

# Dementia & Euthanasia: doubts regarding Advanced Dementia and Advance Directive

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## Abstract

*Severe doubts have arisen in the Netherlands about the applicability of an advance directive in the case of patients with advanced dementia requesting euthanasia. This applicability is firmly based on a widely accepted reading of the relevant subsection of the Dutch euthanasia law. I will question this reading and propose and defend an alternative reading. Arguments are supplied by the actual text of the subsection, by the moral doubts about ending the life of a patient who is hardly aware of what is happening, and by details from the first euthanasia case to go to court in the Netherlands, with the Supreme Court ruling of April 2020. As to euthanasia, alternatives are presented for the patient with a strong conviction and determination 'never to reach that state', the state of advanced dementia.*

## I. Introduction

Section 2 of the Dutch 'euthanasia law' (formally: Law on the Review of the Termination of Life on Request and Assistance with Suicide – LRTS) refers in subsection 2 to the role of an advance directive. This subsection 2 runs thus:

*'If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has written an advance directive requesting that his life be terminated, the physician may comply with this request. The due care criteria in subsection 1 apply mutatis mutandis.'*

The 'due care criteria' the Dutch physician has to comply with in order to be able to grant a request for euthanasia (these criteria form part of the criminal code) are the following:

*'[T]he physician must:*

- a. *be satisfied that the patient's request is voluntary and well considered;*
- b. *be satisfied that the patient's suffering is unbearable, with no prospect of improvement;*
- c. *have informed the patient about his situation and his prognosis;*

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- d. *have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;*
- e. *have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;*
- f. *have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.'*

In actual fact, granting a request for euthanasia in answer to a patient's advance directive, while the patient is no longer mentally competent, is a very seldom affair. Over the last nine years the number of cases would amount to some 19 of which 15 are cases of advanced dementia.<sup>1</sup>

Over the same period of nine years, 900 cases are reported of requests for euthanasia granted in the *early* stages of dementia.<sup>2</sup> The Review Committees (RCs) report about these patients: 'They were considered mentally competent, being (still) able to make a good appraisal of the consequences of their request.'<sup>3</sup>

The Annual Reports of the RCs present an overview of the disorders involved. Up to and including the report over 2011, 'dementia' was never mentioned separately among the 'disorders involved'. If (as indeed it sometimes did) a case occurred in those years, it would find its way to be subsumed under 'other conditions'.<sup>4</sup>

But in the 2017 annual report (total number: 6,585) a new development sets in: among the 'disorders involved', 166 cases of dementia were mentioned, but these were qualified as dementia *in the early stages*; in 2018 this number was 144; in 2019 it was 160. The 2017 report, however, also mentions separately and for the first time among the 'disorders involved' dementia *in advanced stages*, in 3 cases; in 2018 and 2019 this number was 2.

This new development is no coincidence as my paragraph 3, below, will further explain. The use of an advance directive is especially problematic in the case of patients suffering from advanced dementia. In this paper I will discuss recent developments when it comes to euthanasia and advanced dementia and

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<sup>1</sup> See eg G Den Hartogh, 'Euthanasie op grond van een schriftelijke wilsverklaring. Oude en nieuwe rechtsvragen' (2017) 92(31) Nederlands Juristenblad 2226-2233. Den Hartogh counted 12 cases over de past 6 years, up to and including 2016. If we add (at least) three cases in 2017, and two cases in 2018 and 2019, this brings the total number to (only?) 19 cases. The majority of these, some 15 cases, concerns patients with advanced dementia.

<sup>2</sup> On a sum total in those 9 years of 48,697 cases of physician-euthanasia.

<sup>3</sup> Quoted, by way of example, from the Annual Review 2011 II (in Dutch). Cf also 'Euthanasia Code 2018. Review procedures in practice' (<[www.euthanasiecommissie.nl](http://www.euthanasiecommissie.nl)>) 42ff The 'Euthanasia Code 2018' 57-65 presents the full text of the LRTS, the 'due care criteria' on 58.

<sup>4</sup> See for instance I De Beaufort & S Van de Vathorst, 'Dementia and Assisted Suicide and Euthanasia' (2016) 263 J Neurol 1463-1467, table 1.

I will propose an answer to the following questions: (1) Is an advance directive as Subsection 2.2 of the Dutch euthanasia law (LRTS) really applicable in cases of advanced dementia? And (2) what alternatives might there be?

First, a few important definitions relevant for what is to follow.

## 2. Definitions<sup>5</sup>

To avoid misunderstandings, the following definitions are here used for key-concepts:

As by Dutch law *only and exclusively* physicians are allowed to grant a request for ‘euthanasia’ I will use the term *physician-euthanasia* to refer to this as ‘the deliberate termination of the life of a person at his request by another person, in accordance with the demands of the LRTS.’

*Self-euthanasia* is understood 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’. (Every case of self-euthanasia is, by definition, a case of suicide, but the reverse is not true.)

A *good death* or *eu thanatos* is understood as not referring to the *result* but to the *process* leading up to the result. It is the process, in both physician-euthanasia and self-euthanasia, that allows us to speak in terms of a *good death*.<sup>6</sup>

*Self-determination* is, in the context of self-euthanasia and physician-euthanasia, to be understood as ‘the attaining and keeping of control and authority over the process of deciding to, and of preparing and bringing about, the termination of one’s life with due care and concern’. (There is an important difference between both forms of euthanasia as to the measure of self-determination, due to the role and responsibility of either the physician or the individual.)

*Dementia* is understood to refer to general dementia: for instance Alzheimer’s disease, vascular dementia, Lewy body dementia, Frontotemporal dementia, etc. The differences are real but do not affect my argument in this paper. In all

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<sup>5</sup> For a detailed discussion of these definitions: T Vink (2016) ‘Self-euthanasia, the Dutch Experience: in Search for the Meaning of a Good Death or Eu Thanatos’ (2016) 30(9) *Bioethics* 681-688.

<sup>6</sup> This ‘good death’ as a process means a death: (a) decidedly self-chosen after clear and careful consideration; (b) in which the individual’s role is as large as possible; (c) carried out with the utmost care and without adding pain or suffering; (d) that is not executed in forced loneliness; (e) if at all possible, prepared in contact with loved-ones; (f) considered (given the circumstances) as dignified; (g) and accepted by the individual in peace and quiet; (h) death is self-performed; (i) death is self-determined. This ‘good death’ is aimed at in *both* physician-euthanasia and self-euthanasia. But conditions (b), (h) and (i) will be met to a (sometimes very much) lesser degree in the case of physician-euthanasia, while death will still be a *good death*. This ‘good death’ is *an ideal* that you might strive for, *a value* you might strive to realize as completely as possible. (See previous note 5, for a detailed discussion; also: C Maris *Tolerance: Experiments with freedom in the Netherlands* (Springer 2018) ch 6.)

cases, different *stages* of the disease can be distinguished. These differences *are* relevant.

*Advance directive* is in this paper understood to refer to a written request for physician-euthanasia, meant to replace a request that will and can, due to special circumstances, not be done or confirmed in direct (verbal or non-verbal) communication.<sup>7</sup>

### 3. Recent developments

In September 2017, the Office of the Dutch Public Prosecutor announced that it will investigate a case reported in 2016 of physician-euthanasia as possibly a criminal offence. In August 2019, the case finally went to court. Since the 'euthanasia law' came into force in 2002, no physician has ever been prosecuted. More than 70,000 cases of physician-euthanasia have found their way to the RCs and their Annual Reports. The case now before the court concerns a 74-year-old woman whose dementia had seriously advanced and who was no longer mentally competent.<sup>8</sup>

Cases involving advanced dementia are the most likely candidates for actual prosecution, partly because possible conflict with the requirements of due care are most prominent (these conflicts concern: uncertainty about the presence of 'unbearable suffering', uncertainty about the validity of the advance directive, uncertainty about the existence of another reasonable solution, uncertainty about the exercise of due medical care) and partly because of the notable stir and commotion these cases cause, among Dutch physicians, in the media, and in Dutch society at large.

At the beginning of 2017, a number of physicians published a manifesto in which they opposed on moral grounds the granting of requests for physician-euthanasia in the case of patients with advanced dementia, on the basis of an advance directive.<sup>9</sup> In their view, euthanasia in the case of dementia could only be justified when the patient concerned is still able to express or at least confirm the request for euthanasia in direct communication.

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7 In general advance directives 'can be described as statements that allow individuals, before they reach a stage of decisional incapacity, to give directions for future care and how medical decisions are to be made in the event of incapacity.' (De Boer et.al. 'Advance directives in dementia: issues of validity and effectiveness' (2010) 22(2) Int. Psychogeriatr. 201-8). In the special circumstances of the Dutch euthanasia law, however, the advance directive can only play its part as a request for euthanasia on the prior condition that the patient who drew up the directive 'is no longer capable of expressing his will'.

8 This case is also available in English. For the full text ( 54-58 of the 2016 report), go to Download Annual Report 2016 at: <<https://english.euthanasiecommissie.nl/the-committees/annual-reports>>. The case is very instructive and I will return to it in para 6 below.

9 <[www.nietstiekembijdementie.nl/](http://www.nietstiekembijdementie.nl/)>.

This manifesto received a lot of media attention, not in the least because it turned out that in a number of cases patients were secretly sedated prior to the euthanasia, in order to have the euthanasia-procedure later proceed without untoward or inconvenient behavior from the patient.<sup>10</sup>

#### 4. Early and Advanced Dementia

It is usually a severe blow when the diagnosis ‘dementia’ is confirmed. A severe blow, but no surprise as the individual in question was well aware that something was amiss for quite some time already. Of course, it is not always easy to be honest with oneself, especially as it is this ‘self’ that is being threatened now. Most people try to deal with this situation with whatever help and support is offered by family, friends and society.

But to some, the threat of a future mental eclipse is, in its futurity, a form of suffering that they consider unbearable. It is here, and in this early stage of the dementia, that an opportunity to have a request for euthanasia granted by the physician presents itself under Dutch law. But even then, demands are made on both physician and patient:

- a. Granting a request for physician-euthanasia in an early stage of dementia obviously means that the physician considers it possible to answer the requirements of due care. In the case of dementia, not many physicians feel that they can. Especially requirements b and d (see above) are not easy to fulfill. But, it is a real possibility.
- b. Maybe even more important, the individual – the patient – has to be prepared to have his life end sooner than necessary, at least sooner than it would seem necessary. There’s a price to be paid. If he waits too long, he will not be able to make, or confirm, an actual request for physician-euthanasia and that would make his chances slim indeed. This is summarized in the Netherlands by saying the euthanasia has to take place no later than ‘5 minutes to 12’ because it will be too late ‘5 minutes past 12’. The price, therefore, is time of life.

So, both the physician and the patient have to be prepared to take this difficult but important step, and they have to be prepared to do so within the same timeframe. Often a physician expresses his preparedness to maybe grant the request, ‘but not yet now’, as the condition of the patient leaves enough room for doubt. And equally, the patient often expresses his preparedness to make

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<sup>10</sup> This sedation is *not* the officially accepted premedication, foreseen in the ‘Guidelines for the practice of euthanasia’ as a possible part of the procedure, at the patient’s request. Available in English. See <[www.knmp.nl/downloads/guidelines-for-the-practice-of-euthanasia.pdf](http://www.knmp.nl/downloads/guidelines-for-the-practice-of-euthanasia.pdf)> 13. See also the ‘Euthanasia Code 2018’: <<https://english.euthanasiacommissie.nl/the-committees/code-of-practice>> 40-41.

the request, 'but not yet now', as he feels his situation is 'not yet that bad'. As a result, time passes, dementia advances and all of a sudden it is not just '5 minutes past 12' but often much later. However, despite these difficulties, physician-euthanasia in the early stages of dementia is a real possibility.

If next to an early and advanced stage we distinguish a final stage of dementia, this final stage would be the stage for normal but potentially life-shortening medical practice such as withholding or withdrawing medical treatment, pain relief with a possible life-shortening effect, terminal sedation, etc. No cases of euthanasia in the final stage of dementia have been reported by the RCs.

## 5. Advance directive

Often (certainly not always!) the diagnosis 'dementia' is what causes the patient to draw up an advance directive. The motive for doing so is a strong wish or will, a strong conviction and determination 'never to reach that state', 'that state' being the state of advanced dementia. What is to be prevented at all cost, is the state in which one, for instance, no longer recognizes one's partner, one's children; in which one's own home is changed for a nursing home, maybe even a locked ward; a state in which one no longer is the person one was before, that person having mentally disappeared. Never to reach this state is here considered a *critical* (Dworkin) or *ulterior* (Feinberg) interest.<sup>11</sup> And it is the *prospect* of this state that is considered a cause of suffering that is unbearable, with no possibility of improvement (the second of the requirements of due care).

This does however present us with a first anomaly. The advance directive comes into play when in fact the situation one wanted to avoid at all cost has indeed become a reality after all. So, how strong was this wish and will, this conviction and determination 'never to reach that state'? Apparently not strong enough to take appropriate measures at the appropriate time, that is *before* reaching 'that state' in order *not* to reach it.

Chances of having an actual request for physician-euthanasia granted in the early stages of dementia are real but not be too big, but chances of having a

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<sup>11</sup> R Dworkin, *Life's Dominion. An Argument about Abortion, Euthanasia and Individual Freedom* (AA Knopf 1993) 235; J Feinberg, *Harm to Others. The Moral Limits of the Criminal Law* (vol 1, OUP 1984) 37. Clearly, here we are not dealing with one of the 'experiential interests in the quality of our future experiences' (Dworkin) or with one of the 'interests in conditions that are generalized means to a great variety of possible goals' (Feinberg), but on the contrary with one of the 'critical interests in the character and value of our lives as a whole' (Dworkin) or with 'a person's more ultimate goals and aspirations' (Feinberg). Looking after these 'critical interests' or 'ultimate goals' is first of all the individual's responsibility.

written request granted in the advanced stages of dementia are close to zero. On moral grounds (cf. the manifesto above) physicians are not very eager to end the life of a patient while meaningful communication is impossible and the patient is living his demented life, unaware of what is coming (including when death is coming).

This leads to a second anomaly. The advance directive comes into play because the individual in the early stages of dementia – consciously or unconsciously – failed to do what needed to be done ‘never to reach that state’. The ‘price’ (time of life), you might say, was deemed too high, and the decision too hard to take. Now matters are out of his hands. But, as his next of kin now professes, he would still want to escape ‘that state’, even though he now no longer is the person he was. After all, it was to this purpose that he, in his early stage of dementia, drafted his advance directive.

But it looks as though now the price for escaping ‘that state’ after reaching it after all, is to be paid by others, a morally questionable procedure. The price must be paid by the physician who is expected to end the life of a patient who is no longer capable of meaningful communication and who is hardly, if at all, aware of what is happening.<sup>12</sup> It must also be paid by the now advanced demented person, you might say ‘another person’ than the person in his stage of early dementia who drew up his advance directive, but who then (maybe very understandably) waited too long, until he disappeared in the mist after all.

Of course, it is debatable if it really makes sense to talk as if we have here two distinct ‘persons’. If one had the sorry state of early dementia and considered the horrors of advanced dementia, then one could envision himself in ‘that state’, and it is this prospect that constitutes the unbearable suffering. However, once one reaches ‘that state’, the prospect no longer exists, because the person who had it no longer exists, while at the same time the person who now does exist and (for the moment) continues to exist, is not able to relate to the no longer existing prospect and the no longer existing person who had it.<sup>13</sup>

And there is another – third and possibly fatal – anomaly. Subsection 2.2. (cited above in its entirety) of the Dutch ‘euthanasia law’ allows for such an

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<sup>12</sup> It is important to realize that physician-euthanasia in the Netherlands is considered to be ‘non-normal’ or ‘non-normal’ medical behavior, a unique category in this respect differing from other, normal, medical behavior like, for instance, palliative sedation but also non-resuscitation and non-treatment generally.

<sup>13</sup> When I am not a grandfather, the prospect of becoming a grandfather may move me. Once I am a grandfather, I am of course literally no longer the person who was not a grandfather but was moved by the prospect of becoming one. Nevertheless, we have good reason to speak here in terms of just *one* person and the now-grandfather may reminisce about, and thus still relate to, the not-yet-grandfather, contemplating for instance that he, the then not-yet-grandfather, had no idea what it would really be like to be a grandfather.

advance directive and it opens, saying: 'If a patient aged sixteen or over *who is no longer capable of expressing his will*, but...'. It does *not* say: 'If a patient aged sixteen or over *who is no longer mentally competent*, but...' (italics added). Of course, the advanced demented patient is no longer mentally competent, but this is not what the law in actual fact refers to as a prior condition.<sup>14</sup>

The law refers to a patient who is no longer capable of expressing his will, but can we seriously say that an advanced demented individual is no longer capable of expressing his will? It is very likely not the will of the person he or she was before, with all the more and less painful changes and intellectual losses his personality has undergone during the process of the advancing dementia; this person has disappeared. The result may be a totally different person, maybe 'another' person, with whatever will there is.

And it may further be difficult, nearly impossible often, for others to understand the will of the advanced demented individual. But that does not mean that he or she is not capable of expressing what will he or she now has as the person he or she now has become.<sup>15</sup>

In the euthanasia debate in the Netherlands it has simply been taken for granted, from the start, that the possibility offered by subsection 2.2 of the LRTS is available for individuals suffering from advanced dementia, being no longer mentally competent. The debate that took place in both Chambers of the Dutch Parliament before approving of the bill, supports this reading of what this subsection of the LRTS was intended for. So virtually every author on this subject follows this reading, and not only authors, but physicians as well.

The first euthanasia-case brought before a Dutch court August 2019 is worth looking at, as it clearly illustrates the point I wish to make. Did the physician try hard enough to verify the patient's consent? The case also appeared before the Medical Disciplinary Board earlier. The board came with its decision the July 24, 2018 and the physician was reprimanded.<sup>16</sup> The court pronounced its

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<sup>14</sup> This is consistently overlooked. See for instance M Rurup, *Setting the Stage for Death. New Themes in the euthanasia debate* (Amsterdam 2005) 84: 'An advance euthanasia directive is a written request for Euthanasia Made by a Patient, Intended for a Situation in which the Patient has Become Incompetent.' Also JJM Van Delden, 'The Unfeasibility of Requests for Euthanasia in Advance Directives' (2004) 30 *Journal of Medical Ethics* 447-451, referring to 'article 2.2 of the law concerning an incompetent patient'.

<sup>15</sup> It is hardly feasible to say that the expression of will is only accepted as such on condition of its agreeing with the will of the person the individual 'was' before.

<sup>16</sup> ECLI:NL:TGRSGR:2018:165 Regionaal Tuchtcollege (referred to as 'Board'; translations by the author). The physician appealed and in April 2019 instead of being reprimanded received the lesser penalty of an official warning. It is probably due to the more active role of the Dutch prosecutor in this case (and in a number of other cases where the prosecutor did not proceed further than a preliminary investigation) that in 2018 for the first time the number of reported cases of euthanasia has decreased by 7%, relative to the preceding year: 6585 cases in 2017 and 6126 in 2018. (See: Annual Report 2018 at <[www.euthanasiacommissie.nl](http://www.euthanasiacommissie.nl)>)

sentence September 11, 2019; a dismissal of all charges.<sup>17</sup> Obviously, the facts were the same to both board and court, the board focusing on medical professional norms, the court on legal norms.

## 6. Expressing her will...

The decision of the Medical Disciplinary Board in this case has it: *'In the course of 2015, the patient has become completely incapable of giving informed consent'*. (Board, p. 4) And: *'On 28 January 2016, the patient did not know what euthanasia meant when asked and when it was explained to her she said that euthanasia went too far. After having had explained to her a possible admission to a nursing home after further decline in her condition, the patient said: "Ok, maybe then".'* (Board, p.5; Court, p. 8.).

The Board quotes the physician's medical report that states: *'8 March 2016, (...) When she says again that she finds her situation terrible, I ask if she knows that she has dementia. She shows signs of realizing this. I ask if she wants to continue to live in that situation: yes she wants to, she doesn't want to die. She repeats this several times. (...)'* And: *'March 10, 2016 (...) Then I ask her if she would rather be dead: surely, yes, if I get sick, but not yet now! (...)'* (Board, p.5; Court, p. 10.)

And the Disciplinary Board summarizes: *'During her admission to the nursing home the patient showed a rather varying death-wish through her expressions. At times, she explicitly indicated that she did not want to die. The physician states that there was no longer any conclusion to be drawn from the patient's changing expressions of will with regard to the termination of life. From the moment she was admitted, the physician no longer considered the patient to have the capacity to express her will with regard to euthanasia, because she no longer understood the word and no longer had any insight in the matter. According to the defendant, the expressions of the patient should, on account of her Alzheimer's, be seen as expressions of emotions of the moment, and not as expressions of will at a cognitive level.'* (Board, p.10; likewise Court, p. 9/10.)

So, are we allowed to judge of these expressions of will of this patient by a standard prior to her incompetence? The court says 'yes' but it actually does not discuss this specific question any further. Instead, the court simply holds – against the prosecutor – that *'in view of the deeply demented condition of the pa-*

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<sup>17</sup> ECLI:NL:RBDHA:2019:9506 (referred to as 'Court'). In order to spare the physician and at the same time gain clarity on a number of legal questions the Public Prosecutor decided (26-09-2019) not to appeal but to go directly to the Supreme Court and ask for its ruling 'in the interest of the law'. The Supreme Court ruled (21-04-2020) in accordance with the decision of the Court (dismissal of all charges), while at the same time criticizing and overruling the decision of the Board (warning) and therefore in both cases ruling in favor of the physician. (Rulings of the Supreme Court: ECLI:NL:HR:2020:712, and: ECLI:NL:HR:2020:713).

tient, the physician was under no obligation to inquire after the patient's actual wish to live or die.' (Court, p. 18) The LRTS simply holds no such obligation.

The physician, indeed, did judge these expressions of will of her patient by a previous standard, as the Medical Board's decision makes clear: '*The physician has stated that because of the dementia no conclusion could be drawn from a possible expression of will by the patient, shortly before the administering of the euthanaticum.*' (Board, p.10) And the physician also stated afterwards '*that if prior to the actual euthanasia the patient had said that she did not want to die, she would still have gone through with it.*' (Board, p.10) In fact, for this patient the curtain had fallen. Quite remarkably, the Supreme Court in its April 2020 ruling passes this by in total silence.

The problem here is that subsection 2.2 of the LRTS is read in such a way (and in accordance with the traditional interpretation) that it boils down to whether or not the patient is mentally competent. If the advanced demented patient is mentally incompetent – which he or she is – *then* subsection 2.2 is in principle applicable. At least that's the line of reasoning.

This explains why the physician in her defense before the Board says that once the patient was admitted, she no longer considered her to be competent as to euthanasia. But the thing is: is such (in)competence with respect to euthanasia really what the law actually requires?

And on the same grounds, the physician also says about the patient's expressions of will that she saw them as expressions of emotions of the moment and not as expressions of will on a cognitive level. But again, does the law actually require expressions of will on a cognitive level?

The fact that third parties (physicians, relatives, intimate friends) no longer understand the expressions of will of a demented patient, does not alter the fact that these expressions of will are there. Again, in actual fact subsection 2.2 of the LRTS does not require the patient to be no longer mentally competent, nor does it make any demands on the cognitive level of the expressions of will, it requires the patient to be '*no longer capable of expressing his will*'. And if he or she is still able to do so, the subsection does not apply. Period.

It is certainly not without significance in this context that, prior to both Board and Court, the Review Committee comments in this case *precisely on this point* – i.e. mentally competent versus capable to express ones will – thus: '*The committee considered that, although the patient was decisionally incompetent in relation to euthanasia, this did not necessarily rule out that she was able to determine her wishes with regard to actions such as inserting a cannula or a needle, even if she were no longer able to understand the purpose of those actions.*' (Annual Report p. 58, see note 8.)

## 7. Dementia, physician-euthanasia and self-euthanasia

If my (re-)reading is correct, it is simply not the case that subsection 2.2 of the LRTS is available for individuals suffering from *advanced* dementia because these advanced demented individuals are after all capable of expressing their will (whatever its nature), while the subsection of the law explicitly refers to an individual *no longer* capable of expressing his will.

However, the reports of the RCs clearly show physician-euthanasia in the early stages of dementia to be possible (160 cases in the 2019-Report). It is a real possibility, not without its own pitfalls and making serious demands on both physician and patient (see paragraph 4 above).

Is there yet another alternative for the individual who cherishes his self-determination, apart from – and in addition to – this possibility of physician-euthanasia in the early stages of dementia? Yes, there is. It is, equally, not an easy alternative though. It is based on self-determination, not so much just as a *right* but also as an *obligation*, a *responsibility*.

Before coming to my conclusion I will first illustrate this possibility in the most appropriate way: by showing it in actual practice. This brings home the difficulties of the entire process: memory loss; diagnosis dementia; advancing of the disease; the pain, sorrow and struggle of the individual; self-determination; strength of mind; and self-euthanasia.

Mr. Rogers<sup>18</sup>

Well over seventy now, Mr. Rogers looked back on a life of which he was proud indeed. With little initial education or training he worked quite hard, invested in further training and development and thus acquired a good position with corresponding prestige and salary. All this came at a price, but so far the doctors had been able to fetch him up again and again. But now another problem presented itself, a problem he felt was of a completely different order, a problem the beginning of which he described as ‘becoming more and more forgetful’, but which by now had another, more frightening name: dementia.

Prior to our first consultation, together with his wife, Mr. Rogers sent me a letter, a rather extensive ‘note’ in which he tried to explain his situation in his own words, as well as possible. I quote the following passages, with permission, anonymized where necessary.

*‘Initially I just noticed my memory was slowly beginning to go, and that certainly annoyed me a lot; after a few years there was a first testing of my memory-function by a neurologist. Result: not very disturbing. A few years later however, I was referred to the Alzheimer’s Centre, where examination clearly showed damages to the brain.*

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<sup>18</sup> Not his real name.

*A year later further decline was observed. New examination and testing will follow soon.'*

And then things developed pretty fast: *'In the meantime I have to conclude that my memory is clearly and quickly deteriorating. And that means in concrete terms: using a calculator, but also a constantly checking this, checking that, checking and checking payments over and over again, constantly consulting the agenda, sometimes up to twenty times.'*

And he also writes: *'It is good that third parties have not really noticed this so far.'* He thinks he is still able to camouflage this, but has his doubts the same moment. There is *'fear of being exposed.'*

And that's not an easy thing: *'Appointments I make, I often forget, moments after I just made them: what I do not or cannot put down directly in my agenda usually disappears immediately and is forgotten. Moreover, I repeatedly write things down under the wrong day and/or hour: this is hopeless, because when was the appointment? Uncertainty is killing! You also become suspicious: 'they' claim you said things that you, in your opinion, absolutely did not say! My insecurity and suspicion are, it seems, growing stronger and stronger.'*

It is all very confrontational: *'Sometimes things that I am absolutely sure of now often turn out to be absolutely wrong. It seems I often draw the wrong conclusions from what I hear and read! When I get up to do something and I take a few steps, I've often forgotten what it was I wanted to do: and even after racking my brain, it often doesn't come back.'*

The sense of time, of day, date, month and year is also no longer reliable, as is spatial orientation. Fortunately, there is the navigation system, but even then... It is all in all threatening and also causes problems with the night's rest: *'At night when I sleep or sleep halfway, sometimes even when I am awake, my thoughts tumble through my head again, at lightning speed and confusingly and frighteningly fast.'*

Now, there is also fear to participate in social life: *'I'm afraid I might repeat things I've just said or said a few moments before... I seem to misunderstand quite a bit... That's what frightens me - like so many other things. This is a fear, I do not notice, or better: attempt not to notice, with all the power that's in me.'* But there is no denying: *'What I do know is that I now clearly recognize my own decline... Hence I want to pursue the path of self-euthanasia with the energy I have left.'*

And so he lets me know: *'The awareness of the progressing disease, the consequences of this and, above all - as I understand - the fact that I have no certainty about where precisely I stand in this process, these things force me to make my choice at a timely moment. I would certainly prefer to make my choice too early, rather than*

*not being on time. That's why I was looking for an interview with an experienced counsellor in this field.'*

We then had a long and detailed discussion, the three of us – the children were informed later. This consultation also resulted in him being able to inform me a few months later, at our second consultation, that he now had in his possession two 100 ml bottles with a total of 12.6 grams of pentobarbital. This reassured him greatly.

The results of repeated medical examination, on the other hand, were far less reassuring. And that meant that the moment for having to make a difficult and decisive choice was drawing near. He did not want to be too late, and he also realized that he alone carried the burden of responsibility for being in time.

We corresponded about some final questions and precise details concerning the actual procedure of his self-euthanasia; he paid attention to the position of his family and next of kin (who would be present at his self-euthanasia<sup>19</sup>). Little more than two months after our second consultation I received notice of his death.

Mr. Rogers's situation (d. 2014) was not very enviable. Yet he belongs to a small group of people<sup>20</sup> who are in fact able to face up to this situation and also act in time, in accordance with their own strongly felt wishes and convictions concerning what they consider their *critical* or *ulterior* interests. That, certainly, is not easy, I hasten to repeat. And there is also nothing that obliges anyone to do likewise, except – perhaps – the very strength of one's own convictions, the felt responsibility and the resolve 'never to reach that state'.

The story of Mr. Rogers illustrates the most frequently used method of self-euthanasia I have met with in more than 20 years of work as a counselor: by the use of lethal drugs. A second method is Voluntary Stopping Eating and Drinking. This method is also well-documented and the choice between the

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<sup>19</sup> Self-euthanasia does not imply loneliness. Contrary to De Beaufort & Van de Vathorst (2016, note 4) family and friends would *not* 'have to make sure they were absent so as not to be charged with aiding and abetting'. Their presence (in the Netherlands) is allowed and contributes to a *good* death. In its final ruling of April 16, 2019, in the Heringa-case the Dutch Supreme Court even held it *against* the defendant Albert Heringa that he left his mother *before* her death, after having assisted her in taking her lethal dose of medication to end her life. (ECLI:NL:HR:2019:598; 2.3.3.)

<sup>20</sup> Other clients, diagnosed with dementia, who's story of their self-euthanasia reached a larger audience and thus may be verified are: Paul van Eerde (d 2006) in the documentary 'Voor ik het vergeet...' / 'Before I forget...' (info@rosensmedia.nl); Jan-Ru (d 2011) and his wife Nell who tells their story on film in 'Eyewitnesses; Personal Narratives of Self-chosen and Humane Death' (www.dignifieddying.com); and Tom (d 2012), who's story is told in: T Vink, 2016, 684 (see note 5). In these cases, the names are their real names.

two is definitely the choice of the individual it concerns (who, of course, must be well-informed on the ins and outs of both methods).<sup>21</sup>

## 8. Conclusions

The above leads to the following conclusions:

1. Physician-euthanasia, i.e. euthanasia in accordance with section 2.2 of the Dutch 'euthanasia law' may after all not be possible in the case of advanced dementia. The reason for this being that the advanced directive the law allows for, is only applicable – as the law says – when the patient *is no longer capable of expressing his will*. The law does not specify this 'will' as being the will of another person or the same person years ago.
2. Physician-euthanasia in accordance with the law is possible indeed in the early stages of dementia. It does, however, require a concerted effort from both patient and physician, to be right in time and, for the physician, to answer the requirements of due care. The patient's self-determination is restricted by the physician's responsibility before the law. But the possibility is genuine and the patient, though dependent on the physician's decision, carries whatever responsibility he can.
3. No cases of physician-euthanasia in the final stages of dementia have been reported by the Dutch RCs. This final stage is the stage, suited for normal but potentially life-shortening medical practice such as withholding or withdrawing medical treatment, pain relief with a possible life-shortening effect, terminal sedation, etc.
4. Self-euthanasia, using lethal drugs (or by stopping eating and drinking), presents a real alternative, feasible in the early stages of dementia. Here, the self-determination of the individual is fully recognized. It equally requires a timely decision, taken after careful consideration, if at all possible, in contact with loved-ones and intimate friends. The burden of responsibility rests squarely where it belongs.
5. As a final 'conclusion' – maybe better as a 'concluding remark' – I would like to stress that no individual suffering from dementia ought, in any circumstance, to get the feeling to be obliged, or to be forced, to consider asking for any of the varieties of euthanasia. The initiative to do so must

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<sup>21</sup> See eg B Chabot, *Taking Control of your Death by Stopping Eating and Drinking* (Amsterdam, 2014) available at <[www.dyingathome.nl](http://www.dyingathome.nl)>. Also, 'Caring for people who consciously choose not to eat and drink so as to hasten the end of life' published by the KNMG Royal Dutch Medical Association and V&VN Dutch Nurses' Association Guide, Utrecht 2014. A detailed description of the process in terms of a small day-to-day 'diary', kept by the family in an actual case of stopping eating and drinking, may be found in: T Vink, *Onder Eigen Regie. Zelfeuthanasie belicht* (Klement 2018, as yet only available in Dutch).

come from the individual and we must as a society be on our guard for possible failures in this respect.