

## Case Report

# Euthanasia in Patients with Dementia

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Submitted: 16 September 2020

Accepted: 01 October 2020

Published: 02 October 2020

ISSN: 2475-9465

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## Abstract

Even though there is at present in The Netherlands a widely accepted legal framework within which euthanasia is allowed, many doctors find euthanasia in cases of dementia too complex. There are several reasons for this cautious approach. Doctors fear the possibility of a judicial aftermath. Another factor is a faulty, if not downright mistaken, opinion about the nature of the mental anguish that people with dementia sometimes experience. Doctors find it difficult to realize just why dementia can be so terrible. A further reason for this restraint is the problem of deciding whether the patient is mentally still competent when it comes to formulating a wish to die.

## CASE HISTORIES

Patient A was 72 years old when her son brought her into contact with the Expertisecentrum for Euthanasia. She had been diagnosed with Alzheimer's disease 18 months earlier. Her GP was unwilling to arrange euthanasia for her, because he did not agree that the woman's suffering was all that severe. We had four meetings with the patient during which her son and her daughter were alternately present. The patient lived in a lovely cottage, which was only possible because of the help offered by her children and her sister-in-law, who lived right next-door. In earlier times she was a hardworking woman, who ran her own restaurant with thorough efficiency, never shirking to wait at table herself in busy times. Now she had turned into a slow-witted, nervous, shuffling old lady, always afraid of falling. Alzheimer's disease had gradually robbed her of the thing she valued most in life: living her own life, not having to depend on others. Driving her car had become impossible. She also had to give up her bicycle after some nasty falls. She was no longer capable of preparing a meal. She kept on going to the supermarket but felt ashamed when she came back home with useless purchases she didn't need at all.

Her character changed, she lost her temper easily, which was not her usual way of dealing with people. She once got into a row with the cashier in the supermarket. She had visited the shop a couple of times to buy new batteries for her house-telephone. She said the cashier did not put the batteries in her shopping bag. But at home her son chanced on a huge store of new batteries. Two boys in the neighborhood who used to help her in the garden stopped their involvement because she was unkind to them, shouting abuse for no reason.

She was not always fully aware of these details of her decline, but it all added up to a feeling of increasing despair.

She was no longer capable of a deeply probing exchange about these developments. But she remained adamant on one point. She realized that she was on her way to the situation in which her mother ended: she died in a care home, deeply demented, lying in bed in a fetal position, wearing diapers because of her incontinence. She repeatedly voiced her fear that she might be too late with her request, too far gone to request euthanasia.

The second opinion doctor agreed that her request fell within the bounds of the law. We were worried whether she could set a date for the event, but after the second opinion she proposed a date two weeks later. She was greatly relieved by the prospect of her demise and on the appointed day she imbibed the lethal potion without much ado.

Patient B was 67 years old when his son got in touch with the Expertisecentrum for Euthanasia. He had been diagnosed with Lewy Body Dementia a year earlier. The patient worked as a lorry driver until he was 48 when he was found to be unfit for employment due to trouble with his back. He had little formal education and was verbally not very proficient.

But when we first met, he easily managed to explain to us that he wanted to die, and as soon as possible. He was an ardent cyclist, covering considerable distances. But it happened time and again that he lost his way, and on several occasions he was completely lost. This irritated his wife, she blamed him for his incompetence. Gradually he lost his independence, needing help when getting out of bed, washing himself, putting on clothes and visiting the toilet. His wife found this hard to cope with. There was a reversal of roles. He used to be the one in charge, but now he totally depended on her. She shared her misgivings with other people in the neighbourhood. The GP found all this rather difficult and felt it wise to ask the Expertise centre for Euthanasia to deal with his request.

During our visits we met a deeply unhappy man. He was quite well aware of his situation and told us his fear of further deterioration. He could hardly stand, walking was almost impossible. His verbal range was severely diminished which caused extra anxiety at the prospect of no longer being able to express his wish for euthanasia. He lost his way in his own house, another cause of tension and unrest.

All he wanted to do was sit in his chair all day. His wife was slightly relieved when we explained to her that we realized that she too was suffering badly on account of her husband's disease. We visited the couple four times within a relatively short time span. During two of our visits their son was present. The second opinion doctor found the case to be well within the bounds of the law. Six weeks after our first contact the patient, greatly relieved and with firm determination, drank the lethal medication.

## DISCUSSION

A careful exploration of the inner life of a person suffering from dementia enables the doctor to come to a reasonable estimate of how horrible the condition can be in some cases. People battling with dementia, the word is very apt, often fight against a threatening way of being lost. It is not just a matter of being lost in a strange town, they cannot even find their way in their own home, and worse still, they have lost the way within themselves. Often they do not remember who they were. They wonder who they are now, and what is to become of them. Not all people suffering from dementia experience these mental upheavals with the same agonizing intensity. But those who, to a certain extent, realize what is happening to them, may not unrealistically regard a request for euthanasia as the only way out.

### Mental competence

Assessing mental competence in dementia patients who put in a request for euthanasia is difficult at times. The criteria suggested by Appelbaum and Grisso offer a good guideline table 1. It is important to realize that any pronouncement about mental competence must be linked to a specific issue, in this context: the wish to have one's life ended. Does the patient understand what he or she requests? Is there a realization what the request implies, for himself or herself, and also for his or her loved ones? And most of all: is the request durable?

In people suffering from dementia there is always the danger of losing this competence. The Dutch euthanasia law states explicitly that a written advance directive, in which the person describes under which conditions euthanasia is to be granted him or her, may take the place of an oral request. In 2016 a Dutch doctor working in a nursing home euthanized a woman suffering

**Table 1:** Criteria of Appelbaum and Grisso for the assessment of mental competence.

There are 4 cognitive capacities which should be within the mental scope of a person who one would describe as mentally competent.

1.	Capable of choosing between 2 treatment options and uttering that choice.
2.	Capable of understanding proffered information.
3.	Capable of realizing the nature of the situation (awareness of one's own situation).
4.	Capable of rationally weighing information (reason logically).

from Alzheimer's disease, even though at the time of her death she was no longer capable of voicing a request. The doctor acted on the base of her actual suffering and on the text of the advance directive. Understandably there was a lively national debate about this particular case. The doctor was exonerated in court. In April 2020 the Dutch Supreme Court upheld this judgment. We are here confronted with a devastating problem that is continually debated by people suffering from dementia and people who fear dementia in their future. It is also an issue that engages many philosophers, ethicists, medical professionals, lawyers, judges and politicians [1-6].

## CONCLUSION

In The Netherlands euthanasia is legally allowed in certain cases of dementia. However, many doctors regard the issue as too complex. A thorough exploration of the mental state of persons suffering from dementia, enables one to arrive at a reasonably accurate weighing of the severity of the mental anguish. The guidelines formulated by Appelbaum and Grisso may be used when assessing the mental competence of the patient. In this way it is possible in The Netherlands to act on the request for euthanasia from a patient wrestling with dementia within the bounds of Dutch law.

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### Cite this article

van der Meer S, Keizer B (2020) Euthanasia in Patients with Dementia. *Ann Community Med Pract* 5(1): 1045.