

Completed Life

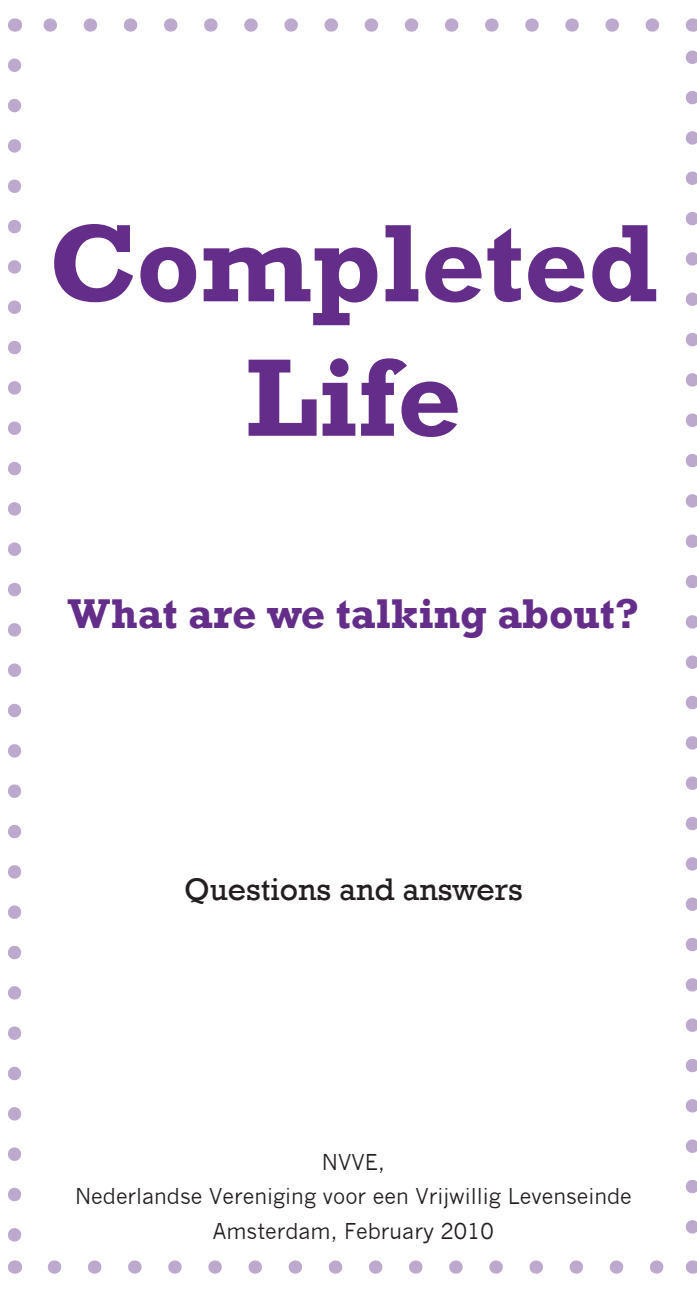
What are we talking about?

Questions and answers

NVVE

NEDERLANDSE
VERENIGING
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LEVENSEINDE

RIGHT TO DIE
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NVVE,
Nederlandse Vereniging voor een Vrijwillig Levenseinde
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NVVE

P.O. Box 75331

1070 AH Amsterdam

Telephone: +31 (0)20 6200690

Weblog: www.voltooidleven.nl

Website: www.nvve.nl

E-mail: debat@nvve.nl

Text: Marleen Peters, project consultant 'Perspectives
on dying with dignity' NVVE

Translation: Maarten Pennink

Creative Director: Kees Wagenaars, Breda

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CONTENT

Preface	5
1 Where did the discussion about completed life originate?	7
2 What do we mean by completed life?	8
3 Is 'finished with life' and 'unduly suffering in life' equal to 'completed life'?	9
4 Why is the subject relevant now?	10
5 Is this the first time that the subject has become relevant?	11
6 Which category of people are we talking about?	12
7 Can people with a life-threatening disease possibly consider their life completed?	13
8 Does the 'Drion pill' (last-will-pill) exist?	14
9 Is assisted suicide permitted in The Netherlands?	15
10 What is meant by the due-care requirements named in the law on euthanasia?	16
11 Is a physician allowed to provide for assisted suicide for someone, who considers life completed?	17
12 What assistance is allowed to be given by non-medical individuals?	20
13 Can younger people also consider their life completed?	21
14 Those who are in favor of self-determination, why don't they obtain life-ending medicines themselves?	22
15 People, who consider their lives completed, why don't they stop with eating and drinking?	23
16 Does the chance exist that elderly people, being depressed or lonely, will ask for assisted suicide?	24
17 Who should be allowed to give end-of-life assistance in case of completed life?	25

'Without much doubt, I have the feeling that many elderly people would be greatly relieved knowing that there is a means to end life respectably at the moment suitable to them, based on what they reasonably can expect from that point on.'

H.Drion, NRC Handelsblad, October 19, 1991
(translation from Dutch)

PREFACE

In 1991, Dr. Huib Drion brought to the fore the problem of elderly people considering their life completed and wishing to have access to medicine with which they can end their life at a self-appointed time. Since then, for this group the discussion about 'making self-determination of life's end' a reality has been placed on social and political agendas. However, equally many times the discussion has been stalled or pushed aside.

In February 2010 the NVVE, Right-to-Die Netherlands, supported by other social organizations, started the campaign Completed Life. Interrupting this societal debate again shouldn't be allowed. The NVVE is of the opinion that the elderly should be allowed to make a well thought-through choice at the end of their lives and that such a choice will be entirely up to them. Of course, people are not forced to make use of assisted suicide, but they should be at liberty to resort to such, if they wish to. When human suffering can be avoided, the NVVE is of the opinion that access to assistance shouldn't be withheld. Obviously, under all circumstances all forms of due-care should be practiced.

Politicians and physicians are afraid to burn their hands on this issue, and, therefore, have called for a societal debate. That is what the NVVE is planning to conduct in the coming years. This folder, 'Completed Life - What are we talking about?' will be the basis for this debate. In this publication, the NVVE does not take a position, but has outlined sequentially the ground rules, facts and results

of the discussions gathered over the past years. All this in the hope, that it will contribute to an open debate, that will lead to the realization of a solution for this difficult and highly emotional problem for people who consider their life completed, and, therefore, prefer death over life.

Dr. P.M. de Jong, director NVVE

Amsterdam, February 2010

Where did the discussion about completed life originate?

In 1991, Huib Drion (1917 - 2004), Professor and Vice President of the Dutch Supreme Court, wrote an essay in the Dutch newspaper NRC Handelsblad, in which he pleaded for the availability of a medicine for the elderly to end their lives humanely and at the moment of their choosing. The reactions to Drion's article were overwhelming. Drion had given voice to the growing problem many elderly people experience: concluding that, after many years on this earth, life has been completed, but that they are in many ways forced to continue. It didn't take long before the 'Drion's Pill' became a common point of discussion.

What do we mean by completed life?

In 2001, during the parliamentary debate on the euthanasia legislation, completed life was being defined as:

'Without having an unmanageable disease or ailment paired with profound suffering, from a medical point of view, the situation for these advanced aged people dictates for them that the quality of life has diminished to such an extent, that they prefer death over life.'

In 2004, the Committee Dijkhuis, while doing research relating to the physician's role in life's suffering (as established by the KNMG, the Royal Dutch Medical Association), came up with a revised description. The committee concluded that the degree of suffering and level of despair for people, who find their life completed, was not adequately addressed in above definition. The committee put forth the following, a consciously broadly described approach to the issue:

'Suffering under the prospect of having to continue life at a profoundly diminished level of quality, which results in persistently recurring longing for death, without being able to determine a somatic or psychological reason.'

Is ‘finished with life’ and ‘unduly suffering in life’ equal to ‘completed life’?

‘Finished with life’, ‘unduly suffering in life’, ‘tired of life’ are all terms used in the discussion about people, who persistently express a death wish, because they are under the impression that they have lived their lives (‘Tomorrow, I hope that I won’t be waking up’). With the term completed life people are going one step further. They are deciding not to wait for a natural death process, but decisively (with or without assistance) taking steps concluding life.

Why is this subject relevant now?

In the first half of the previous century, living conditions were still such that fewer people reached old age. Increased prosperity, improved social conditions and improved medical care have enabled many - under positive or negative sustainable living conditions - to reach an advanced age. It is expected that the number of 65-plussers will increase from 2.5 million now to 4.2 million by 2050 (40 percent of the Dutch population). Also, in the future, comparatively, there will be more 80-plussers.

The high birth rate in the period following the second world war till the end of the sixties will reflect itself in the rise of the number of seniors. Of those who became 65 in 2009, it is expected that 72 percent of those will reach the age of 80. This generation, the so-called baby boomers (also known as the 'protest-generation'), in contrast to the pre-war generation (or 'silent-generation') is more autonomous, focusing on independent choices and is socially critical. The baby boom generation is directed toward free will, assertive orientation and standing up for their self-interest and rights. It is favoring self-determination: they want to decide how to live and die, and no one should decide for them.

Is this the first time that the subject has become relevant?

It is not the first time in the history of mankind that the subject has become relevant. Ever since the classical period, aging populations in various cultures have made the decisions and methods for their own life-ending processes.

Which category of people are we talking about?

By completed life is meant people suffering from a complex set of factors coupled to old age. Frequently it refers to a combination of:

- non-threatening ailments;
- bodily decline (poorer mobility, vision and/or hearing, tiredness, listlessness, incontinence) leading to loss of active life participation, loss of independence and personal dignity;
- dependency on care (one does not want dependency and becoming a burden to family, close friends or the community);
- loss of status and the direction of one's own life;
- declining social network (caused by the death of a partner and/or children, friends and neighbors);
- loss of future and purpose;
- detachment from the community (the bond with people, the material aspect and the 'world of now' is no longer);
- fear for the future;
- absence of prospects.

One possibly can or may want to continue one's life with one or more of these factors (of value). An other may come to the conclusion that life has been lived and, therefore, life should come to an end. So, whether one considers life completed always will be a personal judgment, and never can be spoken of a generally accepted opinion.

Also, above factors do not imply that the discussion about people who consider their lives completed solely pertains to 'forlorn individuals rocking on rocking chairs'.

People may want to avoid one or more of the above factors, such as bodily decline, becoming dependent on others and loss of direction, and conclude that their lives have been completed.

Can people with a life-threatening disease possibly consider their life completed?

It is quite understandable that people having a serious, life-threatening disease consider their lives complete. Therefore, this group will not be excluded from the debate on completed life. The focus, however, will be on the aging who do not have a life-threatening ailment, because in The Netherlands sick people suffering unbearably and with no future in sight can request assistance from a physician for assisted suicide. When the physician can abide by the due-care requirements, then, for the purposes of assisted suicide, the law on euthanasia can possibly be implemented without legal repercussions.

Does the 'Drion-pill' (last-will-pill) exist?

The 'Drion pill' - later also termed 'last-will pill' - has become favored as a metaphor for 'the freedom for the aged to depart from life based on what the future still may have to offer, and after balanced thought and in a legally appropriate way.' Consequently, such a pill does not exist. Drion himself has never spoken of a pill. This was purely a creation of the media. Of course, medicines do exist to end life in an effective and pain free manner, such as the deadly potion provided by the physician, while assisting in suicide. But this potion cannot be purchased by a layman. When someone gathers suicide-type medicine, it never refers to one pill, but always a combination of medicines, such as an anti-vomit remedy (one needs to start this process several days prior to the suicide), sleep-inducing medicine and the death-causing medium. In total, 120 to 150 tablets are involved. In The Netherlands, these can only be obtained through a doctor-issued prescription. Therefore, there is no such thing as a 'pill on the night stand', which brings with it the risk of mishaps and misuse - as in a grand child 'stumbling' onto the pill.

Is assisted suicide permitted in The Netherlands?

According to the Dutch law, committing suicide is not illegal. Assistance in suicide is. The penal law (art. 294) specifies: 'He who purposely assists another in suicide or provides him/her the means to do so will be prosecuted, if this results in end-of-life, with a maximum prison sentence of three years.' Which means that suicide is not punishable by law, but accessory to assistance in suicide is. This is very unusual, since in all other cases under Dutch law, the degree of punishment for complicity is always coupled with the degree of punishment for the main offense.

Under the Dutch law on euthanasia, an exception has been made for physicians. A physician is not punishable when his intervention has been reported appropriately to the municipal coroner and he has abided by the due-care requirements as described in the euthanasia law.

What is meant by the due-care requirements named in the law on euthanasia?

The due-care requirements, as laid down in the law dealing with life-ending requests and assisted suicide (in short the law on euthanasia) imply that the physician:

- a. has come to the conclusion that there is evidence of a voluntary and well contemplated request by the patient;
- b. has come to the conclusion that there is evidence of hopeless and unbearable suffering by the patient;
- c. has informed the patient about the situation in which he/she finds him/herself and about his/her prospects;
- d. has come to the conclusion together with the patient that no reasonable, alternate solution is available;
- e. will consult at least one other, independent physician, who will visit with the patient and who will present his conclusion in writing with regard to above mentioned due-care requirements;
- f. will carefully execute the life-ending procedure or assisted suicide.

Is a physician allowed to provide for assisted suicide for someone, who considers life completed?

In the past, three law suits have been completed in which a judgment has been passed regarding assisted suicide by a physician to people who considered their life completed.

Case ‘Schoonheim’

In 1983, family physician Piet Schoonheim appeared in court. He had given ‘end-of-life’ assistance to a 95 year old lady, whose health was rapidly declining. For ten years, she had been requesting end-of-life medicine. During this process, the court in the city of Alkmaar freed Schoonheim from prosecution. Some of the considerations which lead to this decision were based on the notion that the right for self-determination, regarding ‘end-of-life’ was being more broadly accepted; and that Schoonheim could refer to emergency action, because this was the only way, by which the physician could fulfill the permitted goal (the patient’s right to conclude life gracefully). In 1986, the High Court in The Hague honored the call for emergency action, and thereby freeing this family physician from further prosecution.

Case ‘Chabot’

In 1993, Psychiatrist Boudewijn Chabot was requested to appear in court. He had provided medicine to a woman, with which she was able to conclude her life. The woman was physically in good condition, but, for many years, suffered from complications originating in a past marriage, the subsequent divorce and the loss of her two sons. Prior to this, she had already made attempts to end her life. The courts in the city of Assen and later on in the city of Leeuwarden came to the conclusion that there was evidence of unbearable and hopeless suffering. Apparently, the cause of the suffering was of no importance. The High Court fol-

lowed this line of reasoning, thereby establishing for the first time separation of suffering from the underlying illness.

Case ‘Brongersma’

In 1998, former Senator E. Brongersma ends his own life by taking end-of-life medicine provided to him by his family physician Flip Sutorius. Brongersma did not suffer from serious physical or psychiatric illnesses, but was ‘tired-of-life’. In October 2000, in Haarlem’s court, where the case was being brought to the fore, the central issue was whether one can speak of unbearable and hopeless suffering. The court decided that Brongersma could not expect improvement or significant change and, therefore, his situation could be considered as unbearable and hopeless. Consequently, Sutorius could rightfully appeal to an emergency situation. Sutorius was freed from all forms of legal prosecution. This judicial ruling was eventually supported by the law on euthanasia, which became effective in 2002. According to this law, a physician is not punishable when he/she has adhered to a set number of due-care requirements, including unbearable and hopeless suffering. According to this law, the origin of the suffering is not relevant. With this ruling, the law provides physicians with the interpretation that unbearable and hopeless suffering can be seen as a ‘having suffered enough in life’ condition. However, several months following the introduction of the law on euthanasia, this interpretation was being over-ruled. The High Court established, following the court in the city of Amsterdam, that euthanasia or physician assisted suicide only can be provided when one can speak of a medically classified, physical or psychiatric illness or disease. Regarding existential suffering, the court is of the opinion that physicians are not ‘decision’-qualified, plus that suffering from life is not a legitimate reason for assisted suicide.

The High Court thereby decided that, in case of completed life, physicians are only justified to assist in suicide - strictly within medically established boundaries.

What assistance is allowed to be given by non-medical individuals?

In previous years, jurisprudence, regarding non-medical individuals who were involved in assisted suicide, has concluded that it is permitted to provide information about the manner in which someone is allowed to end his/her life. Also, it is allowed to be present at the actual process of suicide. However, carrying out actions, handing out instructions or taking over the management is punishable under the current legal framework.

Can younger people also consider their life completed?

Every choice for dealing with age limitation to become eligible for assisted suicide is debatable. Since 1991, when the discussion on this subject began, the age limit, however, keeps coming up (Drion suggested 75 years and older). Restricting assisted suicide to individuals of very advanced age seems more understandable. In general, older people have a better insight what portion of future life might be curtailed, than a sixty, forty or twenty year old person. Drion described it as follows: 'Old people have a better view into their life's perspectives than someone younger. Old people know better what their future brings. Younger individuals are not yet familiar with their future 'I'. Also, younger people, who are not emotionally or physically sick, will not readily satisfy the description of a completed life (see question 6). There is probably something else the matter, if they consider their lives completed.

Those who are in favor of self-determination, why don't they obtain life-ending medicines themselves?

Individuals, who consider their lives completed and wish to end their lives, can choose from a number of possibilities: suicide by inhumane methods (jumping in front of a train or out of a window, drowning, hanging or even burning) or in a humane way by taking death inducing medicines. Only a few, such as physicians and pharmacists can have access to such humane medicines. For the great majority of the elderly, medicines for a gracious death are otherwise very difficult to obtain from the family physician (through guile) or (illegitimately) from a drugstore located in another country and via the internet.

People, who consider their lives completed, why don't they stop with eating and drinking?

Abstaining from eating and drinking (deceasing) with assistance of next of kin and other medical accompaniment is a viable option only for the very old whose organs are failing, because of wear or a very serious disease. However, it is not considered a humane method for those who are not in a very weakened state. For those cases, abstaining from eating and drinking may well be accompanied by serious headaches, muscles cramps and epileptic attacks. Then, dehydrating will be a very painful and often a drawn-out process. Certainly not leading to a mild and dignified death.

Does the chance exist that elderly people, being depressed and lonely, will ask for assisted suicide?

Just as with requests for euthanasia or physician assisted suicide with a somatic or psychological illness, great care can be taken with requests for assisted suicide in case of a life completed (see question 17). Combined with this approach, one needs to examine the possibility of the existence of treatable psychological illnesses or other ailments, such as anaemia, which may lead to listlessness and fatigue. One needs to be alert that the depressed mood of people, who consider their lives complete, is not being confused with a psychological or physical illness.

Loneliness is a completely different story. The importance for the need of adequate attention, assistance and care cannot be over-emphasized. With completed life something else plays an important role: the absence of the partner, children and the friends, one has survived. The absence of 'kindred spirits': people who can daily identify with you, with whom you have shared life and loss of life, and who have contributed to the person you are now.

Who should be allowed to give end-of-life assistance in case of completed life?

Exactly who the designated person or authority is giving the requested assistance in dying, is part of the discussion. Is a role for the (family) physician recommended? Or will a non-medical individual be better equipped to assess the situation? Or is the sum total the responsibility of the patient in question?

Outlined below are the various positions of the advocates in the matter:

Assisted suicide by a physician

Existential questions (the ones dealing with human existence) can play a distinct role at completed life, and one may expect from a physician that he/she can deal with these professionally and carefully. After all, every day people turn to physicians for a response to all kinds of existential problems. In addition, physicians fulfill as yet a key role for (the entry way to) assistance in the life-ending phase. Only physicians have access to the 'key to the medicine cabinet'. And within the current judicial framework, only physicians are allowed to call onto the legally based special penal-exclusionary rule.

The advocates for the 'medical route' are of the opinion that the due-care criteria, as established in the euthanasia law (see question 10), also may apply for completed life. However, the legislator (while debating the law on euthanasia in the Dutch Parliament) as well as the High Court (in the case 'Brongersma', 2001) disallowed this path. They ruled that 'enough of life' forms no penal-exclusionary base for life-ending procedures carried out by a physician. A way suggested to solve this problem is, besides unbearable and hopeless suffering, to include the criterium of 'irreversible loss of personal dignity' as an extra due-care requirement in the law on euthanasia. Thereby people, who

consider their lives completed without suffering from a hopeless ailment, they too can refer to a physician for help.

Assisted suicide by a non-medical caretaker

Proponents of the 'caretakers alternative' are of the opinion, in situations of completed life, that the request for assisted suicide is primarily an existential question and not a medical one. Individuals, who strictly consider their life completed are not patients and, therefore, it is felt that this problem does not belong within the medical domain. This type of help should be carried out by specially trained and government certified, non-medical caretakers, such as clerics, professional ethicists or psychologists. Just as with euthanasia and physician assisted suicide, here too due care standards should apply, whereby the caretaker is required to notify his actions taken, followed by a critical evaluation of those actions.

At present, the Dutch law prohibits assisted suicide by non-medical caretakers. A possible solution suggested is scrapping article 294 in the penal code, which states that assisted suicide is punishable by law.

Another option is to revise article 294 to such an extent that only the act itself of suicide remains punishable. A third option named is to add a third subsection to article 294 in which exceptions are being incorporated, outlining that certified non-medical caretakers will not be punishable when they comply with the above conditions.

Suicide without assistance

Not too long ago, barbiturates (euthanatica) were freely available. Proponents of suicide without help (the autonomic route) are of the opinion that this approach has not lead to an increase in the number of suicides. The dependency on a physician or other caretaker for the purchase of death-inducing medicines is being experienced as a hin-

drance to the desired autonomy by proponents of suicide without help. Plus, they don't want to burden the patient's physician or others with their wishes.

They argue for a ruling allowing older people with proper passport identification to purchase this kind of medicine at a specialty shop or pharmacy. Then, only 'the purchasing of these medicines and when' are to be registered. Just as with the pamphlet 'Pregnant and what now?', the pamphlet on 'Completed Life' should be available everywhere. In addition, the possibility exists, not the obligation, to consult about the death wish with an expert. The threshold for such a consultation is low, because the petitioner doesn't have special responsibilities and the expert doesn't have to check or evaluate whether the individual is allowed to have the medicine.

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