

# **The self-chosen death of the elderly**

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*Public debate in the Netherlands about dying assistance for the elderly who consider their life complete*

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'It seems to me beyond any doubt that many old people would find great peace of mind in the knowledge of having access to a way in which to say goodbye to life in an acceptable manner at the moment that this - in view of what life might have in store for them - seems appropriate to them'  
*Huib Drion 1991*

## Summary

In the Netherlands an intense debate has been taking place since 2010 about the self-chosen death of the elderly. The elderly may come to the conclusion that the quality and the meaning of their life has deteriorated to such extent that they prefer death over life. Everything of value lies behind them and only emptiness remains. They consider their life complete and wish to die. Death has become a friend to them. Up to the present time the vast majority of Dutch medical practitioners is of the opinion that dying assistance for the elderly who consider their life completed falls outside the medical domain. Requests for assisted suicide by this group of people are therefore practically always denied by the doctors. The result is that at present the elderly see few possibilities to end their life in a dignified way.

The initiative group 'Of Free Will', a group of fifteen Dutch people with a background in politics, science and culture have organised a citizen's initiative with the purpose of legalising the dying assistance for the elderly who consider their life complete. This has been very successful: the support for this initiative is great. Of Free Will has worked out this proposal in drafting a 'Law for dying assistance for the elderly'. Of Free Will founds its proposals on the principles of self-determination, mercy and humanity.

The purpose of this document is to describe the public debate in the Netherlands and to summarise the proposals for careful dying assistance in cases of completed life. We begin with a short outline of the formation and content of the euthanasia law that entered the statute books in the Netherlands in 2002. This writing however does not supply a summary of the total euthanasia practice in the Netherlands. Euthanasia in the Netherlands is defined as: the intentional termination of life of a person at that person's explicit request. Assisted suicide is defined as: to intentionally assist with a person's suicide or to supply the resources thereto.

In the Netherlands euthanasia has developed from a medical perspective. In the euthanasia law unbearable and hopeless suffering and dying assistance by a doctor are central. In 2008 the NVVE – the Dutch Association for a Voluntary End of Life – has in addition to the medical perspective also discerned other perspectives. It is proposed, in addition to the criterion 'suffering' to also introduce the criterion 'loss of personal dignity'. Also proposed is, besides medical practitioners to introduce 'counsellors in dying'. It has been enlightening to discern three routes to a self-chosen end of life: (1) the medical route: medical dying assistance by a doctor in cases of unbearable and hopeless suffering; (2) the caregiver route: dying assistance for the elderly who consider their life completed by a new category of counsellors in dying. (3) the autonomous route: dignified suicide without assistance.

Of Free Will stresses that each of these three routes has its own target group and merits. They do not compete but rather supplement each other. Each of these routes is alright in principle. Every human being should be able to choose which route to his end he wishes to take.

Of Free Will has formulated this assistance with suicide for the elderly with a completed life in a draft Bill. The core points of this bill are as follows: (1) The criteria to be considered for this assisted suicide are: the request for assistance must be voluntary, well considered and sustainable. The elderly person must be 70 years of age or over. (2) The counsellor must after a series of interviews be convinced that the criteria have been met. He must also request the opinion of a second counsellor. (3) 'Counsellors in dying' form a new group of professionals recruited from professionals who are

acquainted with the problems at the end of life (such as spiritual caregivers, psychologists, doctors and nurses.) They must follow a special training and be certified. They are members of a professional organisation responsible for the protocols, training, guidance and oversight. (4) The counsellor in dying is required to report cases of dying assistance. The existing independent Review Committees that explore the compliance with the requirements in cases of euthanasia also review the dying assistance provided by the counsellors in dying.(5) Counsellors in dying who comply with the requirement demanded by law will not be prosecuted. All in all this is a complex of regulations that guarantee the careful, professional and verifiable effectuation of dying assistance for those elderly who consider their life complete and wish to die.

The Dutch euthanasia law and the Bill dying assistance for the elderly each have their own perspective and target group. The euthanasia law deals with the medical perspective where unbearable and hopeless suffering are central. The law dying assistance for the elderly deals with the humanity perspective where loss of quality of life of the elderly is central. These two laws do not compete but supplement each other.

## Self-chosen end of life in the Netherlands

### Euthanasia law

#### *History*

In 1972 a Dutch general practitioner was tried in court because she terminated the life of her mother who was suffering unbearably and in compliance with her mother's explicit request. Her patients and other inhabitants of her village started a petition of support: their doctor was no criminal but on the contrary someone who had acted passionately and properly. This was the start of a fierce public debate about euthanasia. It led to the founding of the Dutch Euthanasia Society NVVE (now: Dutch Association for a Voluntary end of Life) in 1973.

Termination of life on request has from there on developed from the widely held conviction that no one needs to suffer unbearably and hopelessly. Doctors came forward who helped patients who suffered awfully and who asked for ending of their lives gently and peacefully. They acted out of compassion with their fellow humans and had the courage to defy the law. This led to trials and an intensive debate. Reports appeared from the Royal Medical Association KNMG, the euthanasia association NVVE, the National Health Council (1982) and the State Commission on Euthanasia (1985). In this climate judges decided that doctors who act according to medical professional standards and to valid medical ethics ought not to be prosecuted. Herewith they formulated a number of criteria the doctor needs to comply with in the granting of dying assistance on explicit request. The Ministry of Justice refrained from prosecuting cases of euthanasia performed with due care. Doctors were required to report their dying assistance to the Public Prosecutor.

During the period 1970 to 2000 – parallel with the developing practice of assisted dying – a wide reaching public debate about euthanasia took place. It became clear that no valid arguments exist against euthanasia requested by a competent patient and performed with due care. A medical practitioner has the professional duty to save the patient from an acrimonious end of life. A broad and constant support developed for euthanasia. More than 80 per cent of the Dutch population supports the possibility of euthanasia.

In 1984 the first Euthanasia Bill was submitted by MP Wessel-Tuinstra. No parliamentary majority could be found. In 1999 a variant of this Bill was submitted to parliament by the second Cabinet Kok. In 2000 and 2001 the Second chamber and the Senate of the Dutch Parliament passed the euthanasia law. This happened under overwhelming interest from abroad. The name of the minister of Health Els Borst will always be connected to this milestone. The Netherlands was herewith the first country in the world where euthanasia is legalised. The law entered the statute books in 2002.

#### *Euthanasia law*

The euthanasia law is for an important part the codification of already existing practises and jurisprudence. In addition the law introduces new rules for the reviewing procedure. In the law euthanasia has remained punishable. However a ground for exclusion of punishment has been added. Euthanasia and assistance with suicide are not punishable if: (1) The procedure has been

performed by a medical practitioner (2) The doctor in question has complied with the due care requirements. (3) The doctor has reported his dying assistance.

The due care requirements in the law pertain partly to the purported criteria that must be satisfied for euthanasia and assisted suicide and partly to the procedural performance. The criteria concerning content that must be satisfied are: (1) It must be a matter of a voluntary and well considered request from the patient; (2) It must be a matter of hopeless and unbearable suffering of the patient. As to the question whether or not it is a matter of hopeless suffering the medical opinion of the doctor is final. It needs to have been determined that according to a responsible medical view no improvement in the situation of the patient is possible any more. For the question if the suffering is unbearable the perspective of the patient, his physical and psychic stamina and his personality are determinative. The patient himself has to experience his suffering as unbearable. For the doctor this feeling must be palpable.

The procedural conditions that must be satisfied are: (1) the doctor must fully inform the patient about the situation in which he finds himself and about his prospects; (2) the doctor and the patient must be convinced that for the situation in which the patient finds himself there is no reasonable alternative solution; (3) the doctor must consult at least one other independent doctor; this doctor must express his opinion about the due care requirements; (4) the doctor must perform the termination of life or assisted suicide in a medically careful manner. All this makes it clear that the euthanasia law is above all focussed on the doctor. The law determines under which circumstances a doctor is allowed to grant the requested assistance with dying. The patient has no right to euthanasia or assisted suicide. He can only request it. The doctor decides.

The doctor is required to report the euthanasia or the assisted suicide to the public prosecutor (coroner). Herewith he hands over his report about the granted assistance. Every report is assessed by one of the five Regional Review Committees; each of this committee exists of a lawyer (chairman), a doctor, and an ethics expert. The commission determines if the doctor has satisfied the due care requirement.

### *Evaluation of the euthanasia law*

Since 1990 the practice of euthanasia and assisted suicide is, on government orders, scientifically evaluated every 5 years. These are very extensive assessments wherein by means of interviews and surveys, among others, it is assessed how dying assistance by doctors has developed. The most recently conducted assessment also gave a judgement on the practice of the at that moment recently adopted euthanasia law.

In the Evaluation report from 2007 [1] one can read: 'All in all, from the above emerges a positive picture. In general terms the goal achievement of the law is good. The frequency of euthanasia and assisted suicide is down and the reporting percentage is up. Of a "slippery slope" concerning termination of life, with and without explicit request, there is no sign. Therefore there is little reason for a substantial amendment of the law or policy'.

A research report published in June 2011 [19] concludes that among citizens and professionals there is wide spread support for the euthanasia law. Citizens feel positively about the law, professionals have great appreciation for it. A large majority of the Dutch citizens is in favour of the possibility of euthanasia. The percentage opposed has dropped from 12% in 2002 to 5% in 2010.

### *Definitions*

*Euthanasia*: the intentional termination of life of a person at that person's request [2].

*Assisted suicide*: The intentional assistance to a person with suicide or to supply the means there to. (Euthanasia law, article 1.b).

### **Three routes to self-chosen end of life**

#### *Changes of perspective*

As will have become clear from the previous the help with the self-chosen end of life in the Netherlands has developed from a medical perspective. The hopeless and unbearable suffering of the patient in a medical context is central. Only the doctor is allowed to grant dying assistance.

When the euthanasia law came into force in 2002 the Dutch Euthanasia Society NVVE has contemplated its future. This led in 2008 to the policy document 'Perspectives on Dying with Dignity' [4]. Herein different perspectives on the self-chosen end of life are pictured. In addition to the medical perspective also other perspectives must be developed further.

The first change of perspective includes the proposal to include the criterion 'irreversible loss of personal dignity' in addition to the criterion 'hopeless and unbearable suffering.' Research finds that for the person in question the loss of personal dignity is often a more important reason for the self-chosen end of life than unbearable suffering in the narrower sense. While for the doctor the suffering is central, for the patient the loss of dignity can be paramount. Here the matter is more physical, social and emotional tarnish, severe loss of self-reliance and the loss of direction over personal life. A large scale research has been initiated into the feasibility of making the dignity criterion operable (2007 - 2011).

The second change of perspective concerns the position of the person who wishes to end his life. In the euthanasia law this person has a weak position: he can ask the doctor for assistance to die, but the doctor decides. Of Free Will commits itself to the emancipation of the human being who finds himself at the end of his life. Human beings at the end of their lives must be able make a well-considered choices how they wish to die. Others will have to respect the choices of these people.

The third change of perspective concerns the counsellors in dying. Starting from suffering caused by illnesses only doctors have understandably occupied a central position in the euthanasia law. When that suffering is no longer the only criterion it is logical that also others can become counsellors in dying.

#### *Three routes to the self-chosen end of life*

In the document 'Perspectives on dying with dignity' [4] mentioned earlier for the first time three different routes to the self-chosen end of life are distinguished: the medical route, the caregivers route and the autonomous route. The medical route is the one of the euthanasia law. On this route assisted dying can only be practised by medical practitioners. On the caregivers route – which at present is not permitted in the Netherlands – dying assistance is performed by counsellors in dying. These are defined as specially trained and certified counsellors. The autonomous route is the one where the person who wishes to die performs his suicide independently and without assistance.

Distinguishing these three routes appears to clarify things greatly. It explains that the medical route is not the only one. It has also led to the fact that the autonomous route receives more attention. Because of gruesome and lonely suicides the autonomous route has a bad name. It has now become clear that within the autonomous route there are also dignified ways.

The three routes to the self-chosen end of life each have their own characteristics. These routes clearly do not compete, they complement each other. There is no such thing as one best route. Each of the routes is alright in principle. Every human being ought to be able to choose in perfect freedom which route he wishes to follow.

In the following pages some numbers are mentioned derived from the Dutch practice. In order to present these the population of the Netherlands is briefly indicated here: In 2010 the Netherlands had a population of 16.6 million. The number of persons of 65 years and over was in that year 2.5 million (15.3%). In 2008 the number of deaths was 135.100.

#### *Medical route*

On the medical route three methods are distinguished: palliative sedation, euthanasia and medical assistance with suicide. Palliative sedation is defined as: bringing the patient in a deep coma and withholding artificial administration of food and fluid as a result of which the patient dies a short time later without suffering. Palliative sedation is seen as normal medical practice and therefore is explicitly no euthanasia. In 2005 palliative sedation was practised on 11.200 patients (8.2% of the deaths) [5].

In the case of euthanasia the patient's life is terminated by his doctor by means of an injection, on the patient's explicit request and on conditions of due care. In 2005 this happened with 2.325 patients (1.7% of deaths) [6]. In the case of medical assistance with suicide the patient terminates his life himself by the ingestion of a lethal agent. This is supplied to him by his doctor on conditions of due care. In 2005 this happened with 100 patients (0.1% of deaths) [5].

#### *Autonomous route*

In case of the autonomous route the termination of life is done completely independently and in a dignified manner by the person himself. Dignified means that the patient does not die in pain and not in solitude. Since suicide in the Netherlands is not punishable the autonomous route is perfectly legal. On the autonomous route three methods are distinguished: abstinence from life prolonging medical treatment, cease eating and drinking and ingestion of lethal agent.

In the Netherlands every patient has the right to refuse medical treatment, even when this refusal leads to death. Doctors must respect a treatment prohibition by the patient. In 2005 21.300 persons (15.6% of deaths) died as a result of abstinence of life prolonging treatment [5].

For old or sick people stopping with eating and drinking can be an acceptable and natural way to die. For a humane course of events adequate medical and nursing assistance is essential (because of these indispensable medical treatments stopping eating and drinking does in fact not quite fit in the autonomous route). How long it takes before death occurs depends very much on the condition of the person. Sometimes it occurs after about 6 days, often after one or two weeks but it can also take longer. To stop with eating and drinking is a difficult but not an impossible way. The better the condition the harder the way. Of the next of kin 75% holds it a dignified end [6]. Estimated annual number of termination of life by starvation in the Netherlands is 2.800 (2.1% of deaths) [7].

Even the way of ingesting lethal agent requires an adequate knowledge and proper preparation. Failure is dramatic after all. One requires sleeping medication, anti-emetic medication and the lethal agents. Lethal agents are available only on medical prescription in the Netherlands. Persons who wish to go this route can only obtain the required medication through cunning and guile (under false pretences, far away overseas) or on the internet. This method occurs an estimated 1.000 times per annum (0.7% of deaths) [7].

In recent years various excellent books (*in Dutch only*) have become available in the Netherlands describing in detail abstinence from food and fluids and the medication method. These books are available in every book store.

In addition to the above mentioned dignified methods of suicide there are also the awful and lonely suicides: hanging, suffocation, ingesting an overdose of medicine, drugs or alcohol, jumping in front of a train or from a height, drowning etc. These suicides often happen impulsively, in solitude and in a mutilating way. They are awful, undignified and traumatising for the next of kin and other people concerned. In the Netherlands approximately 1.500 commit suicide in an awful way (1.1% of deaths).

#### *Caregivers route*

On the caregivers route the dying assistance is granted by specialised caregivers. These counsellors in dying are not recognised in the Netherlands right now. At present their assistance is punishable. In the following chapters the caregivers route is expanded upon for elderly persons who consider their life complete.

### **Citizen's initiative completed life**

#### *Initiative group Of Free Will*

In 2009 Yvonne van Baarle has founded the 'Initiative group Of Free Will' in order to realise the citizen's initiative Of Free Will. The goal that this group pursues is to legalise dying assistance for elderly persons who consider their life complete; this on their explicit request and on conditions of due care and testability.

The group consists of 15 persons with a background of politics, science and culture, all are aged 65 or over. Some of them are persons well known in the Netherlands. The members are: Hedy d'Ancona, Yvonne van Baarle, Wouter Beekman, Frits Bolkestein, Mies Bouwman, Marie-José Grotenhuis, Eylard van Hall, Jit Peters, Milly van Stiphout-Croonenberg, Theo Strengers, Eugène Sutorius, Dick Swaab, Katuscha Tellegen, Jan Terlouw and Paul van Vliet.

The initiative group has drafted a manifest wherein it is forcefully argued why dying assistance for those elderly who consider their life complete can be necessary. Also drafted are the principal policies how this dying assistance can be arranged. Much attention is given to the due care and testability of this dying assistance.

#### *Citizen's initiative*

Since 2006 every Dutch citizen has the possibility to make a proposal to the Second chamber of Parliament. This is called a citizen's initiative. The proposal must satisfy a number of conditions. When a proposal is supported by a minimum of 40.000 persons the proposal is discussed by the Second chamber and this chamber forms an opinion about it. Little experience has as yet been gained with this new possibility for the citizen.

In February 2010 the initiative group has started the citizen's initiative 'Completed Life'. The manifest appeared on the website of Of Free Will. Dutch citizens could lend their support to the proposal either digitally or on paper. The action received massive media attention. This was also caused by impressive documentaries shown on television. The following few weeks there was daily discussion on television about the theme of the completed life. In dailies and magazines articles and

editorial comments appeared. Readers reacted by letters to the editor. Within a week the required 40.000 declarations of support were received. When the citizen initiative was submitted in May 2010 there were 117.000 declarations of support. It has surely been a help that a number of well-known Dutch people have stood behind the citizen's initiative 'Completed Life'. But apparently the matter is alive in society and has touched a sensitive nerve.

At the time of writing (August 2011) no discussion of the proposed bill had yet taken place in Parliament. In February 2011 the Second chamber of Parliament conducted a hearing with Of Free Will. In May 2011 the Chamber has conducted round table discussions where a large number of experts and representatives of organisations have expressed their opinions about Of Free Will proposals. In these discussions many persons have insisted on research into the nature and magnitude of the problem of the elderly who consider their life complete and wish to die.

## Completed life of the elderly

### Who are the people concerned

This chapter concerns the concept of 'completed life of the elderly'. It is best to begin with stories from some of the elderly. The following quotes under *One of many* come from a book by Hans van Dam with interviews with next of kin of people who have died by means of euthanasia or physician assisted suicide [8].

#### *One of many*

'Evelyn was born on the 27 March 1896. She died on 7 April 2000. One hundred and four years old. A woman of two millennia and two world wars. The last twenty years of her life she longed for death. And that certainly not in silence. She talked about it with her children and with her doctor. But further than talking and longing it didn't get. Evelyn just wouldn't get ill so she was obliged to live. She suffered from this, more than she could have suffered from an illness, her daughter Lenny says. For a number of people old age is a blessing, for others a disaster. The well-known saying that "getting old is not an art but being old is" does therefore not apply. The story of Evelyn says it all, it doesn't matter how old someone is but how he is old. Then the difference between 84 years and 104 years disappears. The mental age determines how the biological age is experienced. Daughter Lenny tells about her mother. A story of love, death and old age.'

'The elderly are closer to death, more than anyone they know exactly what they are talking about. For them it is not a matter of a reality that might be a long way off, but a reality that is forth coming. On this ground alone their view of their own end and their wishes concerning this should be taken far more seriously. More seriously in actual fact I mean! Lip service abounds. About respect, independence, freedom of choice, "even if you're old". But reality is different. Freedom of choice: yes, until you ask for death. Then suddenly there is no one home. Then freedom of choice suddenly becomes an empty notion, suddenly it wasn't meant that way.'

'Her life waned and she became more and more dependent on others. She suffered badly from it. She knew that a human being doesn't have eternal life and the ripe old age limits the range. But knowing is one thing, to experience it is another. How much she has suffered under this experience has been underestimated by many. During this period arose the longing for death, not sporadically but persistently'.

'It is difficult to clearly communicate the feeling that grew in her with all the inherent nuances. She drifted away, that is the gist of it. She became detached from life. Detachment...yes, that perhaps is the right word. She often said: "It means ever less to me, life". And then she often apologised. Others could find it insulting or reach the wrong conclusions. For instance that my mother was no longer interested in her children. But that wasn't the case, she has never felt that way, not for a moment. The point was that life, including for instance the fun she had with her grandchildren, did not nourish her any longer. She was drying up so to speak. Even though she remained warm hearted. A distance developed, but no aloofness.'

#### *Paying attention to the elderly*

The stories of the elderly are important. They bring reality. They prevent diverting attention from a difficult but serious question. The penetrating stories of the elderly must be taken seriously. They

illuminate a desperate cry for help, a cry that will not go away. The problem of the elderly with a completed life has up till now been invisible.

Marten Toonder [*a famous Dutch strip cartoonist*] has said the following in an interview with Hans van Dam [9]. 'Ageing is detachment. And to detach means to die. And dying is something you do yourself. Dying is an action, a deed. Therefore Huib Drion's plea to give old people the right to possess the means to die at a self-chosen moment is so much more than an opinion. It is an attempt to free the spirit. (...) A freedom where death has its place, where death is allowed to be dead simple for someone. A freedom where a person must be allowed to say that enough is enough and is able to accept the consequences thereof. That freedom does not now exist. People lock each other up in commandments and taboos. Even, or stronger yet, precisely **in** this so very personal, **in** this most private domain: dying. Forty year olds know exactly what I should think and especially that I should live. In their opposition to what has been dubbed the "Drion's Pill" people say that herewith the elderly are disdained, but precisely this statement itself is in disdain for the elderly. It attests of not listening and therefore of a dangerous misunderstanding. Here lies the foundation of the modern patronisation leading to: "Thou Shalt Live". If these same forty year olds would really listen to the elderly, their words would come back and haunt them.'

#### *Number of elderly with a completed life*

How often do the elderly have a death wish? About this little is known. The only available Dutch scientific research gives the following numbers [10]. 18.7% of the Dutch population above the age of 58 has sometimes had a death wish. 3.4% indicated to have had a death wish within the past week. 0.7% had a strong death wish at the time of the interview.

Research from abroad indicates that 9.5% of elderly persons (65 years of age and over) has death wishes and suicidal intentions. Only 0.14% makes indeed a real attempt at suicide [11].

The NVVE has researched the problems of the completed life in nursing homes (2010). This resulted in the following picture. In 53% of the nursing homes one or more of the occupants found their life completed during the past three years. In every nursing home elderly people are living who do not wish to live on and who express this clearly and repeatedly.

## **Completed life**

### *The self-willed end of old people*

In 1991 Huib Drion, ex vice-chairman of the Dutch Supreme Court, published the article 'The self-willed end of old people' [12] which has become famous in the Netherlands. The opening paragraph reads: 'It seems to me beyond any doubt that many old people would find great peace of mind in the knowledge of having access to a way in which to say goodbye to life in an acceptable manner at the moment that this - in view of what life might have in store for them - seems appropriate to them'. This article received massive interest and caused a torrent of reactions that lasted a year. People began to call the remedy Drion had in mind 'Drion's Pill' which in fact is meant as a metaphor. Such a pill still doesn't exist.

In 1992 Drion reviewed in a book the public debate which had taken place [13]. 'A few points were – and are – central here. In the first place that the problem of suicide by old people is not primarily a medical problem. Determining is the personal judgement of old people concerning their

dignity and need for independence, and their personal preparedness to burden their environment with the consequences of their old age.

My second point was and is that there are fitting reasons to argue that, when we are thinking about a right to voluntary ending of one's own life, it is not appropriate to place old people on one line with those whose life has not yet reached the digressive state that is characteristic of the last phase of the life of those who have not – through illness or accident – died too early'.

'A third point, perhaps the most essential, in my article in the NRC (*Nieuwe Rotterdamse Courant*) I have not stressed this, probably because for me it goes without saying that this formed the starting point: to wit that it is up to the elderly himself to decide when the time has arrived that for himself his life is complete, when the time has come that in his own eyes to live on would detract from the fullness of his life.'

#### *What is meant by completed life?*

Of Free Will defines completed life as: 'the position wherein an elderly person has come to the conclusion that the value and meaning of his life has diminished to such extent that he has begun to prefer death over life'. We are talking here about the explicit and lasting death wish of the elderly. The initiative group Of Free Will focuses on legalising dignified termination of life for persons 70 years of age and over who consider their life completed.

Completed life is not in all respects a satisfactory term. It can sound as if life is a manufactured product, detached from nature and the social environment. Other possible terms are: tired of life, finished with life, suffering from life. Each of these terms has its drawbacks, the reason why in the end the term completed life has been chosen.

It will be clear that completed life is wide ranging and not easy to define. There is here a parallel with the notion hopeless and unbearable suffering of the euthanasia law. This notion is in the law not further defined. The unbearable state of the suffering is decided upon by the patient. Completed life can likewise not be further defined and likewise the elderly person decides if he considers his life completed.

In the public debate attention has been focused on the elusiveness of the notion. When is a life completed? What determines this? Is it about a natural process or a cultural construct? What do we introduce into our society with this notion? There is no unambiguous answer possible to the question when a life is completed. A manifold answer is actually characteristic for this kind of dilemmas. The conclusion that life is completed is reserved exclusively for the elderly person himself. Never for the state, society or any social system. Only the elderly themselves experience their own life. They alone can reach the consideration whether or not the quality and value of their own life are diminished to such an extent that they choose death over life. External standards of a completed life - and consequently the loss of autonomy to decide over one's own life - are absolutely rejected by Of Free Will.

#### *Further descriptions and motivations*

Elderly people can experience that life has definitely turned against them and that an unrelenting natural order is at work. They begin to long for death. Death becomes a friend. They feel that they have become too old and wish to be released from life.

People live as a rule much longer than before and with happiness. But the time may come that the elderly come to the conclusion that the value and purpose of their lives has diminished to such extent that they are going to prefer death over life. The reasons therefore are varied. Sometimes the

elderly no longer find the possibility to continue their life in a for them meaningful way and they get the feeling that they are surviving themselves. Everything of value lies behind them and only emptiness remains. Sometimes the elderly become totally dependent on the help of others and they lose every form of direction of their own life. Sometimes they are confronted with physical tarnish and irreversible loss of personal dignity.

During round table discussions in the Second Chamber [of Parliament] Hans van Dam has described in a beautiful way how the experience of completion and detachment are characteristic of reaching a ripe old age. Detachment is an unavoidable result of ageing. As part of the deterioration of all functions they experience diminishing vital involvement. All that was meaningful in life is impoverished and so the artery of life clogs up.

Usually there is a combination of reasons that can lead the elderly to the conclusion that he considers his life complete. The following reasons can be distinguished. [1] Detachment: the elderly has feelings of detachment and stillness. He experiences a strong decline of involvement in life. Life doesn't mean quite so much anymore. [2] Loss of meaning: the elderly has feelings of isolation and loss of meaning. The elderly is tired of life. He is no longer able to do things that are meaningful to him. The days are experienced as useless repetitions. [3] Loss of independence: the elderly is largely dependent on the help from others, loses control over the personal situation and loses direction of his own life. [4] Loss of personal dignity: the elderly struggles with physical, social and mental decay. The loss of functions and increasing physical tarnish cause feelings of degradation and shame. Loss of dignity appears in many instances to be the deciding factor for the conclusion of the elderly that his life is completed. [5] Missing the partner: people who lived together for a very long time can experience the loss of a partner as an unbearable emptiness that can no longer be filled.

The decision to end ones own life is naturally very far-reaching. The ties to life are very strong. This makes deliberations between continuing a life which is felt as unliveable and the ending of it so difficult. However when it becomes clear that in his life nothing substantial can be changed any longer the elderly can come to the conclusion that his life is completed. This elderly person then wishes to die in dignity and peace.

#### *Increasing attention for end of life care*

The increasing prosperity, the improved social services and the improved medical care led to the fact that people in developed countries live substantially longer. Not so very long ago many people didn't even get to the state we call elderly. Sometimes however living much longer appears to have a flipside. Then the elderly survive themselves. These developments will lead to increasing attention for the self-chosen end of life.

The post war generation which is familiar with the principles of freedom and responsibility which are part and parcel of our culture comes in the coming years to the last phase of their lives. More than the previous generation this generation will want to make their choices, including concerning dying in dignity and the self-chosen end of life.

In the last decades palliative care has also in the Netherlands come to further development. Palliative care is not in the first place focussed on medical treatment – a cure is for the person involved no longer possible – but on the quality of life until death. The focus is on easing pain, and support in psychological, social, existential and spiritual areas. Wrapping up life and saying goodbye to life are focussed on here.

## Moral considerations

### *Self-determination*

Every Dutch citizen has the freedom to arrange his own life according to his own perception and preference and to make decisions accordingly. This freedom also includes the last phases of life and decisions about dying and death. No one has a duty to live. The individual freedom to decide about one's own death is from a moral point of view not or hardly ever brought in question. A decision to commit suicide and suicide itself are not punishable in the Netherlands.

Self-determination and autonomy are enshrined in the Universal Declaration of Human Rights: everyone has the right to life, freedom and inviolability of his person (article 3). This humanitarian constitution like text provides protection to the personal integrity of the human being and his freedom and responsibility about the way in which he arranges his life. This has everything to do with self-determination and dignity. Self-determination applies to living and dying.

Nobody has a veto over the decision of another over another's own life, not even if this includes voluntary dying. Nobody can be made to continue living on by another person. The state nor any other system can place any obstacle in the way of an elderly person who wishes to die voluntarily because he considers his life completed, unless it concerns a lawful exception (as for instance in the case of a forced psychiatric custody). Self-determination is an intrinsic principle of modern western civilisation. This principle is fundamental in our culture. Self-determination is the foundation of the proposals of Of Free Will.

### *Self-determination in social context*

People are social beings. Every human being belongs to one or more communities where care for each other is offered out of love, friendship, tradition or duty. A community offers its members support and cohesion. Every person derives the way he perceives himself also from the meaning he has for others. Individual questions of meaning are rooted in society.

Absolute autonomy in the meaning of unlimited individual freedom therefore does not exist. The self-chosen end of life of the elderly has great influence on their nearest and dearest. Therefore alone it is not purely a personal question. Elderly who consider their life complete will wish to discuss their deliberations and decisions with their nearest and dearest. Stronger yet, many elderly persons will only make their final decision after intensive discussions with key-members of their circle of family and friends. For these nearest and dearest these probing discussions are a support in trying to accept the inevitable.

The self-chosen and planned end of life offers the possibility to say farewell, perform meaningful rituals and visit *lieux de mémoire* prior to the passing. As becomes clear from the testimony of next of kin these farewell rituals can be of very great value for them.

### *Mercy and humanity*

The far reaching public support for the Dutch euthanasia practice is founded on the principles of mercy and respect for the explicit request of the person involved. On humanitarian grounds the request for the termination of unbearable and hopeless suffering has to be honoured. The principles of mercy and humanity apply equally to the request for assisted suicide in cases of completed life. The explicit wish of the elderly to die deserves respect and support. Ignoring the problems of the elderly with a completed life is unmerciful.

### *Respect for living and dying*

Respect for life is a fundamental value of Western civilisation. But when the carrier of this life after careful considerations and on valid grounds wishes to relinquish his life, others cannot force him to live. Respect for life also means likewise respect for dying. Life and death are inseparably connected. Out of respect for life and death self-terminating a completed life should be respected.

### *No paternalism*

Are there moral considerations to deny the elderly a peaceful exit from existence? Paternalism – decision making for others against their will – can be morally justified when a person is not mentally competent or causes extensive damage. For the elderly with a completed life there is however no question of incompetence and death is indeed urgently wished for. Often the death wish is viewed in medical terms by others: it is seen as a sign of depression or a pathological longing for death. With the mentally competent elderly however it is a realistic appraisal of his situation and of what the future may have in store for him. The conclusion therefore will have to be that there are no moral arguments to be found for the unjustified paternalism that denies the elderly the autonomy over his own life. Society will have to realise that for the elderly death can be a friend.

## **Dying assistance with completed life**

### *Current legislation and practice*

During the debates in Parliament about the euthanasia law the problem of the completed life has been discussed extensively. The government has then explicitly decreed that the euthanasia law does not apply to the completed life problem. This decree was necessary, because without it the law would not have obtained parliamentary majority. The text of the euthanasia law itself however does not exclude dying assistance in cases of completed life.

Very few doctors take notice of requests for dying assistance in cases of completed life. Annually circa 500 elderly persons who consider their life completed ask in vain for euthanasia or assistance with suicide [14]. Only 1% of these requests is granted [15]. Doctors refuse because it is not a question of terminal illness or a phase of the dying process. They are of the opinion that it is not a question of unbearable and hopeless suffering. And finally, but possibly most fundamentally, many doctors are of the opinion that dying assistance in cases of completed life does not belong in the medical domain. It is not a matter of medical but of existential problems.

During the past years doctors have in a very limited number of cases granted assisted suicide to elderly persons who suffered from life. With those it was a matter of a combination of medical problems and unbearable and hopeless suffering from life. The Regional Review Committees have decreed that in all these cases the due care requirements of the euthanasia law have been met.

It is forbidden for non-doctors to grant assistance with suicide. Jurisprudence has made clear what falls under this prohibited dying assistance. Prohibited are: issuing instructions, granting direct assistance and taking over direction. Not prohibited are: issuing information, giving moral support and being present at the time of suicide.

### *Why dying assistance can be necessary*

The decision to end one's own life requires courage and capacity. It is a decision nobody makes lightly. Self-determination demands that the suicide is preferably committed completely independently.

Assisting with suicide makes the counsellor in dying partly responsible for the suicide and that is a burden on the conscience and aggravating.

For a portion of the elderly both methods toward dying with dignity via the autonomous route can be impassable. Stopping with eating and drinking can be too difficult. The procurement of the necessary lethal agent can be practically impossible for the elderly. When an elderly person is no longer capable to perform his dignified suicide independently, when therefore the autonomous route is no longer passable, this elderly person needs assistance with his dying. The dying assistance focuses on guidance and being helpful to the elderly with his suicide, including the supply of lethal agent.

Practice shows that the certainty of the availability of assistance with the dignified suicide is for many elderly a great reassurance. Often this reassurance gives them the strength to continue living and offered dying assistance is not taken up.

## Drafting a law for Dying assistance for the elderly

Practically not a single doctor presently takes notice of requests for dying assistance in case of completed life. They refuse because they are of the opinion that this does not come under the euthanasia law or that dying assistance in cases of completed life does not belong in the medical domain. The initiative group Of Free Will advocates legalization of dying assistance for the elderly who consider their life completed. Of Free Will makes concrete proposals about the way in which this assistance can be granted, performed with due care, professionally and testable. 'Of Fee Will' has tied all this down in a Bill 'Dying Assistance for the Elderly' (16). This Bill has been presented by Of Free Will to the Second Chamber [of Parliament]. In this chapter the keynotes of the Bill are described and summarized.

### Key notes

#### *New perspective*

The Bill 'Dying assistance for the Elderly' assumes a different perspective than the strictly medical perspective of the euthanasia law. An essential feature of this new perspective is that the problem of the completed life of the elderly is seen as an existential problem of the free person. An elderly person might for various reasons conclude for himself that the value of his life has deteriorated to such extent that he chooses death over life. The free human being deserves the right to decide for himself over his life and death. The voluntary and well considered decision of the elderly to wish to die deserves respect. When the elderly asks for professional assistance with his decision to die, this assistance on condition of due care and testability should be available to him. This form of assistance, as long as it complies with the legal requirements of due care, should as a deed of mercy and humanity not be prosecuted.

#### *No right to dying assistance*

The key points on which the law is based are: self-determination within the social context of the elderly, careful and professional dying assistance and a transparent and testable state of affairs. The law is seeking an equilibrium between on the one hand the autonomy of the person who requests for assistance and on the other hand social carefulness. The requirement of social carefulness asks for judgement of the requested dying assistance and in doing so is in prejudice to the autonomy of the person requesting help. In the proposed law the person requesting assistance has – as in the euthanasia law - no right to dying assistance. If the due care requirements prescribed by law are not met, the request for dying assistance must be denied.

#### *Protective mechanisms*

As stated the elderly requesting dying assistance does not have the right to it in the proposed Bill. He must express his request and explain it to the counsellor in dying. In a series of discussions the counsellor must convince himself that the required conditions have been met. It has to be a case of voluntary, well considered and durable wish of the elderly. It is mandatory to request the judgement of a second counsellor in dying.

All this forms a barrier against hurried, lonesome and impulsive decisions of the elderly. It also

offers protection against the subtle pressure to which vulnerable elderly could be exposed. This safety valve could be called paternalistic. To a certain extent the elderly is indeed being protected against himself. Of Free Will finds this protective mechanism necessary for the sake of social carefulness. The self-aware elderly will have to accept the price for this social carefulness. His request is tested on the required conditions and can be denied. Automatic approval of every request for dying assistance is for Of Free Will unthinkable.

Lethal agent remains behind lock and key. They remain exclusively available on prescription and under expert guidance. A freely available Drion's Pill' is in the eyes of Of Free Will absolutely socially irresponsible

#### *Design comparable with euthanasia law*

The law 'Dying assistance for the elderly' is designed as much as possible identical to the euthanasia law. The law 'Dying assistance for the elderly' also includes the 'exclusion of punishment' principle: dying assistance remains punishable but when the required conditions have been met dying assistance will not be punished. The law also includes due care conditions. Granted dying assistance is required to be reported and reviewed by a Regional Review Committee.

#### *Careful, professional and testable*

Because the granting of assistance to the elderly who consider their life completed is highly radical, rigorous requirements are demanded. These focus on the professional conduct of the counsellor in dying, the criteria the elderly requesting help must meet, the conditions required for the dying assistance process, the reporting of granted dying assistance, and the testing of granted dying assistance by an independent committee. The counsellor is obliged to follow the standards of his professional institution. When the counsellor acts without due care he risks prosecution and can lose his licence.

## **Dying assistance**

### *Conditions*

(1) Central is the condition that the request for dying assistance is voluntary, well considered and lasting. The person making the request must make it personally and in full freedom. It cannot be a decision under pressure from others. The person making the request must be fully capable to make up his mind. He must be mentally competent. The request must be enduring and lasting.

(2) The second condition concerns the person himself who makes the request. He must be 70 years of age or over. Elderly persons through their life experience are better capable than younger people to decide whether or not life is still valuable for them. Elderly persons who consider their life complete are in general well able to assess which possibilities of life they cut short in doing this. For elderly persons it is also true that their quality of life in many respects cannot be improved. Their lives are in the downward line characteristic for the last phase of life.

(3) The person requesting assistance must have the Dutch nationality or be subject of a member state of the European Union and a minimal two years Dutch residency. European law decrees that the Dutch access to dying assistance applies equally to subjects of member states of the European Union. The condition of two years residency prevents undesirable attraction of dying assistance tourism.

### *Procedural conditions and process of granting assistance*

In the proposed law four procedural conditions are set.

(1) The counsellor must inform the person asking assistance about the content and procedural aspects concerning the requested dying assistance. The counsellor in dying must have at least two sessions with this person. These sessions must be spread out over a period of minimum two months. The sessions serve to make sure that the death wish is voluntary, well considered and lasting. If the elderly person has no objection family members and people close to him will be involved in the discussions. If the counsellor has doubts if the person requesting assistance is mentally competent, he shall with permission of the elderly person ask for a medical consultation with his family doctor or specialist.

(2) The person asking for assistance must record his request for dying assistance in a written declaration. When the elderly person after the sessions with the counsellor has come to an affirmative decision about his death wish, he makes a written declaration in which he confirms his death wish. He hands this declaration to the counsellor in dying. The counsellor must then come to a conclusion whether or not the due care requirements have been met.

(3) The counsellor in dying must consult at least one other independent counsellor. This other counsellor must speak with the person asking for help and then announce in writing his judgement about the question whether or not the required conditions have been met. The elderly person's counsellor decides whether or not the judgement the consulted second counsellor has any influence over his own conclusions. When this is not the case his decision about the dying assistance in question is definite.

(4) The counsellor is responsible for the professional carrying out of the dying assistance. This concerns among other the careful provision of the lethal agent by the counsellor to the person requesting assistance. The counsellor monitors that the person requesting assistance ingests the agents. In that way he makes certain that the lethal agent is not used for different purposes.

After the person has died the counsellor reports to the regional coroner by means of a completed form about the cause of the death. He also hands the coroner the report of the dying assistance granted by him. This report is remitted to the Regional Review Committee. This judges if the dying assistance has been performed according the rules of the law.

### *Lethal agent*

The lethal agent required for dying demands separate attention. In the Netherlands the issue of prescriptions for medicines is restricted to medical practitioners. Only doctors have the keys to the medicine cabinet. The counsellor in dying himself can therefore not issue a prescription for the medication. He requests from a doctor belonging to the foundation 'Dying assistance for the elderly' a prescription for the medication (more about this foundation in the next paragraph). With this prescription the counsellor in dying gets the medicines from an ordinary chemist shop.

Is a doctor prepared to issue a prescription for lethal agent in such a way? Belonging to the foundation is a multi-disciplinary team of doctors, pharmacists, ethicists and others. This team can trust that the counsellor in dying works according to the determined protocols and standards. The doctor has access to the dossier the counsellor keeps and can question him about this. All this provides the doctor sufficient basis to issue the prescription.

## **Counsellor in dying**

### *Counsellor in dying*

The problem of the completed life of the elderly is an existential problem not belonging to the exclusive medical domain. Therefore in the law the dying assistance is placed in the hands of a new professional group. In professional groups with experience in guidance of people who are at the end of life – such as spiritual caregivers, psychologists, doctors, and nurses – people may be found with affinity to these problems. People who chose to become counsellors in dying chose personally for this difficult and burdensome work (which is therefore very different from doctors, who saw as a professional group medical dying assistance added to their job by the euthanasia law).

They must qualify themselves specifically in the dying assistance for the elderly. After admission to the training they follow a thorough course in dying assistance. Government can dictate further requirements for the curriculum. After a successful course the participant receives a certificate. On the strength of this he can be certified as counsellor in dying by the foundation 'Dying Assistance for the Elderly'. It is mandatory for certified counsellors in dying to belong to the foundation. This requirement ensures that the counsellors are members of a professional organisation.

### *Professional organisation*

The foundation 'Dying Assistance for the Elderly' is a professional organisation responsible for the quality of the counsellors training and for the monitoring of the quality of dying assistance. In addition to counsellors in dying a multidisciplinary team of spiritual caregivers, psychologists, ethicists, doctors, nurses and pharmacists belong to this organisation. This team takes care of formulating the curriculum of the course and the professional standards and for refresher courses and peer review. The team is available for support to the counsellors in dying. It is important that the counsellors can fall back on this professional home base. The doctors of the team issue prescriptions for the lethal agents on request from the counsellors.

The foundation has a board and an advisory council. The Foundation has a complaints procedure that enables the elderly to file complaints about the counsellors in dying. The foundation reports periodically to the authorities about the practice of dying assistance. The foundation issues annual public reports. The authorities can wield influence over the foundation, for example the right to appoint members of the board and members of the advisory council, the approval or amendment of statutes and the ability to require information and to command inquiries. The public sensitivity of the foundation's work justifies this interference by the authorities.

## **Reporting and testing**

### *Reporting*

The counsellor in dying is obliged to report the dying assistance granted by him to the local coroner. He must include the details of the assistance granted. This report is remitted to the regional Review Committee for judgement.

### *Testing*

Since 1998 there are five Regional Review Committees in the Netherlands. These judge whether or not the euthanasia and medical assistance with suicide have been carried out in accordance with the

due care criteria of the euthanasia law. The law 'Dying Assistance for the Elderly' decrees that the assistance granted by the counsellors is also judged by these Regional Review Committees.

## Public debate in the Netherlands

### Public debate

#### *Great interest and intensive debate*

In February 2010 the Dutch Euthanasia society NVVE initiated a campaign to focus attention on the problem of the completed life. On television some impressive documentaries were shown of real life cases. At the same time the initiative group Of Free Will published its citizen's initiative. The well-known Dutch citizens of this group received full attention by the media. The result was that in the media for many weeks daily attention has been focussed on the problem of elderly people with completed life. Major newspapers published editorials about the subject.

In order to reflect the atmosphere of the reactions some citations follow: 'The difficult question the initiative group is asking is if the threshold for assisted suicide in cases of completed life can be lowered in a responsible manner. But important ethical, cultural and philosophical questions remain'. (NRC Handelsblad). 'Easy solutions are not available. Assisted suicide can prevent that someone resorts to humanly unworthy methods. But first an answer must be found to the uncomfortable question what a completed life is' (De Volkskrant). 'What is the value of the quality of life in a society that so easily allows death on request? This paper maintains that suicide should never be allowed to become normal because that way life loses in value and, however paradoxical this may sound, society loses in compassion' (Trouw). 'Suicide is the easiest solution that soon can lead to doubtful decisions. People must have the courage and wisdom to accept the inevitable and to not evade the natural end of life' (Telegraaf).

#### *Opinions on completed life*

In February 2010 an opinion poll was held in the Netherlands [17]. This showed that 85% of the population could imagine that old people who do not have a life threatening illness can consider their life completed. This percentage varied little with age or level of education. Almost 70% of the population is of the opinion that an elderly person who considers his life completed should be able to have access to help from a doctor to terminate his life. 53% is of the opinion that it should be possible for this dying assistance to be granted by well trained and certified non-medical counsellors. 21% is of the opinion that an elderly person who considers his life completed is never allowed to end his life.

#### *Preliminary conclusions*

The subject dying assistance for the elderly with completed life attracts much attention and evokes fierce reactions. A vast majority of the Dutch population (85 %) recognises the problem. A majority judges positively over the dying assistance for the elderly with a completed life, but about the nuts and bolts thereof too many uncertainties still exist.

## Reaction from medical practitioners' organisation

#### *Report about suffering from life*

In 2004 the Dijkhuis Committee, a committee instituted on instigation of the Royal Dutch Medical Organisation KNMG, published an impressive report: 'Seeking standards about manner of acting by

medical practitioners faced with requests for ending of life in cases of suffering from life' [18]. The committee finds that doctors are only sporadically confronted with requests for assisted suicide in connection with suffering from life. Doctors are reluctant to reckon this sort of request to be within the medical domain.

The Dijkhuis Committee distinguishes four possible views about the role of doctors in the termination of life because of suffering from life: (1) Suffering from life falls outside the domain of the doctor. (2) The medical domain of the doctor has wider boundaries. Only if the doctor possesses the necessary medical-professional skills is he in a position to consider cases of suffering from life. (3) Involvement of a number of experts is necessary. Specific expertise is required which is not exclusively the terrain of the doctor. (4) Assisted suicide belongs outside the professional sphere. The committee finds that none of these views can count on sufficient support within the professional group of doctors and/or society. Eventually the committee prefers view 2, where the dying assistance in cases of suffering from life can be granted by doctors who possess the necessary expertise.

The committee is aware that it has approached the problem of termination of life in cases of suffering from life from the question about the role of the doctors herein. The committee realises that a view of the problem from the perspective of the autonomy of the patient will yield different considerations and perhaps different conclusions. 'In the event that (in the future) a more wide ranging re-orientation on suicide and the legitimacy of assistance by others arises, it is less likely that doctors' organisations will play a pioneering role therein'.

#### *New position about the role of the doctor in self-chosen end of life*

The Dutch doctors' organisation KNMG rejects the proposals by Of Free Will for dying assistance for the elderly with a completed life. The KNMG fears that these proposals will lead to the erosion of the euthanasia law.

Early 2011 the KNMG reacted to a statement by the Regional Review Committees, to the proposals of Of Free Will and to the intensive public debate about it. The KNMG then published a new policy paper about the role of the doctor in the self-chosen termination of life. ('KNMG - draft policy regarding the role of the doctor in the self-chosen termination of life'). In this paper the KNMG accepts the advice of the Dijkhuis Committee. This new position can be summarized as follows. For a doctor to be allowed to proceed to euthanasia, the patient must be suffering unbearably and hopelessly. It has to be a matter of suffering of a medical condition. The notion suffering is wider than most doctors are aware of. Vulnerability, loss of functions, being bedridden, loneliness, tarnish, loss of dignity and loss of autonomy can be included in the judgement of a request for dying assistance. The mixture of medical and non-medical problems can lead to the conclusion that there can indeed be a matter of unbearable and hopeless suffering in the sense of the euthanasia law. Suffering without medical condition however falls beyond the reach of the medical practice and therefore also beyond the reach of the euthanasia law. A medical condition is defined as follows: a condition that can be defined as a combination of illness and complaints. So far the KNMG.

## **Criticisms**

In this paragraph a summary is presented of the reviews on the proposals of Of Free Will. Hereby it is attempted to classify the most important criticisms. It will be clear that herewith only limited justice

can be done to the often extensive and well-grounded critical opinions. After every group of reviews a short reaction on that will be given. These reactions are given from the perspective of the initiative group Of Free Will. When the word 'we' is used the initiative group is meant.

#### *Life is in principle sacrosanct*

For a part of religious people life is in principle sacrosanct. A human being shall not kill another and a human being shall not kill himself. Interference with the God given life is for human beings forbidden. God has life and death reserved to Him. The human being is not allowed to interfere and shall bide his time. This view is not shared by all believers. The in the Netherlands well known theologian Kuiters is of the opinion that the request for a soft death is not contrary to entrusting in Gods guidance. If the God given life is experienced as unliveable it is allowed to give it back to God.

The initiative group Of Free Will has respect for the views of believers who reject dying assistance in principle. Considering that in our proposals the voluntary nature and personal choice of the elderly is central, nobody - and therefore neither the believers with fundamental objections - can be forced into suicide. The principle of the sacrosanct life shall be valid for him in unabridged sense. We ask of the believers in question that they also have respect for our view. In a multiform, modern and tolerant society such as the Dutch it is inappropriate that one group imposes its moral views upon others. Believers cannot lay a claim to the absolute truth. Dying of free will does not harm outsiders.

#### *Suicide means ethical decay*

In the western philosophy suicide has for centuries nearly always been labelled as immoral. To help someone with it was a crime. Christianity formed the basis for this morality. Only in the 20<sup>th</sup> century did the inalienable right to self-determination obtain a more important place in morality.

Opponents of Of Free Will use in the discussions sometimes weighty moralistic words. 'Suicide is abhorrent no matter how carefully performed'. 'Behind the proposals hides an abyss of barbarism'. 'The almost smooth acceptance of the fact that people choose suicide, bears witness of an alarmingly cold morality'. 'What is quality of life in a society that puts so few obstructions in the way of death?'. Other criticism is aimed at the notion of the constructable human who wants to have everything under control from cradle to grave.

Of Free Will does not assume a Christian morality but the idea of a free and responsible human being. In this perspective the assistance with dignified suicide of the elderly on request is a deed of humanity and solidarity. We conclude that a society that allows such dying assistance for the elderly, has respect for the elderly and their wish.

#### *The proposals come with potential danger*

The possibility of dying assistance for elderly people with a completed life alone may be a threat for some. This possibility can put some ideas in the minds of the elderly, it can seduce and entice and confuse. The fear exists that the elderly persons who are not in the least bit tired of life may get the feeling that society may put the hard word on them. The elderly would too easily begin to believe what is foisted to them, to wit that the elderly have had their allotted time and should step aside for the younger generation. No one can foresee the consequences of legislation. It is too dangerous.

Besides these dangers also more concrete dangers are indicated. A death wish could be temporary and disappear again. People who have a death wish may be ambivalent about it and decide in a chaotic and impulsive fashion. Also an elderly person can be put under pressure by his nearest in connection with for instance an inheritance.

Firstly Of Free Will observes that the elderly as a rule are very well capable to defend themselves against possible pressure by their nearest or by society. Elderly people who are attached to life, do not allow others to drive them to death. In addition Of Free Will has paid a lot of attention in the Bill to the design of a careful and testable procedure. The expertise of the counsellor in dying, the series of discussions with the elderly and his nearest, the independent judgement of the second counsellor and the judgement of the Regional Review Committee offer in our opinion more than enough counterweight against the dangers mentioned. The built in protection mechanisms will work satisfactorily. At earlier discussions about the euthanasia law these objections were pointed out as well. In practice nothing like this has turned up. The introduction of this law has not led to undesirable developments. Obviously the regulations of the euthanasia law and the implementation thereof by honest professionals make sure that the law is not abused. We are of the opinion that the proposed law 'Dying assistance for the elderly' is just as trustworthy.

In the Netherlands medicines and drugs are available only on a doctor's prescription. The reason is pretty obvious. It is of course socially irresponsible if everyone could at random without any restrictions have access to lethal agent. In the propositions of Of Free Will the lethal agent remain behind lock and key. They can only become accessible to the elderly after a careful and controlled procedure.

#### *A death wish is caused by other problems*

Some reviews state that every death wish is in fact a scream for attention, respect and appreciation. The death wish of the elderly is a result of lack of attention and care. It is an indictment against society that leaves the elderly in marginalised and lonesome anguish. The answer to the death wish of the elderly is not death but good care and attention. Instead of going along with the death wish attention must be focussed on the life problems of the elderly.

No doubt there are elderly persons who languish and grow very lonely and therefore would rather be dead. Of Free Will agrees with the critics that in situations like these a proper solution must be found. It is to be expected that the counsellor in his sessions with the elderly person will help him to look for other solutions. When the elderly person finds back his zest for life by loving care that is to be applauded. But in case of a persistent heartfelt death wish more attention and care are not the suitable answer. No matter how well meant such a reaction doesn't take the elderly seriously. Elderly persons who consider their life completed are not interested in conversation therapy, occupational therapy, social contacts or other attempts to mitigate the loneliness and emptiness of their existence. They long for death and want to be listened to and to be respected.

Doctors point out that the death wish of the elderly can be caused by medical problems or medication taken. In order to preclude this it is advisable to always consult the elderly person's family doctor. Of Free Will agrees with this advice, but considers it going too far to include this in the legally prescribed procedure. In order to preclude that the death wish has a medical cause the counsellor will demand to consult the elderly person's family doctor.

#### *An age limit is wrong in principle*

There is criticism about the age limit chosen by Of Free Will. This is not about the chosen limit of 70 years, but about the choice to apply the law only to the elderly. People younger than 70 years of age can also consider their life completed. Why is the possibility of dying assistance denied them?

The short answer from Of Free Will is that we only work toward dying assistance for the elderly. The long answer has already been answered earlier. The elderly are at the end of their life. They have

lived the greatest part of their life and have a good overview of the remaining future. They feel the burden of the physical and spiritual limitations of their age and experience completion and detachment. Detachment is part of ageing. Many of the actual conditions of their lives are no longer improvable. All this makes it understandable that the elderly can consider their life completed and wish to die.

#### *The proposed law is superfluous*

Mostly from the doctors' side it is argued that the proposed law 'Dying assistance for the elderly' is superfluous. According to the KNMG the euthanasia law offers sufficient possibilities for dying assistance for the elderly who consider their life completed. The KNMG has formulated this in the new policy paper of the KNMG about the role of the doctor in the self-chosen end of life.

It remains to be seen to what extent this new point of view about the role of the doctor in the self-chosen end of life will actually be implemented by members of the KNMG. Many doctors find it difficult to perform euthanasia or dying assistance in a complex of medical and non-medical problems. At the present time nearly all doctors refuse dying assistance in case of completed life when it is not a matter of a terminal illness, unbearable and hopeless suffering or a dying phase. A recent poll of 800 doctors showed that 65% of doctors are not prepared to practice euthanasia on a person who considers his life completed (20% is prepared to do so and 15% has no opinion; 'One Today' TV opinion panel, July 2011). The ensuing years will reveal to which extent the elderly who consider their life completed can count on dying assistance by doctors.

Suffering without medical causes falls beyond the reach of medicine and the euthanasia law. For the elderly who consider their life completed without being ill, neither the euthanasia law nor doctors offer a solution. For dying assistance in this category of elderly persons the proposed Bill of Of Free Will remains necessary in spite of the new position of the KNMG.

#### *The proposed law erodes the euthanasia law*

The doctors' organisation KNMG and others are of the opinion that the law proposed by Of Free Will will erode the existing euthanasia practice. The KNMG is even of the opinion that the due care requirements of the euthanasia law will be lost. The elderly person who finds his euthanasia request denied by his doctor because it does not comply with the due care criteria, can try again via the route of Of Free Will. It is not right to create two routes to the self-chosen death beside each other, where one route is more difficult than the other. In that case the more difficult route of the euthanasia law is abolished: the elderly chose the simplest route and the doctor refers to the counsellor in dying. Says the criticism.

Of Free Will does not agree with this criticism. The two laws aim at two different target groups; the euthanasia law at seriously ill and suffering patients and the law 'Dying assistance for the elderly' at elderly persons who consider their life completed. It is also strange to call one of these routes easier than the other: as if suicide in case of a completed life would be simple. Of Free Will does not expect that seriously ill patients who have gone a long way with their doctor, will change to an unknown counsellor in dying. These patients count on their trusted doctor, even for possible dying assistance. Of Free Will sees both routes next to each other. Both routes are careful and good. There is no possible notion of erosion of the euthanasia practice. And eroding the euthanasia law is completely out of order. It is however recognised that with the acceptance of the proposals of Of Free Will doctors will lose their monopoly in dying assistance.

## Commentary

### Looking back

#### *The problem of the completed life is on the agenda*

What has Of Free Will achieved during the past two years? In the first place that the citizen's initiative has led to the fact that the theme completed life has a prominent place on the agenda. The problem of elderly people who consider their life completed has been presented in a penetrating fashion. The Dutch population recognises the problem of the completed life and the majority is of the opinion that a sound solution must be found.

The public debate can no longer be stopped. The theme completed life of the elderly disappears never again from public attention. There will be new cases out, new documentaries, publications and television programs. The result of parliamentary debate on the Bill is uncertain. It is not to be expected that parliamentary acceptance of the law will happen in 2011. Of Free Will recognises that the politics in medical-ethical questions are not in the limelight. The public debate must take place and only when there is sufficient public support politics will follow.

#### *Broadening possibilities for the euthanasia law.*

The public debate concerning the citizen's initiative 'Completed life' has had as result that the Dutch doctors organisation KNMG has revised its position on the practical possibilities of the euthanasia law. Until 2011 the KNMG was of the view that suffering from life falls outside the domain of the doctor and that the euthanasia law is not intended for the problem of the completed life. Only 1% of the requests for assisted suicide by elderly persons who consider their life completed is at present granted by doctors.

Early 2011 the KNMG has adopted a new position. Death wishes of elderly persons with age related ailments can indeed fall under the euthanasia law. Condition is that it must be a matter of unbearable and hopeless suffering with a medical basis. This new position of the KNMG can offer a solution for elderly persons who consider their life completed. Of Free Will is pleased with this new position. With this assisted suicide for the elderly with a completed life has become possible under the existing law. Of Free Will finds it courageous of the KNMG to implement this important change. The new position of the KNMG demands a big change indeed in the attitude of doctors. Where doctors until now did not consider the problem of the completed life to belong to the medical domain this now requires a drastic change. The ensuing years will reveal whether or not doctors are able to make this change. It can be expected that realisation of the new KNMG position will be closely watched. Also the periodic scientific evaluation of the euthanasia law will without doubt pay attention to this.

### Law dying assistance for the elderly

#### *Law dying assistance for the elderly remains necessary*

While Of Free Will is pleased with the wider possibilities of the euthanasia law, the proposed law 'Dying assistance for the elderly' is still necessary. The end of life of elderly persons must not

unnecessarily be brought into the medical scope. At the end of life existential and spiritual care is often more important than medical care. The problem of the completed life is an existential problem that is not exclusively reserved for doctors. It is therefore desirable that there will come counsellors in dying with different backgrounds and working from another perspective than the medical.

The second reason why dying assistance for the elderly remains necessary lies in the limitation to suffering on medical basis to qualify for medical assistance at suicide. When it is not a matter of suffering on a medical basis a doctor does not grant dying assistance. For this category of the elderly another solution than the one within the euthanasia law is necessary.

The autonomous route struggles with important limitations. The two methods – to stop eating and drinking and the medicine method – are often difficult ways that require proper knowledge and preparation. (Because for stopping with eating and drinking medical and nursing care is indispensable, this method fits in fact not quite in the autonomous route). It is not every elderly person's prerogative to practice this method. The medicine method is dubious because this is based on trickery and deceit in the procurement of the lethal agents. When the autonomous route is not passable for the elderly, they are dependent on assistance with their suicide.

Of Free Will finds the proposed law 'Dying assistance for the elderly' therefore necessary for three reasons: (1) Dying assistance for the elderly who consider their life completed should not be drawn into the medical field; (2) Elderly persons who are not suffering on a medical basis – and therefore are not eligible for assistance on basis of the euthanasia law – are dependent on the law 'Dying assistance for the elderly'; (3) Not for all the elderly the autonomous route is a passable route to the end; they are then dependent on dying assistance on basis of the law 'Dying assistance for the elderly'.

#### *Two laws side by side*

Why are there two laws required for the self-chosen end of life, the euthanasia law and the law 'Dying assistance for the elderly'? Why does the euthanasia law alone not suffice? For Of Free Will the answer to these questions lie in the different perspectives of these laws.

The euthanasia law assumes a medical perspective: the unbearable and hopeless suffering of the patient is central. Here it concerns suffering on a medical basis. Only the doctor can release the patient from his suffering at the patient's explicit request. By doing so the doctor steps in a different role: from practitioner he becomes counsellor in dying. In the euthanasia law the self-determination of the patient is not central. The law concerns the difficult position the doctor can find himself in when he is confronted with a seriously suffering patient whose suffering he is unable to mitigate and who makes an urgent call on him to release him from his suffering.

The Bill 'Dying assistance for the elderly' assumes the human perspective: the judgement of the elderly person that he considers his life completed is central. Here the matter is the loss of quality of life, the loss of dignity. The matter of completion and detachment. It does not have to be a matter of terminal illness or of suffering in the medical sense. The judgement about the completion of his life is the prerogative of the person in question only. Consequently the position of the counsellor in dying differs from that of the doctor: the counsellor does not judge whether or not the life of the elderly person is completed. He limits himself to make sure that it is a matter of a voluntary, well considered and lasting request. The consequence of this is that in the law 'Dying assistance for the elderly' it is in much greater measure a matter of self-determination of the elderly.

The two laws have therefore each their own perspective and target group. The euthanasia law

assumes the medical perspective, wherein the suffering of the patient is central. The law 'Dying assistance for the elderly' assumes the human perspective, wherein loss of quality of life is central. These differences are so essential, that they justify two different laws. These two laws do not compete, they complement each other.

## **Two visions on suicide**

In the previous paragraph is outlined that the euthanasia law and the Bill 'Dying assistance for the elderly' differ in target group and perspective. What can be the backgrounds of a preference for one of both laws? Firstly a preference will to a large extent be determined by the circumstances, the views of the person who wishes to die, his biography and his future perspective. Besides that the preference is based on the vision one has on life.

The euthanasia law has its roots in a vision wherein suicide is found unacceptable in principle and must therefore be avoided as much as possible. This vision leads to the notion that euthanasia and assisted suicide must be made very difficult and that strict criteria must be applied to dying assistance (unbearable and hopeless suffering). It must be a matter of an emergency situation. The great reluctance of doctors with the granting of dying assistance is seen as guarantee against too rash dying assistance.

The Bill 'Dying assistance for the elderly' is rooted in another vision. Herein every human being has the freedom to decide himself about his living and dying. In this vision well considered suicide is a choice to be respected. To assistance with suicide only criteria must be applied that refer to a social and public responsible state of matter (voluntary, due care and testability). The great reluctance of doctors with the granting of dying assistance is seen as an unjustified attenuation of the application possibilities of the euthanasia law.

Both visions deserve respect. Every elderly person must be able to choose in freedom from his vision on life to which law to give his preference.

## Accountability

### *Sources*

In this document in a number of places reference is made to the source of the statement. Five publications are named here separately.

(1) Firstly the book 'The self-chosen end of the elderly' by Huib Drion (1992). The citations in the paragraph 'Completed life' are from this book. The inclusion of these citations is also homage to the man who opened the debate about completed life in the Netherlands in 1991.

(2) In 2008 the policy statement of the Dutch Euthanasia Society NVVE 'Perspectives on Dying with Dignity' was published. In this memorandum next to the known medical perspective also other perspectives were mentioned for the first time. The autonomous route obtained a full place and the caregivers' route was introduced.

(3) In 2011 the book 'Of Free Will, Dying with dignity at advanced old age' was published. This book describes the thoughts of Of Free Will. The book contains among others a proposal for a Bill 'Dying assistance for the elderly'. This Bill was drafted by Eugène Sutorius, Jit Peters, and Samantha Daniels. This book forms the basis of this document.

(4) The book 'Euthanasia, a different view of the practice; interviews with survivors' by Hans van Dam describes many moving interviews with survivors of people who died through euthanasia or medically assisted suicide. The example 'One of Many' is from this book.

(5) In 2007 'Evaluation Law Testing Life Ending on Request and Assisted Suicide' was published (this is the official name of the euthanasia law). A number of texts in this document are derived from this evaluation report.

### *Initiative group Of Free Will*

While this document was written by one of the members of the initiative group Of Free Will, the contents are the thoughts of the entire group. The various backgrounds of the members of this group contributed to the intensive and fruitful discussions. It is therefore appropriate to name once again the members of the group: Hedy d'Ancona, Yvonne van Baarle, Wouter Beekman, Frits Bolkestein, Mies Bouwman, Marie-José Grotenhuis, Eylard van Hall, Jit Peters, Milly van Stiphout-Croonenberg, Theo Strengers, Eugène Sutorius, Dick Swaab, Katuscha Tellegen, Jan Terlouw and Paul van Vliet.

## Notes

[a.o. = and others]

- [1] B.D. Onwuteaka-Philipsen a.o.: Evaluation Law Testing ending of life on request and assistance with suicide. 2007 (page 29)
- [2] B.D. Onwuteaka-Philipsen a.o.: Evaluation Law Testing ending of life on request and assistance with suicide. 2007 (page 47)
- [3] J. Peters, E. Sutorius a.o.: Of Free Will, dying with dignity at advanced old age. 2011 (page 27)
- [4] NVVE, Dutch Society for a Voluntary End of Life: Perspectives on dying with dignity. 2008
- [5] B.D. Onwuteaka-Philipsen a.o.: Evaluation Law testing ending of life on request and assistance with suicide. 2007 (page 220)
- [6] B.E. Chabot and Stella Braam a.o.: The Way Out, a dignified end of life in your own hand. 2010 (page 67)
- [7] B.E. Chabot: Auto-euthanasia: Hidden ways to die in communication with nearest. 2007
- [8] H. van Dam: Euthanasia, the practice viewed in a different way. 2005 (pages 173, 177,178)
- [9] H. van Dam: The decision that it's enough it is a holy decision. Relevant 1/2003.
- [10] M.L. Rurup a.o.: Wishes to die in older people, a quantitative study of prevalence and associated factors. 2011
- [11] P. Scocco, D. De Leo; One-year prevalence of death thoughts, suicide ideation and behaviours in an elderly population. Int.J.Geriatri.Psychiatry 2002,17.
- [12] H. Drion: The self-willed end of old people. NRC Handelsblad 19 October 1991
- [13] H. Drion: The self-willed end of old people. 1992 (pages 117,118)
- [14] B.D. Onwuteaka-Philipsen a.o.: Evaluation Law testing life ending on request and assistance with suicide. 2007 (page 224)
- [15] M.L. Rurup a.o.: Experiences of doctors with elderly who are 'finished with life'. Doctors & Science 2005/48
- [16] J. Peters, E. Sutorius a.o.: Of Free Will, dying with dignity at advanced old age. 2011 (pgs.45-54)
- [17] NVVE Dutch Society for a Voluntary end of Life: Completed life, what are we talking about?
- [18] J.H. Dijkhuis a.o.: Looking for standards for doctors how to act when asked for ending of life in cases of suffering from life. 2004 (pages 39 – 42).
- [19] J.J.M. van Delden a.o.: Knowledge and views of public and professionals about decision making and how to act concerning end of life. 2011 (page 200)

It is noticed that except [10] and [11] all references are in the Dutch language.