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Message for the government coalition negotiation table

The Euthanasia Law does not provide protection to people with dementia and psychiatric problems, says Boudewijn Chabot. “Silently, the foundation of the law is being eroded.”

Boudewijn Chabot is a geriatric psychiatrist and researcher of voluntary end-of-life choices.

About twenty years ago, I was sitting on the bench for the accused in the High Court. This was ten years before the adoption of the Euthanasia Act, after I had given a fatal drink to a 50-year-old, physically healthy social worker. Judgment: ‘guilty without punishment’. I fought – and fight- for self-determination. However, I am now worried about the rate at which euthanasia is performed on demented and chronic psychiatric patients.

Recently, the third evaluation of the Euthanasia Act, which came into force in 2002, came out. And like the previous evaluations, the tone was positive. “The goals of the law have been realized. All actors are satisfied about the content and functioning of the law.” That sounds all very well, but it’s not. Since this contentment hides problems which the researchers fail to mention.

To understand what has gone wrong, the reader must know the three most important “due care criteria” of the law. There must be: 1) a voluntary and deliberate request; 2. unbearable suffering without prospect of improvement; 3. No reasonable alternative to euthanasia.

The second and third requirements are closely linked because if another solution, such as specialist palliative care, is indicated, the suffering is not without prospect of improvement. If the patient

refuses that option, the physician will not be convinced of the “unbearable” nature of the suffering and will not provide euthanasia.

At least as important is what is *not* in the law. There is no requirement that the disease has to be physical, and the doctor need not have a treatment relationship with the patient. Many doctors and lay people thought this was the case. But such restrictions are deliberately omitted to allow for the development of concepts such as “unbearable suffering without prospect of improvement.”

In the last ten years, the number of euthanasia reports has increased from two thousand to six thousand per year. People ask for it more often, doctors are more often willing to provide it, and consultants who assist the doctors give more often the green light. In 2016 the review committee found that only 10 of the 6,091 (0.16 percent) cases was done without due care.

All of this indicates a shift in culture in relation to self-selected dying under the custody of the doctor. Apparently doctors heed the increasing demand for euthanasia in the context of all kinds of nasty diseases, particularly cancer. In and of itself, this increase does not disturb me – even if the number exceeds ten thousand in a few years.

What does worry me is the increase in the number of times euthanasia was performed on dementia patients, from 12 in 2009 to 141 in 2016, and on chronic psychiatric patients, from 0 to 60. That number is small, one might object. But note the rapid increase of brain diseases such as dementia and chronic psychiatric diseases. More than one hundred thousand patients suffer from these diseases, and their disease can almost never be cured. Particularly in these groups, the financial dismantling of care has affected patients’ quality of life. One can easily predict that all of this could cause a skyrocketing increase in the number of these euthanasia cases.

Strikingly, doctors from the End of Life Clinic Foundation* are often euthanizing these patients, while as a matter of principle they never treat patients for their illness. By 2015, a quarter of euthanasia cases on demented patients were performed by these doctors; in 2016 it had risen to one third. By 2015, doctors of the End of Life Clinic performed 60 percent of euthanasia cases in chronic psychiatric patients, by 2016 that had increased to 75 percent (46 out of 60 people).

There appears to be a realization that something is going wrong, because the review committee has recently been strengthened with a few specialists in the field of geriatric medicine and psychiatry. However, their vote will be lost in the choir of the forty-five commissioners who are responsible for the current ‘jurisprudence’.

These figures also cannot be found in the annual report of the committee or in the statistical tables of the researchers. For sure, the fact that in 2016 euthanasia has been granted to a total of sixty psychiatric patients is included in the annual report of the review committee. But nowhere in the report is it mentioned that in 46 of these cases, it was a physician at the End of Life Clinic who granted the request. That number you have to dig up from the annual report of the End of Life Clinic. Is this fog purely coincidental?

Cornerstone of the law

Is it still possible to put a break on this development? It won't come from the review committee, which cannot go back on its ‘case law’. Already back in 2012, at the time of the second review of the law, it became apparent that the review committee no longer discussed whether the due care criteria of “unbearable suffering without prospect of improvement” were fulfilled. The committee members found this difficult to evaluate, as was already apparent from the previous review of the law: “If the notifying physician and the consultant found the suffering to be unbearable, who are we to say something more about it here?”

The interpretation of this cornerstone of the law already came down to what the doctor and consultant accept as unbearable suffering without prospect of improvement.

This is also clear from the reviews. In 2016, the committee found in only one of the 201 cases of euthanasia in dementia and psychiatry that the evaluation had been careless [not in line with due care] because the requirement of “unbearable suffering” had not been met. What problem is this evaluation structure, which costs about four million euros annually, really solving? The researchers fail to answer this question.

Once upon a time, moving to a nursing home or receiving treatment with some medication was still considered a “reasonable alternative” for euthanasia. At least it had to be tried. Many doctors now accept that a patient can refuse a reasonable alternative and that this does not create a barrier for euthanasia. That brake has now also disappeared.

In the Chabot judgment, the Supreme Court had still required “exceptionally great caution” with respect to psychiatric patients. Those words are now trite, because a reasonable alternative to death can now be refused and the committee will still provide its stamp of approval that the euthanasia was done with due care. This has been the case for many years, since already at the time of the previous evaluation of the law the majority of the review committee did not find that doctors were too easily accepting that patients reject a reasonable alternative.

Within the End of Life Clinic, a group culture has emerged in which euthanasia is regarded as virtuous labor

Ethicist Govert Hartogh, who has for many years been a member of the Evaluation Committee, has identified this subtle but steady process of erosion: “The patient suffers unbearably when he says he suffers unbearably and an alternative is not a reasonable alternative if the patient rejects it. In fact, these requirements then add little to the

requirement of a voluntary and thoughtful request.”

The erosion of nice words reminds us how it has gone with the abortion law. In order to get abortion, a woman had to be in an “emergency” situation. Soon every woman knew that she got what she wanted if she requested it and rejected any other solution. The Dutch legislature has often been creative in areas of morality, with big words that, after a while, completely lost their bite. Consider the “enduring disruption” that was required for divorce.

The fading of legal requirements does not have to be a problem. Sometimes this leads to an amendment of the law, such as with “enduring disruption.” Sometimes we also accept that the core idea behind the law has shifted to favour self-determination, such as in the case of abortion. The problem is, however, that the euthanasia committee continues to speak of “unbearable and hopeless suffering” in its annual reports, as if these words still really have great weight.

While researchers are pointing to the growing emphasis on self-determination, they fail to mention the erosion of the two other legal requirements. Silently, the very foundation of the law is eroded.

The doctors working within the End of Life Clinic consider themselves at the “forefront” and call the clinic a ‘centre of expertise’. Unfortunately, there is very little expertise in palliative care, for the simple reason that when a patient rejects treatment it is accepted as an expression of self-determination.

In 2016, about 40 physicians working part-time at the End of Life Clinic performed euthanasia 498 times. On average, this amounts to 12 euthanasia’s per doctor, one per month. Within the clinic, a group culture has emerged in which euthanasia is considered to be virtuous labour, especially in severe dementia and chronic psychiatric patients. The fact that the End of Life Clinic also rejects many requests is thereby irrelevant, since many people who do not at all qualify for euthanasia contact the clinic.

What happens to doctors for whom a deadly injection becomes a monthly routine? They are surely well-intended, but do they also realize how they are fanning a smoldering fire that can become a blaze because they fuel the death wish of vulnerable people who are still trying to live with their disabilities?

The End of Life Clinic is now actively recruiting psychiatrists. It justifies this by pointing to the long waiting list. Their task: relieving the unbearable and unrelievable suffering from psychiatric patients through euthanasia. Every time the Clinic is in the news, a wave of depressed patients whose treatments are allegedly exhausted but many of whom have never been properly treated report to the Clinic. Ever since budget cuts turned chronic psychiatry into a diagnosis-prescription business, good treatment has become scarce.

The newly recruited psychiatrists won't need to enter into a treatment relation with the patient. The evaluation committee has accepted that in the case of severe physical illnesses. Now it has also applied this to incurable brain diseases—without discussing it with members of the psychiatric profession by the way.

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This has been an overly hasty step. Without a therapeutic relationship, by far most psychiatrists cannot reliably determine whether a death wish is a serious, enduring desire. Even within a therapeutic relationship, it remains difficult. But a psychiatrist of the clinic can do so without a therapeutic relationship, with less than ten 'in-depth' conversations? Well ...

With dementia there is another concern. The Euthanasia Law has added that a written letter of intent may replace an oral request, while the other due care criteria remain applicable. According to ethicist Den Hartogh, this implies that for a demented patient, two of the three due care criteria disappear—the requirement of a well-considered request and the requirement that reasonable alternatives

have to be dropped—because they cannot be applicable.

What remains is the requirement that there should be unbearable suffering that cannot be alleviated. But it is often very hard to determine whether there is unbearable suffering in advanced dementia, as five professors of geriatric medicine recently stated in NRC. The personal colouring of ‘suffering’ in dementia plays a major role.

Yet, that uncertainty doesn’t appear to be a problem for the review committee. When a physician and a geriatric specialist note in their report that a person with dementia suffers unbearably, the committee may occasionally ask a question about that, but it doesn’t cause any further problems.

With the erosion of the concept of “unbearable suffering” and the determination that a written consent is the same as an oral request, the door has been opened wide for euthanasia of patients with severe dementia.

Yet, we still face a formidable obstacle in the context of severe dementia: how do you kill someone who does not collaborate because he has no realization of what will be happening? Already in 2012, NRC described how this works. A spouse mixed sleep medication in the porridge of his demented wife before the GP arrived with his deadly syringe. At the time, the review committee failed to mention anything about this assistance. In later cases of euthanasia with advanced dementia, the committee also remained silent about the precise details of the execution.

In 2016, there were three reports of euthanasia of deep-demented persons who could not confirm their death wish. One of the three was identified as having been done without due care; her advance request could be interpreted in different ways. The execution was also done without due care; the doctor had first put a sedative in her coffee. When the patient was lying drowsily on her bed and was about to be given a high dose, she got up with fear in her eyes and

had to be held down by family members. The doctor stated that she had continued the procedure very consciously.

Thus, a doctor can kill someone surreptitiously, because you cannot resist after being sedated. If necessary, physical force is used. A large group of doctors called this “sneaky” and published a full-page advertisement, including in NRC, letting our society know that they will not do this.

History repeats itself

In the third review of the law we can find the following remarkable sentence about the surreptitious administration of a fatal drug: “This can in those cases be inherent to the nature of the situation and has not been previously considered a problem.”

The surreptitious administration of medication has previously occurred, but has never been mentioned in an annual report. That is odd, because the committee queries doctors relatively frequently about the medications they administered and judges deviations from the Euthanasia Directive relatively frequently as careless. In a deeply demented person, we are dealing with a morally problematic act: how do you kill someone who does not understand that he will be killed? Remaining silent about the precise way of execution appears very far removed from the transparency that the committee expects of doctors.

The researchers compare this form of cover-up to be “inherent to the nature of the situation”. When it comes to the killing of a defenceless human being, everything that is deemed “inherent to the situation” should be very clearly identified in the evaluation and in the annual report. The review committee has failed in transparency, for five years now. And the researchers smoothen this out.

Would the Public Prosecutor’s Office now take up its responsibility after being laid back about it for fifteen years, and submit the case to

the court? Earlier, when the review committee considered in one euthanasia case that due care had not been met for all three legal requirements, the public prosecutor failed to prosecute.

In the context of severe dementia, the following legal questions can only be answered with authority by the Supreme Court: can people be killed surreptitiously? Isn't that a form of duress, since any possible resistance is being prevented? Isn't it precisely when we're dealing with a defenceless person that any hint of coercive force must be avoided?

In the case of the woman who got up with fear in her eyes, the public prosecutor can launch an appeal in the interest of the law. He can then submit the matter directly to the Supreme Court. I think that the public prosecutor will very likely take a wait and see approach. In that case, geriatricians, for whom clarity on this legal question is of utmost importance, can appeal the decision not to prosecute in a court of law.

History repeats itself when it comes to laws dealing with challenging ethical issues. Self-determination around the end of life is for many people as important as in the context of abortion. It is therefore not surprising that the first due care criterion, a voluntary and well-considered request, has gained in importance. And that criterion has pushed the other two due care requirements to the margins. What is astonishing is that in the third evaluation of the law, the researchers still keep up the smoke screen around 'unbearable suffering without prospect of improvement'.

Where did the Euthanasia Law go off the tracks? The euthanasia practice is running amok because the legal requirements which doctors can reasonably apply in the context of physically ill people, are being declared equally applicable without limitation in the context of vulnerable patients with incurable brain diseases. In psychiatry, an essential limitation disappeared when the existence of a treatment relationship was no longer required. In the case of dementia, such a restriction disappeared by making the written advance request equivalent to an actual oral request. And lastly, it

really went off the tracks when the review committee concealed that incapacitated people were surreptitiously killed.

I don't see how we can get the genie back in the bottle. It would already mean a lot if we'd acknowledge he's out.