Physician Assisted Dying Outlaws: Self-Appointed Death in the Netherlands

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Introduction

The Dutch parliament broke new ground in 2002 when the Netherlands became the first country in the world to enact legislation permitting physician assisted death (hereafter PAD). However, the legislation by no means provides PAD on demand; Dutch citizens can only avail themselves of an assisted death provided their physicians consider that the legislative criteria have been met. Recent Dutch studies suggest that doctors are reluctant to provide an assisted death and it seems that other methods of attaining a self-appointed death are being utilised by individuals who are denied access to a medically assisted death. Two such methods that these individuals - PAD outlaws may opt for, are an illegal assisted death involving lay assistors or a lawful method of a self-hastened death by stopping eating and drinking. Having analysed the limits placed on respecting patient autonomy under the Dutch model of PAD and paying special attention to the matter of existential suffering, this paper explores these two alternative methods of securing a self-determined death. It raises the question of how far the law should recognise autonomy in the context of PAD.

The limits of autonomy in the context of lawful physician assisted death in the Netherlands

The Dutch statutory law which enables physicians to practise PAD is the Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002 (hereafter the 2002 Act). A doctor acting in compliance with the 2002 Act does not commit a criminal offence under
Articles 293 and 294 of the Dutch Penal Code, which prohibit euthanasia (the termination of ‘another person’s life at that person’s express and earnest request’) and assisted suicide (‘intentionally assist[ing] another to commit suicide or provid[ing] him with the means to do so’). The doctor must act in accordance with the due care criteria laid down in the 2002 Act, as follows:

- the patient made a ‘voluntary and carefully considered’ request;
- the doctor informed her of her situation and prospects;
- her suffering was ‘unbearable’ with ‘no prospect of improvement’ (the due care criteria have been interpreted as requiring a physical or psychological medical condition);
- the doctor and patient were convinced that the suffering could not be alleviated through any other reasonable means;
- the doctor acted with ‘due care and attention’;
- the doctor consulted an independent physician who has given a written opinion as to the criteria being satisfied.4

The doctor must then notify the municipal pathologist of the assisted death as required by the Law on Burial and Cremation.5 Regional Review Committees review reported cases of euthanasia and it is only if the particular Committee decides that the physician involved has not complied with the law, that the prosecution authorities become involved.6 Recent figures indicate that PAD accounts for 1.8% of all deaths annually.7
The Dutch law is framed around justifying the doctor’s actions on the basis of necessity and a conflict of duties between the duty to preserve life and the duty to alleviate suffering.\(^8\) Although the value of autonomy is a commonly raised justification for permitting physician assisted death,\(^9\) it has in fact never been the formally recognised rationale behind the Dutch law.\(^10\) Griffiths, Weyers and Adams observe that the legal developments which led to permitting PAD:

‘... began not so much with a demand for “patients’ rights” as with the insistence by doctors, supported after some initial hesitation by the Medical Association, that under limited circumstances, euthanasia is a legitimate medical procedure. This issue was legally formulated not so much in terms of what patients have a right to demand as in terms of what doctors are authorized to do.’\(^11\)

Yet whilst autonomy has not been the foundation upon which the PAD law has been built, it is an important value in Dutch society and culture and has featured in the assisted dying debate.\(^12\) The NVVE,\(^13\) the largest right-to-die organisation in the Netherlands, has recently observed that ‘the post–war generation – familiar with principals of freedom and responsibility anchored in our culture – is now steadily approaching the last phase of life. More so than previous ones, this generation will want to make its own choices... with regard to dying with dignity and the self chosen end of life.’\(^14\)

Such choices are only likely to be actionable in limited circumstances, however, under the current lawful model of PAD. Because this model is based on the medical professional’s assessment of the patient’s condition, whether or not the patient’s autonomous wish to die
is respected is dependent on the doctor’s judgement and it appears that one of the due care criteria in particular is hard to satisfy. Research findings suggest that the unbearable suffering requirement is the most difficult of the criteria for doctors to reach a judgement upon.\textsuperscript{15} This should not really come as a surprise, given that physicians are being asked to make an objective assessment of something that can surely only be measured accurately by the person subjectively experiencing the suffering. As Rietjens el al comment:

`\ldots the question of whether and when symptoms lead to unbearable suffering ultimately depends on the experience of the person who is suffering, and hence is an individual matter depending on the patient’s personality, physical and mental perseverance, history and perceptions of the future. Hence what is still bearable for one person may be unbearable for another.`\textsuperscript{16}

The findings of one research study have revealed that physicians most frequently cite a failure to meet the unbearable suffering criterion as a reason for refusing a request for PAD.\textsuperscript{17} In cases where doctors refuse a request for PAD, it appears patients perceive that their physicians lack an understanding of their suffering and whilst patients emphasise psychosocial suffering, their doctors are more likely to focus on physical suffering.\textsuperscript{18} This presents a real problem in terms of respecting autonomy. The patient’s wish to die stems from their \textit{experience} of suffering but this experience may only be relevant for the doctor when making her assessment if it meets \textit{her} conception of the type and level of suffering required under the due care criteria. Thus, the patient’s autonomy will only be respected if his expression of autonomy meets an objective standard of (perceived) legitimacy. Notably, according to recent studies, it appears that doctors are reluctant to provide an assisted
death even when the due care criteria have been met\textsuperscript{19} and two out of every three requests for PAD are refused.\textsuperscript{20}

It is even less likely that an individual’s autonomy will be respected if she requests PAD on the basis of suffering that is not considered to have a medical origin but, rather, is existential in nature. It seems that approximately 400 individuals a year in the Netherlands request PAD because they are ‘weary of life’.\textsuperscript{21} Suffering caused by this state derives from psychosocial factors, ‘circumstances such as the loss of a partner, increasing isolation due to death of people around them, and physical ailments [which] can make everyday life... a negative experience’.\textsuperscript{22} It should be borne in mind that the concept of existential suffering is ill-defined.\textsuperscript{23} Furthermore, whether being tired of life even constitutes suffering has been contested. In Varelius’s view for example, ‘One can... be tired of living or have continuous feelings of futility and uselessness to the extent that one wants to die without suffering.’\textsuperscript{24} Yet this is in discordance with the understanding of the Dijkhuis Committee, a committee established by the Royal Dutch Medical Association (KNMG) in 2001 to consider norms surrounding assisted dying requests in cases of existential suffering. In its Report, the Committee uses the phrase ‘suffering from life’ in order to convey the real impact of the suffering in such cases and defines this as suffering from the prospect of continuing to have to live when the individual experiences no or only limited quality of life and this results in a persisting wish to die, where the lack of or poor quality of life is not caused by a somatic or psychological condition.\textsuperscript{25}

Significantly, being tired of or suffering from life is not an acceptable ground for PAD for the majority of doctors, who do not see being weary of life as constituting unbearable
Moreover, in 2003, the Dutch Supreme Court judged that existential suffering is not a legitimate ground for lawful PAD in the Brogersma case. In this case, the defendant, Doctor Sutorius assisted his patient, Mr Brongersma’s suicide. Mr Brongersma was weary of life, which he considered to be futile and lonely without his deceased friends and family. He made repeated requests to his doctor to assist him in his suicide. The Court drew a distinction between suffering caused by a medical condition (whether mental or physical), and psychosocial suffering. In the case of the latter, a doctor’s medical expertise did not equip her or him to decide whether the due care criteria had been met.

But is it correct to exclude existential suffering from the lawful model of PAD? The Dijkhaus Committee recommends that existential suffering as well as suffering that stems from a medical condition should be considered to fall within the medical profession’s expertise, since both can be unbearable and hopeless. For the Committee, the source of the suffering should not be the deciding factor. This may be supported by research findings that reveal that being “tired of life” is also a cited reason for desiring an assisted death for individuals who have a severe disease. Griffiths, Weyers and Adams are critical of the limitation of the due care criteria to unbearable suffering caused by a medical condition. In their view, it is hard to defend a distinction between suffering derived from medical conditions and existential suffering, and any such distinction would be problematic in practice. Drawing this distinction is surely hard to defend on the basis of autonomy. Indeed, it seems that the exclusion of existential suffering from lawful model of PAD is currently a ‘hot topic’ in Dutch society. There have been calls for a change in law from the NVVE and a Citizen’s Initiative entitled ‘Accomplished Life’ was put forward in February 2010, demanding that
individuals over 70 who are tired of life should have the right to an assisted death.\textsuperscript{34} 116,871 signatures were gathered in support of the proposal.\textsuperscript{35}

It should be clear from the above that there is a real tension between the individual autonomy of those who desire PAD but are judged not to meet the due care criteria, and the views of medical profession and the law. Consequently, as Chabot and Goedhart note, ‘it is to be expected that some individuals whose repeated and explicit request for PAD has been turned down will look for methods to control their death that will make them less dependent on the medical system’.\textsuperscript{36} One such method I will now explore is lawful, the other is not.

**Option one: stopping eating and drinking**

Research on the subject of a self-hastened death by stopping eating and drinking involving the examination of 110 cases where individuals had died via this method has been conducted in the Netherlands by Chabot.\textsuperscript{37} In 80\% of these cases, the individuals were over the age of sixty and in 40\%, they suffered from cancer. 32\% of individuals had a serious somatic disease and in the remaining 28\% of cases, the individuals did not have a serious illness or medical condition, but ‘had suffered seriously from ailments of old age (blindness, deafness, walking impairment, arthritic pains, speech and/or memory impairment)’.\textsuperscript{38} Following a survey conducted on self-directed deaths occurring in the Netherlands between 1999-2003, Chabot and Goedhart computed an annual frequency of 2.1\% for deaths occurring by stopping eating and drinking while receiving palliative care, which, they note, appears to be roughly on a par with the annual number of PAD deaths.\textsuperscript{39} Notably, the
authors found that a request for PAD had been turned down in 49% of the cases where individuals had subsequently voluntarily refused food and fluids in their study.\textsuperscript{40} It is also significant that research conducted in another jurisdiction where physician assisted suicide is lawful - Oregon - has found that some patients who are denied access to physician assisted suicide choose to have a self-directed death by this method.\textsuperscript{41} The study involved 307 hospice nurses, 102 of whom had cared for a patient who had hastened death by stopping eating and drinking in four previous years. The hospice nurses reported that ‘the most important reasons for the decision to stop food and fluids were a readiness to die, the belief that continuing to live was pointless, an assessment of the quality of life as poor, a desire to die at home, and a desire to control the circumstances of death.’\textsuperscript{42}

Chabot records the process and cause of a death by stopping eating and drinking, which occurs by dehydration or an intervening complication. After a period of time, the individual will experience a general weakness which ‘resembles the last phase of a fatal illness but without the symptoms of pain or breathing difficulties’. After about a week without fluid intake, the kidneys stop producing urine and thus the metabolic waste products are not removed from the blood. This usually leads to drowsiness and then ultimately ‘the heart can no longer beat regularly and the person will die while asleep from a cardiac arrest’.\textsuperscript{43} For individuals who were not in the terminal stage of an illness and stopped eating and drinking at the same time, death occurred after seven to fifteen days in 70% of the cases Chabot examined. In 20% of the cases, the individuals died after sixteen to thirty days. Although death took longer to occur for these individuals (because they had stopped eating first and then gradually stopped drinking), it seemed to be a less harsh process.\textsuperscript{44} In the remaining cases (just over 10%), death occurred over a longer period - after thirty one days or more.
This was because these individuals took longer to restrict their fluid intake. Chabot’s findings appear to tally with those of other researchers who have studied the length of the dying process where an individual stops eating and drinking concurrently.

The dying process in cases of stopping eating and drinking is thus a lengthy one and it is necessary to have some knowledge of the palliative care required to enable a death via this means to be ‘good’. Chabot emphasises that ‘the day-to-day care by relatives and nursing staff is indispensable during the process’, and ‘[a] good or bad death depends to a large extent on the quality of the care offered by well prepared and informed relatives, by nurses and by GP’s who have been trained in palliative care.’ Palliative care (such as analgesics or antipsychotics) might be required to alleviate symptoms such as anxiety, pain or confusion. Thus, in order to be successful, this method of dying clearly requires assistance from others and importantly, it is likely that at least some of this will need to be provided by a health care professional. Whilst, therefore, individuals who avail themselves of this option will not need to convince a medical professional that they satisfy any particular criteria relating to suffering, they will still be reliant on health care in order for the dying process to be tolerable.

A common perception exists that a death by stopping eating and drinking will be an unpleasant one: ‘Many people think that stopping eating and drinking to hasten death will cause a great deal of suffering. However research... has shown that this does not necessarily have to be the case if the mouth care and any necessary pain management are administered effectively.’ Good mouth care is necessary to keep one of the harshest symptoms at bay (the feeling of thirst), and to prevent fungal infections. According to Chabot’s research,
74% of relatives and others involved in the cases he examined considered the individual’s death to have been a dignified one. However, he also notes that there is a need for Dutch GPs to receive more training in the ‘terminal care’ that is required to better ensure that the individual’s experience of the dying process is ‘as favourable as possible’.

At certain times during the last decade, dying by stopping eating and drinking was a prominent feature within the Dutch public debate on assisted dying. Pool reports that it attracted significant media attention between 1996-1998. Initially, according to Pool, it was a paper written by Chabot in which he coined the phrase *vertsterven* to refer to a self-appointed death by stopping eating and drinking that generated interest. Although Chabot suggested that stopping eating and drinking offered individuals a method of controlling their deaths, the issue became controversial because ‘[m]any interpreted *vertsterven* as a transitive verb, i.e. a kind of killing’. Consequently, the spectre of non-voluntary death raised its head, with relatives reporting that family members had been left to die via dehydration in nursing homes. Whilst the controversy subsequently died down, it may be difficult now for stopping eating and drinking to receive a ‘good press’ in the Netherlands because of the negative connotations attached to the phenomenon during the time that it was in the media spotlight.

What should be apparent is that achieving a self-appointed death by stopping eating and drinking demonstrates both autonomy and self-determination because it is not an easy option. Indeed, it may turn out to be too difficult an option for some individuals and/or their relatives. Chabot notes that ‘Abstaining from eating and drinking could turn out in practice to be too hard for someone, or relatives might persuade their loved one to
postpone the decision to die, so that he/she starts eating and drinking again.\textsuperscript{57} Yet the fact that such deaths occur demonstrates that some individuals clearly do have the determination to carry out their decision to achieve control over their death through this means. In fact, the research conducted on deaths via stopping eating and drinking in Oregon revealed that during the study period, the number of reported cases of hospice patients who died by stopping eating and drinking was almost twice as high as the number who had a PAD and the authors state that such deaths ‘may occur often enough to be of clinical relevance to hospice care across the United States’.\textsuperscript{58}

\textbf{Option two: lay assisted suicide}

There are obvious reasons why an individual with a persistent wish to die might prefer the idea of an assisted suicide via medication undertaken with the help of an assistor over hastening death by stopping eating and drinking. Provided the right medication is obtained, then the result should be a more comfortable, much quicker death than stopping eating or drinking. As such, a lay assisted suicide is more likely to better reflect the idea of death that the individual desires. The nature of assistance required will depend on the individual’s particular situation. For instance, they may require assistance by way of acquiring the necessary medication, or physical assistance if they are physically infirm. If they have no knowledge of the ‘right’ medication to use, they will need advice, which can be obtained from right-to-die organisations.\textsuperscript{59} The greatest difficulty that an individual who wishes to commit suicide by medication is likely to face, and might well need assistance with, is getting hold of the necessary medication.\textsuperscript{50} It does seem, however, that some doctors are
prepared to knowingly supply pills and that some individuals are able to obtain medication by false pretences.\(^{61}\)

The 2002 Act only provides an exemption from the criminal offence of assisted suicide for physicians who comply with its provisions. Thus, if a lay person assists in another’s suicide and his actions are discovered, s/he faces prosecution and conviction under Article 294 of the Penal Code, for which the maximum penalty is three years. Case law suggests that the offence is made out where the individual provides the means to commit suicide, or is present at the suicide and takes an active role (giving instructions or directing the suicide, for instance).\(^{62}\) Whilst, therefore, the option of lay assisted suicide may offer a ‘better’ death than stopping eating and drinking, individuals who wish to avail themselves of this method must find someone who is willing to assist and run the risk of their actions being discovered, assuming that they themselves are prepared for their assistors to take this risk and face the possible legal consequences.

There is a recent, well-publicised incidence of lay assisted suicide that has become known as the ‘Moek’ case. At 99 years old, Maria Heringa (‘Moek’) was a very independent woman who lived in a nursing home. She was tired of old age, felt she was increasingly losing control over her life and found no more pleasure in life. She requested PAD, but the doctor considered that she failed to meet the due care criteria and was unable to express her wishes with clarity. Her family were aware of her desire for an assisted death and she was a member of the NVVE. When her request for physician assisted death was turned down, Moek asked to speak to a member of the NVVE. This person suggested the possibility of stopping eating and drinking, but Moek did not feel able to do this. The other suggestion
made was for Moek to gather and store pills which could cause her death if she took a sufficiently high dosage. Moek subsequently collected pills and showed these to her stepson, Albert Heringa, informing him of her intention to take her own life. However, Heringa realised that taking these drugs would not cause her death. Although he tried to dissuade her from her intentions, she was determined and adamant that she wanted to die. Thus, to enable her to commit suicide, he gave Moek anti-malaria medication he had obtained from a visit abroad, in addition to sleeping pills and anti-vomiting pills. On the night in question, he and his daughters stayed with Moek after she had taken the drugs and fallen asleep. Heringa was informed of her death by a member of the nursing home staff early the next morning. Although a doctor recorded Moek’s death as a natural one, Heringa had consulted a criminal lawyer and made a video-recording of what occurred. He did this in case of future prosecution, so that he would have evidence that she herself had made the final decision and taken the medication. It was decided that the video recording would be shown as a documentary on a Dutch television network as part of the NVVE’s Completed Life campaign (Heringa too is a member of the NNVE).63 He was subsequently questioned by the police and the Public Prosecutor in the Zutphen became involved.64 He is currently awaiting trial. It will be interesting to see the outcome of the Moek case in terms of Heringa’s punishment if he is found guilty by the court. Although the court may choose to impose a strict punishment to deter other lay assistors, it seems more likely that any sentence will be a lenient one given the previous sentences that have been imposed in more recent lay assisted suicide cases.65

Besides its outcome, perhaps the greatest significance of the Moek case is that the video recording provided clear evidence of Heringa’s assistance and the prosecuting authorities
were made aware of his actions. In fact, very few non-medical cases of assisted dying are reported to the Dutch Public Prosecution Service. This suggests one of two things: either 1) that cases of lay assisted suicide rarely occur, or 2) that they are being reported as natural deaths by doctors and families. Research suggests that the latter is the more realistic explanation. In their study involving cases where individuals achieved a self-directed death by ‘independently taking lethal medication attended by a confidant’ (ILMC), Chabot and Goedhart note that ‘Many sudden deaths of elderly people who die at home in bed without any obvious signs of pill boxes or farewell letters pass unnoticed into the death statistics as a “natural death”. Some informants reported that a death by ILMC had been registered as a “heart attack” or just “frailty in old age”.’

Of course, the likelihood of being prosecuted for assisting the suicide of a close relative of friend is reduced if one’s actions can be concealed from the authorities and there is evidence to suggest that a relative who assists may face a more sympathetic response from the prosecuting authorities than a member of a right to die organisation. It is worthy of note that in the cases where there have been prosecutions, the assistor tends to be a member of a right-to-die organisation. It is clear, therefore, that although lay assisted suicide remains an option, its unlawfulness places obstacles in the path of someone who is refused PAD and requires assistance to commit suicide. Not only must they somehow obtain the necessary medication, they must also find a lay person who is prepared to break the law and face the potential consequences of this.

**Conclusion: between a rock and a hard place?**

A Dutch resident who has an enduring wish to die but does not meet the lawful criteria for PAD and does not wish to end their life by more violent means, faces a stark choice. They
can act within the boundaries of the law and elect to stop eating and drinking, but this entails a slower, less pleasant death than that achieved through PAD. Or if they are unable or unwilling to self-hasten their own death in this way, and cannot commit suicide without assistance, they could look to a relative or a friend for assistance to die an ‘easier’ death via medication. But they then take the risk that their relative or friend will be prosecuted for assisting them if their actions are detected.

On the one hand, it seems unjust that those who are deemed to meet the due care criteria have access to PAD, when others who also consider their suffering to be unbearable and have an equally persistent desire to die are denied PAD because of a strict interpretation of the due care criteria and an objective assessment that their suffering is not unbearable. Yet, on the other hand, necessary limits must be set on autonomy to keep lawful assisted death within certain boundaries and to avoid a trip down the slippery slope. And it is important to remember that the rationale behind the Dutch PAD law is not autonomy, but rather, necessity and the conflict of duties faced by a physician. As such, it is legitimate to maintain the restriction that the individual must be suffering unbearably from a medical condition, provided existential suffering has been appropriately categorised as non-medical and provided that physicians are assessing the level of suffering correctly. I have suggested that the categorisation of such suffering can be challenged and have highlighted the difficulties doctors face in applying the unbearable suffering criterion generally, which can only be exacerbated when the suffering lies outside of what they perceive to be the medical realm.

The fact that cases of self-hastened death by stopping eating and drinking and lay assisted suicides are occurring suggests that at least some of those for whom life has become
subjectively unbearable for non-medical reasons (or, at least, reasons that are deemed illegitimate under the lawful medical model of PAD) have a persistent desire to die. The strength of their autonomous wish to die and growing public support for the extension of law to cases where individuals are ‘weary of life’ indicates that self-directed death in the Netherlands is not a matter that will go away. It should give us pause for thought that even in a jurisdiction where PAD is lawful, there are still PAD outlaws who are left between a rock and a hard place when trying to achieve their desire for a self-appointed death.

1 In this paper, I apply this term to both euthanasia and assisted suicide carried out by a physician, since both are permitted under the lawful medical model of assisted dying in the Netherlands.
2 By this term I mean individuals who remain outside the law on PAD and have to resort to lawful or non-lawful means to achieve the self-appointed death they desire. Thanks are due to Hazel Biggs, for allowing me to ‘borrow’ her well-chosen term. See Biggs, H. Criminalising Carers: Death Desires and Assisted Dying Outlaws in Brooks-Gordon, B, Ebtehaj, F, Herring, J et al (eds) Death Rights and Rites. Oxford: Hart, 2007: 57-73.

5 Ibid., 126-7.
6 Ibid., 85-90.
8 As evident from early case law such as Alkmaar, Nederlandse Jurisprudentie 1985, No.106, 451. See also Griffiths, J, Weyers, H and Adams, M. Op cit ref 4: 33.
A survey involving 412 physicians, requests for PAD based on being ‘weary of life’ were only granted in approximately one case. See Rurup, ML et al. Op cit ref 21: 669.  

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In the Netherlands, Dutch citizens can put a proposal forward that will be put on the agenda for consideration by the Second Chamber of the Dutch parliament, so long as the initiators gather 40,000 signatures in support of the proposal.

See www.uitvrijwil.nl.


Ibid., at 26.
See Chabot BE and Goedhart A. Op cit ref 36.

Ibid., at 1748, 1749.

Ganzini, L, Goy, ER, Miller, LL, Harvath, TA, Jackson A and Delorit, MA. Nurses’ Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death. NEJM 2003; 394(4): 359-365, at 360. The authors interviewed 35 physicians, 7 of whom were aware of such patients.

Chabot B. Op cit ref 41: 362.

Chabot B. Op cit ref 37: 18 and 22.

Chabot B. Op cit ref 37: 21 and 27.

Ibid., at 28.


Chabot, B. Op cit ref 37: 30; McCann et al. Ibid.: 1266.

Chabot B. Op cit ref 37: 33.

Ibid., at 37.


Pool R. Op cit ref 12: 963 and see also 956 and 964.


‘Senior experienced specialists in palliative care have observed that even determined patients may become disheartened and give up the attempt when they find that a week or two after starting the process they are still alive.’ Warnock, M and Macdonald, E. Op cit ref 46: 105-6 and see also 107-8.


See also Chabot, 2008: 52.


Chabot and Goedhart, 2009: 1749.

Griffiths, J, Weyers, H and Adams, M. Op cit ref 4: 184; Personal communication with John Griffiths in April 2010, who has spoken to prosecutors from the Dutch Public Prosecution Service on this matter.