



1. What is the Dutch Patients Association's position on euthanasia?

Our organization de *Nederlandse Patiëntenvereniging* (NPV) (www.npvzorg.nl) is a Christian, pro-life organization with 63.000 members (in 2012). We reject the practice of euthanasia. We believe God is the Creator of life. The NPV is not affiliated with a particular church. All churches are represented, Protestant (reformed/evangelical), Roman Catholic, some Jewish, a single member without any church background.

We have compassion for all the people who are dying as a result of a disease. We think it is important to invest in high quality care, assisted by doctors, nurses, relatives and specialized volunteers. That care is not to terminate life, but to accompany a natural, not speeded up or slowed down, death as good as possible. That is dying with dignity.

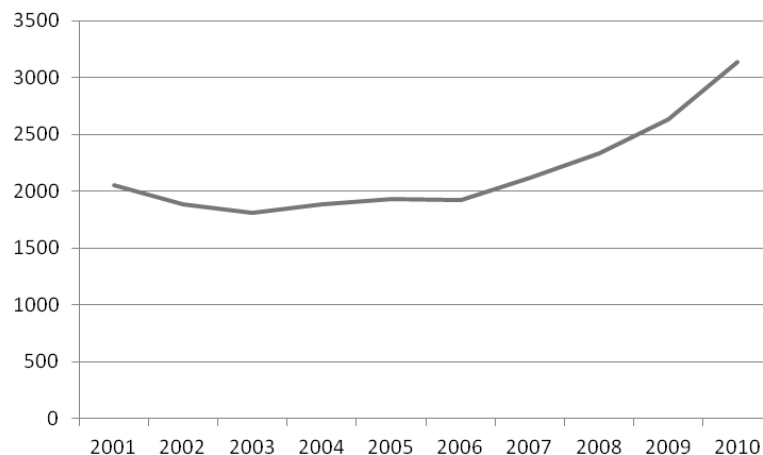
We want to tell you something about the Dutch practice and our organization, the NPV:

Christian faith en moral (the basics of Dutch history) has led - contradictory - to the euthanasia law. The Netherlands as a Protestant Christian nation in combination with an open culture has led to a public discussion about dying. The sixties and seventies were characterized by negotiation and discussion about a lot of topics. The breaking through the taboo of subjects as *suffering* and *death* was inspired by a request of knowing the truth. People want to talk openly en honestly about death and euthanasia. In discussion, the choice of the individual was a very important criterion. Christian norms and values *outside* people were replaced for norms *inside people*: they want to make their own choice and decisions.

The Netherlands were the first country where a euthanasia law went into force. There is a different way people think and speak about *suffering*. A little - but defining - elite started the discussion. In 1973 a Dutch physician, miss Postma, gave her mother a mortal injection. She was condemned by court (Openbaar Ministerie (OM), the highest Dutch Court) for a week imprisonment. This case has led to the start of the NVVE (Nederlandse Vereniging voor een Vrijwillig Levenseinde). This is the Dutch association for death out of free will. In 1984, the first bill concerning a euthanasia law was presented by ms. E. Wessel-Tuinstra (D66).

The euthanasia law went into force 1 April 2002. From this time, there is an increasing number of reported cases of euthanasia to the *toetsingscommissies*. This is a committee that reviews the practice of euthanasia after the patient's death.

Line Chart reported cases in the Netherlands



Aantal euthanasiemeldingen in Nederland (bron: jaarverslagen Rte)

1998	349	
1999	2.216	
2000	2.123	
2001	2.054	
2002	1.882	
2003	1.815	
2004	1.886	
2005	1.933	
2006	1.923	
2007	2.120	
2008	2.331	
2009	2.636	
2010	3.136	→ increase of 19% compared to 2009
2011	3.695	→ increase of 18% compared to 2010

At the moment 2.7% of all deaths in the Netherlands is caused by euthanasia which is reported at the committees.

There are a lot of indistinct cases. We think a lot of physicians are afraid of the condemnation of the Openbaar Ministerie. Or maybe there is an increase of 'terminale sedatie', a way of sedating people to make people die. That is a wrongful use of sedation, because the right way is to use sedatives to diminish pain when people are dying, not to make people die. The NPV called this 'het grijze gebied', the grey area. We firmly request an inquiry to clarify this cases.

2. What is the Dutch Patients Association's position on the Levensende kliniek or mobile service Life Unit?

It is an absurd idea!

- There is no relation between doctor and patient.
- We wonder if these 'mobile doctors' are truly focused on the patient as a whole. What in fact is the real question or what is the question below the question to die? You never can analyze this in a few days!
- There is not enough time to explore alternatives. We know from research that 10% of the euthanasia requests are withdrawn in case of qualitative care. The clinic has no interest in people who change their minds and withdraw a request.
- Hardly any health-insurance company in the Netherlands will pay for this 'living-end-clinic' at this moment. They possibly fear for their image...

This development is contradictive to the development of palliative care in the Netherlands. Before the creation of 'mobile euthanasia teams' we should have questioned ourselves: How well-developed is palliative care in the Netherlands? What is the percentage of terminally ill patients (roughly) who have access to palliative care? How much effort is taken by the government to increase the number of palliative care facilities and to improve the specific training of medical professionals?

There is an increasing attention for palliative care since 1990. Good research after the possibilities of palliative care has never been done, but according to the 'common sense' theory in the Netherlands there is a decreasing demand for euthanasia during good palliative care. The government is stimulating palliative care and both people pro and contra euthanasia are convinced that palliative care is really necessary.

The character of euthanasia requests has slightly changed in the last thirty years, researchers of the NIVEL (Nederlands instituut voor onderzoek van de gezondheidszorg) presented in January 2012. In the seventies of the last century the most important reason for euthanasia was pain. Nowadays loss of dignity and significance are also important reasons for a request of euthanasia.

3. What is the Dutch Patients Association's position on the citizens' initiative called Out of Free Will?

We think this initiative is a clear expression of the fact the Netherlands are on a so-called 'slippery slope':

- Look at the numbers (see before): annual increase of euthanasia cases in relation to declining mortality rates of the population in the Netherlands.
- Euthanasia is practiced to elderly, dementia people, when they are no longer mentally competent.
- Psychiatric patients can also call on the euthanasia law.

In the Netherlands the discussion about 'completed life' was started in 2010. According to this citizens' initiative that was signed by 116,000 people, it should be possible for elderly people who are 70+ (but not ill!) to ask a 'counselor' to die. They ask for legalization by law. 8 March 2012 the government has discussed this initiative, but at the moment there is not enough consensus about: How many people want this? What is the difference between this population and the population of sick elderly people? How do we organize this? But also: is this the right solution for elderly people? It is a question to our complete society.

The NPV considers: The question is not: 'How can we help people to die?' But the question should be: 'How can we help people to live?'

In a completely secularized society, it is not amazing that questions rise about dying.

4. When/How did the association create the living will declaration (the NPV-Levenswensverklaring)? How many have been distributed so far?

The NPV has a 'declaration of intent' (de NPV-Levenswensverklaring) in which people can indicate how they want to be taken care of in their final stage of life. The *NPV-Levenswensverklaring* is a declaration of somebody's last will. People can explain which medical and nursing care they would like to receive in the final period of their lives when they are incapable of pronouncing thus.

Subjects that are mentioned in this declaration are:

- I want optimal medical cure and care, with the intention of healing.
- When healing is not possible, I want optimal care and concentration on welfare and relief of suffering.
- I do not want others to judge about my 'quality of life' and I want treatments which are proportional (with the purpose to ameliorate my situation).
- Euthanasia is no option to alleviate my suffering.
- When I am dying, I do not want to receive treatments to lengthen my life.
- The physician has to communicate openly and honestly with my relatives or representative.

At the moment (December 2012) 6,487 declarations have been provided.

5. Has the association organized other interventions to prevent euthanasia?

Most people mention unbearable pain and suffering (seen by relatives) as a reason for euthanasia. However, a lot of people do not know enough about the increased opportunities in pain control of the last decennia.

The opinion of the Dutch anesthesiologist Ben Crul, a pioneer in the field of pain management and palliative care, is that euthanasia is unnecessary for most people with a terminal illness, with the current progress of pain management and palliative care. This view is expressed by many doctors in the Netherlands. Ben Crul is a respected emeritus professor of pain management to the Radboud University in Nijmegen, who has dedicated his life to the improvement of palliative care.

It is necessary to invest in palliative care. Even health-care minister Els Borst (she was responsible for the introduction of the euthanasia law) admitted that 'the law was introduced too quickly' (<http://vorige.nrc.nl/article2424976.ece>).

6. Does the association have polls on citizens' opinion on euthanasia?

In 2011, the KOPPEL-research was published:

- 75% of the Dutch people knows the definition of euthanasia
- 95% knows there is an euthanasia law
- 20% knows what palliative sedation is

There is indistinctness about the concept of 'unbearable suffering':

- 5% of the Dutch citizens is opposed to euthanasia
- 7% of the doctors is opposed to euthanasia
- 14% of the nurses is opposed to euthanasia

The NVVE has also published a research, but one wonders whether this is independent. Sjoerd Notting, former lecturer at the Amsterdam University, thinks the results are not reliable (<http://napnieuws.nl/2010/02/05/euthanasieonderzoek-onbetrouwbaar/>).

7. The annual report of the *toetsingscommissies* says the number of euthanasia cases reported to one of five special committees was 3,695 in 2011. Does the association believe this number is high? Why?

It is 2.7% of the Dutch death cases.

The number is growing. In 2010 there were 469 cases that were not judged in time. In 2011 this concerned even more cases (the number was not exactly mentioned in the report). The waiting time for review is unacceptably long, but the intention is that all cases will be judged. Therefore doctors have to wait for months before their case will be judged. The question is what will happen in future, when we know that there will be an increasing demand for euthanasia, also stimulated by the End of Life Clinic/mobile teams.