is so high that it is good an outsider has a look. But if the

physician adheres to his NO, euthanasia will not go on.' The SCEN-physician is explicitly for the physician. He gives juridical advice and helps to prevent the physician making mistakes which will lead to juridical procedures.

What to do if the physician is against euthanasia?
Sytske van der Meer: 'The patient has to look for another physician. Yes, that is difficult. But you may expect the physician will help in finding someone who stands in.'

Sheepfleece
SCEN-phyicians should be for euthanasia, in principle. Some people think that should not be. 'There are one or two physicians who became SCEN-physician in order to halt euthanasia. That is a shame!'

In a case of a patient with bone cancer, a metastasis of prostate cancer, constant in pain in spite of morphine, he got bedsores and eating and drinking was hardly possible, euthanasia was asked for by the patient. His family and his physician wished it should happen. The SCEN-physician did advice negatively. And the euthanasia did not go on.
A family member asked about this case in Relevant May 2010: 'If a SCEN-physician advices negatively, can a physician ask anew? Or are SCEN-physicians holy and should their advice never be doubted? Van der Meer: 'An attendant physician does not have to follow the advice of the SCEN-physician. If he thinks euthanasia is justified he may go on. And if the criteria are followed the controlling committee will not be harsh. If I read this case the physician had plenty of arguments. It was not necessary to let the patient suffer for even more weeks.'

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FOREIGN COUNTRIES RUN FOR THE FIGURES OF THE NETHERLANDS.

The announcement of the Regional Review Committees Euthanasia that the number of (mentioned) death by euthanasia in The Netherlands went up with 13 percent made all the newspapers, even abroad. A comparison was made to Nazi-Germany by a fairly respected British paper the *Daily Telegraph*.

Walburg de Jong, press officer of the NVVE and Rob Jonquière, head communications of World Federation of the Right to Die Societies wrote a letter to the editor.

Walburg de Jong about the comparison to the Hitler period: 'This is an insult to the Dutch government and to everyone who wants to decide about his life's end. We don't know why the numbers are higher in 2009. More and more people like to make their own decisions, including life's end. They are well informed and want to die in dignity. Every five years the Department of Health inquires into the matter of end-of-life decisions. We hope your paper will find the NVVE to get the right information.'

Rob Jonquière wrote among others: 'Do realise that it concerns the number of *reported* cases which means that the Dutch physicians do report those cases, contrary to the majority of other countries in which euthanasia is not legalised. (.....) The comparison of the Dutch practice to Nazi practises is invalid; under Dutch law the free choice is essential and when the Nazi's were in power there was no choice at all. (…) Last but not least, what makes you say the Dutch law lends itself to misuse. Did you ever ask yourself which misuses occur in The United Kingdom, and in which degree?

Chairman Margo Andriessen is intensely concerned

MORE HELP IN DYING, LESS CRIMINAL LAW

'More help in dying, less criminal law' is the credo of Mr. Dr. Margo Andriessen, chairman of the NVVE since April. She understands that changes will take time, but her ambitions are clear.

By Leo Enthoven

The public concern is important to Margo Andriessen (1946). She has a Protestant background, but now she has said farewell to the church.

Death was close by. She lost at an early age her father and later on her mother. Her brother died by a brain haemorrhage. Her sister died from cancer, her dying process was moving and ended in euthanasia, twenty years ago.

Finish a chapter.
Around the wish to end one's life, dying and the help in the dying process lies a big undeveloped area: long time illness, hopeless psychiatric patients, demented people, people who consider their life as being fulfilled. 'Looking round me I think: why don't we arrange this, we have arranged abortion, woman emancipation, sexual disposition emancipation. We should finish this chapter.'

When death is near, often there is panic in the dying person and his family. There is not much accompaniment. Dying does not get much medical attention or pharmaceutical attention and too little attention of auxiliary persons

For people who consider their life as being fulfilled, she finds it worthwhile to investigate if three routes are passable: the medical route, the auxiliary route and the autonomic route.

Hospice
She underlines the NVVE-policy not to give concrete dying help. But it would be of help if the NVVE could make appointments for their members to find a willing physician.

Furthermore she advocates a hospice for people who are dying or want to die. A feasibility study will start this fall.

For the auxiliary route it is absolute necessary that assisted suicide comes out of the penal code. Requirements of due care should guarantee a good process.

The autonomic route is preferred by the NVVE-members. 'It means that the person can get the means for suicide himself.'