Self-euthanasia, a good death & end-of-life autonomy

Ton Vink (Amsterdam 2016)

Si vis vitam, para mortem; S. Freud.

Ladies & Gentlemen,
A hundred years ago, the First World War – the world's biggest 'slippery slope' – was raging and Sigmund Freud paraphrased a well-known saying that we also find in Plato's *Laws* and that we now know as *Si vis pacem, para bellum*. If you want to enjoy peace, prepare also for war.
In trying days and developing his theory of psycho-analysis Freud paraphrased this saying in a short paper (*Imago, 1915*) as *Si vis vitam, para mortem*. If you want to enjoy life, prepare yourself also for death. Plato, by the way, also defined philosophy as 'training for dying'.
In 1991, Huib Drion former Dutch Supreme Court judge and professor of civil law, introduced the idea of what we now know as 'Drion's pill', an as yet fictitious pill. This pill was not meant for terminally ill who expected to die within 6 months. Its purpose was: *Si vis vitam, para mortem*. If you want to enjoy (the rest of) your life, prepare also for your death.

Probably it will not be far off the mark when I say we would all of us like to die a *good death*. But how does your 'good death' look like? Before entering our debate in my lecture, I suppose it would do no harm to present my idea of my own good death. I can do so in the words of the German philosopher Arthur Schopenhauer. In his *Aphorisms on the Wisdom of Life* he refers to euthanasia or a good death as follows:

' ... only those who passed the age of ninety, will enjoy euthanasia, which is to say that without disease, without a stroke, without hawking, sometimes even without fading, usually while seated, they will, after having enjoyed their meal, die, or maybe better not so much die, but simply stop living'.[1]

It is worthwhile to remember that if this 'good death' were a certainty for us, we would not be having this world-conference. But as we are well-aware, sometimes painfully aware, there is no such certainty. And therefore I will feel free to continue our on-going debate.

Represented in diagram-form a 'good death' may take a four-fold shape:
(1) As in Schopenhauer it means you simply stop living at an advanced age.
(2) In a final stage of palliative care you might glide away into the big sleep.
These two shapes of a good death, many of us would prefer, are registered as 'natural deaths'.
(3) But you might also end your life as a result of physician-euthanasia.
(4) Or you might end your life as a result of self-euthanasia.

[1] Arthur Schopenhauer, *Parerga und Paralipomena*, geciteerd uit *Aphorismen zur Lebensweisheit*, Marnixverlag, Wiesbaden, 2010, [1851], blz. 222.

The last two shapes of a good death are as yet considered non-natural.

In my lecture I will focus on two connected notions: euthanasia or a good death and self-euthanasia. I will establish the meaning of a 'good death' *when death is self-chosen* (as in 3 and 4 in the diagram). In doing so I will take as my point of departure the new notion of 'self-euthanasia' and the corresponding practice that has evolved in the Netherlands in recent years.
'Euthanasia' in accordance with the so-called Dutch 'euthanasia law' will be referred to as 'physician-euthanasia'.
As to self-euthanasia, I will restrict myself to the use of lethal drugs and will leave out the use of helium or other gasses and the process of voluntary refusal of food and drink.
Apart from establishing the meaning of a 'good death' when – I repeat – death is self-chosen, I will also defend an order of preference between the shapes this self-chosen good death may take. This order of preference will partly result from the very meaning of a 'good death' and partly from considerations of a moral or ethical nature.

1. Some definitions are required first

Following the Dutch State-Committee on euthanasia (1984) in the Netherlands physician-euthanasia is understood as 'the deliberate termination of the life of a person on his request by another person' (I strongly recommend to add to this: in accordance with the demands of the euthanasia-law). This covers, without much distinction, both procedures of the termination of the patient's life by drip and lethal injection, and assistance with the patient's suicide.
Somewhat in the same vein, I define the new notion of self-euthanasia as 'the deliberate termination of his or her own life by the person himself, under his own control, after clear and careful consideration and carried out with due care.' (Please note: This is not to define self-thanasia but self-*eu*thanasia; I will expand later on what makes it good.)
In physician-euthanasia as well as self-euthanasia death is 'self-requested'. However, by way of vital distinction, only self-euthanasia is also 'self-performed' and 'self-determined'.
Self-requested refers to the individual himself wanting, requesting, an end to his life.
Self-performed refers to the individual preparing and carrying out all of the act.
Self-determined refers to the individual having the only autonomously deciding voice.

Finally, I will define 'self-determination' (or 'autonomy') in the context of self-euthanasia and physician-euthanasia as: 'The attaining and keeping of control and authority over the process of preparing, deciding and bringing about the termination of one's life with due care and concern.'

2. A remark on suicide and *eu*thanasia

If you jump from a 20-storey building, then, when you hit the pavement you will be good, that is: very, dead.

Further, depending on the circumstances, some of those who are well-acquainted with your dire situation might after your suicide even say that, irrespective of the way you ended your life, it is good, that is: something positive for you, that you're dead.
But did you die a good death? Obviously, jumping from the 20 storey building results in what we know as plain suicide, but for such a suicide to qualify as self-euthanasia, more is needed.
The comment that it is good for you that you are dead, will also be subject of debate.
For the moment, please remember that every case of self-*eu*thanasia is, by definition a case of suicide, but the reverse is not true.

3. A further remark, about the physician's role

It is of vital importance to realize that in the Netherlands under the euthanasia-law the requirements of due care are legal requirements that have to be met *by the physician*, not by the patient[2].
Though the patient must indeed make his well-considered request, the decisive voice is the physician's, that is to say: the physician has to decide whether he or she is *in principle* prepared to put an end to a patient's life on request. If 'no': the affair ends and the physician is expected (but not formally obliged) to refer the patient to a colleague. If 'yes': the physician has next to determine whether or not he (the physician) is able to answer the requirements of due care. Again, if 'no': the affair ends; if 'yes': the affair may proceed.
The physician's autonomy is decisive. The patient's autonomy is of importance in his *requesting* euthanasia, however, respect for personal autonomy is not the leading principle of the Dutch approach to euthanasia. The leading principle of the Dutch legal norms for euthanasia is compassion.

4. Some further remarks on the Dutch law

Is the Dutch euthanasia-law really about euthanasia or a 'good death'?
For a start, euthanasia isn't mentioned a single time in the entire law. It certainly pays off to look at what this law is literally called: *Law on the Review of the Termination of life on request and assistance with Suicide* (LRTS).
This type of termination of life was already taking place for years. What the law does is introduce a statutory review procedure, such that while the termination of life remains punishable, a physician answering the requirements of due care as formulated in the law (or LRTS), will not in fact be prosecuted.

The *reviewing* is the core business. This *reviewing* is done by a small number of committees that style themselves *Regional Review Committees on Euthanasia*. One

[2] For the readers convenience, this is what the law requires the physician to do in art. 2.1 of the LRTS: 'The physician: a. must be convinced that the patient's request was voluntary and well-considered, b. must be convinced that the patient's suffering was hopeless and unbearable, c. has informed the patient about his situation and his prospects, d. has come to agree with the patient that there was no other reasonable solution to the patient's situation, e. has consulted at least one other, independent physician who saw the patient and gave a written report on the requirements of due care, referred to above in a to d, and f. has performed the termination of life or given the assistance with suicide, with due medical care.'

might therefore think that these committees review whether the patient had died a *good death*. But no. What these committees (in whose formal name the word *euthanasia*, equally, doesn't appear[3]) review, is whether the physician answered the requirements of due care.
And you will look in vain among these requirements for the requirement of the patient dying a 'good death'.

Over the years now some 50,000 cases have been reported to the review-committees. Virtually *all* cases (close to 99.9%) where judged to meet the requirements of due care, and even when review-committees had some criticism, so far not a single physician has ever been brought to court, let alone been convicted, due to the review of the committees.

But what about the patient? Did he or she die a *good death*? We may have little reason to doubt that an overwhelming majority of the 50,000 died a good death, but we don't really know; *the question simply isn't asked* by the review-committees and it seems to be taken for granted.
However, what we *do* know, is that on occasion a patient dies a death that in no way can be called 'good'.

A well-documented case in point[4] is the death of a patient suffering from advanced dementia. The physician acted on the well-kept advance directive of the patient who had left no doubt about her views and wishes over the years, but who was now no longer mentally competent enough to verbally ask for the termination of her life. The physician acted in accordance with Section 2.2 of the law. The review-committees judged that the physician met the requirements of due care.
However, the patient was described in the Annual Review as 'in fear', 'in panic', 'desperate' and 'no longer mentally competent'.
As it turned out, the requirement of consulting 'at least one other, independent physician' was not really met. A firstly consulted physician reported negatively. The next consulted physician who reported positively was *before-hand* known to take a favourable stand.[5]
Also, the patient was no longer really aware of what was happening when death came[6], and previous to the official procedure sleeping medication (*not* pre-medication as mentioned in the official formal procedure) was administered secretly[7].

---

[3] They are formally called: Regional Review Committees for termination of life on request and assistance with suicide. From here on: RRC. Reported cases of physician-euthanasia now total some 5000 a year. In 2010: 3136; in 2011: 3695; in 2012: 4188; in 2013: 4829; in 2014: 5306; in 2015: 5516.
[4] Jaarverslag (Annual Review) 2011, pp.21-24, Casus 7, www.euthanasiecommissie.nl.
[5] There is no doubt about this, given the honest story as published by the surviving partner, in *Wils Verklaring. De alzheimerepidemie en het recht op zelfbeschikking* (*Wil's Advance Directive. The Alzheimer-epidemic and the right to self-determination*) by Hans Smit & Henri van Gelder (2013). See: www.wils-verklaring.nl. A firstly consulted physician reported negatively.
[6] Investigative journalist Antoinette Reerink published her report 'The woman who no longer knew she wanted to die' (*NRC* Feb. 2, 2012).
[7] See: Reerink (note 6) and Smit & Van Gelder, p. 148 (note 5).

Most conspicuously, the physician told the family that he would *not* proceed with the termination of life if any member of family insisted on being present[8]. (The presence of a trained ex-nurse and friend of the family was allowed).
The physician, who kept his promise to his patient in dire circumstances, was well-aware that members of family would not be looking at a pretty sight. (The surviving partner later told his story in a small book.)

It is certainly debatable whether this patient died a good death. This is especially interesting, as this is a case in which it might be argued that it is good that the patient is dead.

5. Next, time for a case of self-euthanasia

Thomas, who was 83 when we met, was suffering from the onset of dementia. It was an illness he had seen progressing in both his parents for years. Already a long time ago he, therefore, had decided that, should he be diagnosed with the same disease, he would put an end to his life in time, on his own conditions before his dementia would have the better of his autonomy. This was his reason for contacting a counsellor. Thomas had a partner who supported him, and children who did the same. In this respect, despite his illness, Thomas was well off. Needless to say however, the family was in pain about his impending final goodbye. Later they published a small booklet, telling their story.

Thomas' physician, who felt he could not answer the requirements for physician-euthanasia, nevertheless continued to give his support to Thomas and his family. The local pastor – obviously of a free-thinking kind – was also aware of what was going to happen and he offered his spiritual support to the family. So, the evening before Thomas was going to take his lethal dose of medication, the pastor held an intimate service at their home.
Next morning, surrounded by his family, Thomas said his final good-by.

6. But, what about a good death?

Did Thomas die a *good* death? His death was self-requested (as it would have been as physician-euthanasia), but it was also self-performed and self-determined (thus distinguishing it as self-euthanasia).

But what would allow us to call his death an example of '*eu* thanatos', a '*good* death'? Thomas' obituary opened quoting the Roman Stoic philosopher Seneca: 'Dying well means escaping from the danger of living bad'.
This is certainly not to suggest that Thomas liked to die, but there was a danger lurking: the mental darkness of his progressing dementia. And that, to him, meant a future of 'living bad'. To avoid this danger, he himself chose to die – the lesser of evils. And being able to make this choice, autonomously and independently, and thus avoiding the danger, meant he died well.

[8] Smit & Van Gelder, p. 134: 'Strange as it may sound, I would have loved to be present at my mother's death. But the physician wouldn't have it.' (Says one of the children)

Seneca's saying is therefore also aptly chosen as it does not say that it is good that Thomas is dead. It doesn't say 'Being dead means having escaped from a bad life' because being dead means having escaped from any life, good or bad.
Seneca's 'dying well' refers to the quality of a deliberate choice in the face of an impending danger. A good death in self-euthanasia therefore refers to a *process* (autonomously led by the still living individual), to a process rather than to a *result* (the individual being dead).

What are the constituent parts of such a 'good death', the qualities of this process? There certainly is an individual, indeed subjective, maybe even arbitrary element involved in such a choice, as we are dealing with the self-determination of individuals in situations that are specific to the individual. After all, it is *their* life (and self-chosen death).
But nevertheless, I will propose as such constituent parts of a 'good death' the following.

Such a 'good death' means a death:
-(1) decidedly self-chosen after clear and careful consideration
-(2) in which the individual's role is as large as possible
-(3) carried out with the utmost care and without adding pain or suffering
-(4) that is not executed in forced loneliness
-(5) if at all possible, prepared in contact with loved-ones
-(6) considered (given the circumstances) as dignified
-(7) and accepted by the individual in peace and quiet.
Two further constituent parts, vital in the case of self-euthanasia, are:
-(8) death is self-performed, and
-(9) death is self-determined.

This 'good death' is aimed at, in often difficult circumstances, in *both* physician-euthanasia and self-euthanasia.
But there are differences, as conditions (2), (8) and (9) will be met to a (sometimes very much) lesser degree in the case of physician-euthanasia, while death will still be a *good* death.

In (2) we have a quality that is cause for debate in physician-euthanasia, and if it *is* not cause for debate, than it *should be*.
It is only in less than 4%[9] of the Dutch cases of physician-euthanasia that the patient has lethal medication handed over to him by the physician to end his life by drinking it, in the presence of and under the responsibility of, the physician.
Of course, the patient's condition may be such that it is impossible or irresponsible to have the patient (try to) drink lethal medication; in this situation drip and/or lethal injection will be not only inevitable but mandatory. However, it is highly questionable if this is the condition the patients where in, in all of the 96% of the cases where drip and/or injection was in fact taken to.

[9] See the Annual Review 2015, p. 17, www.euthanasiecommissie.nl.

So: why isn't the patient required to perform himself all the acts he *responsibly* can? The weight and importance of the occasion would surely justify this. Considerations of convenience and duration should not be of overriding importance.

As to self-euthanasia, (2) – and even more (8) and (9) – , are constituent and distinctive parts; they must be, as it is *self*-euthanasia and also in order to prevent others from coming into conflict with the Dutch law against assistance with suicide. This does not mean that some form of help by next of kin may, in exceptional cases, not be required and allowed (the Dutch Supreme Court is going to rule on this in the important Heringa-case, but I will have to let this rest here).
Further, though it is surely possible to obtain reliable drugs without too much difficulty, this may easily constitute a criminal offence, as many of these drugs are prescription drugs.
This is equally part of an ongoing debate: is an individual allowed to decide *that* the value of gaining and keeping control over the end of his or her own life, is of such importance that this allows this individual to put aside as (far) less important the value of obeying the law on pharmaceutics? That is to say: if it is not *legal* to obtain these reliable drugs, it may nevertheless be *legitimate*.

These several constituent parts distinguish self-euthanasia and physician-euthanasia from plain suicide and killing on request. And what should also be clear by now is that the difference lies primarily in the *process* and its constituent parts, not in the *result*. Comparing the example of Thomas' self-euthanasia with the case of physician-euthanasia of the no longer mentally competent dementia-patient, underlines this. Given this patient's consistent wishes and views, it is tempting to say that it is good and a relief that she's dead (as a result), but she certainly did not die a good death (as a process). Thomas' relatives will never say that it is good and a relief that he is dead; but they are grateful that he died a good death.

7. Finally my moral issue and order of preference

Both physician-euthanasia and self-euthanasia refer to an ideal process of a *good* death, the first being ultimately the physician's responsibility, while the second is definitely the responsibility of the individual choosing to die. They differ in the extent to which conditions (2), (8) and (9) are met, and this ultimately boils down to the difference between ending or terminating another person's life, and ending or terminating your own life.

How important is this difference? Are we not to say that the only life that we are master of, even to this extreme extent of terminating it, is our own life? And not the life of another human being, excepting maybe certain very special situations? (Even if you *deny* this mastery over your life, this denial is your own choice and ought to be limited to your own life.)
So what, then, is the moral weight and justification of asking someone else (your physician) to end your life (physician-euthanasia), while you could do this yourself (self-euthanasia)?
Isn't this an unburdening of yourself of a responsibility that is actually inalienable, again excepting certain very special situations?

The law on physician-euthanasia provides for an advance directive. In case of a sudden and speedy deterioration, loss of speech, loss of consciousness, coma, etc. this may supply the physician with valuable information on how to act in agreement with the patient's views.
However, the advance directive is hotly debated when it comes to Alzheimer's and other forms of slow but certain loss of mental capacities.
Isn't an advance directive here equally an unburdening of yourself, by you yourself writing down when someone else is supposed to terminate your life, in an adverse situation that you see coming ahead and before the arrival of which you could end your life yourself?
And given that the law on physician-euthanasia specifies the *necessary* conditions that have to be met, does this mean that therefore *sufficient* conditions to end another person's life, are met at the same moment as well?

These questions all seem to point in the same direction, when dealing with a self-chosen death: that we ought on moral grounds to prefer, whenever possible, self-euthanasia to physician-euthanasia and in the case of physician-euthanasia, whenever possible, assistance with suicide to drip and injection.
Currently, the Dutch order of preference is that firstly physician-euthanasia by drip and/or lethal injection will be taken to; secondly, but reluctantly, physician-assistance with the patient's suicide; and thirdly, but with a sense of disapprobation, self-euthanasia.
However, my arguments lead to the opposite order of preference, the fundamental reasons being (1) the constituent parts of a good death as a process, discussed above, supplemented by (2) the moral weight of the difference between ending or terminating another person's life, and ending or terminating your own life.

A self-chosen *good* death may result from both physician-euthanasia and self-euthanasia, both being normatively laden processes, representing an ideal one might wish to realise as fully as possible and as such to be distinguished from plain killing on request and plain suicide. However, if we also accept the existence of a fundamental moral difference between ending another person's life and ending your own life, and if we accept this moral difference to be also relevant to the normatively laden *good* death, *then* this difference represents a strong reason for preferring self-euthanasia to physician-euthanasia.

Thank you kindly for your attention.

Ton Vink, philosopher & counsellor
World Conference WFRtD Euthanasia May 2016 Professional Challenges

For an extended and more detailed version of the above, see:
http://onlinelibrary.wiley.com/doi/10.1111/bioe.12279/full
The interested reader may also want visit www.ninewells.nl.