

SUBMISSION INQUIRY INTO END OF LIFE CHOICES VICTORIA

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As former CEO of the Dutch Right to Die Society NVVE (retired) and now Communications Director for the World Federation of RtD Societies WFRtDS, I consider myself as having extensive experience in the field of legalization of assisted dying by physicians. I have been involved in the discussions around the Dutch Euthanasia Bill, right from the moment it was introduced in the Dutch Parliament in 1999, up to its endorsement by the Senate in 2001 and its implementation in 2002 and later evaluations.

I have been in the position to explain to great extents the ins and outs of our law in many countries in the world in general and recently also in Australia and New Zealand. My thus built experience has learnt me to understand on one side the impossibility to export Dutch Law to other countries one-in-one (how much our sister societies would like to) because of different cultural and juridical/legal systems, but also on the other side it has taught me that “our” experience (now over 35 years of tolerated and legalized practice) forms a sound basis and even may provide valuable concrete contributions for other jurisdictions to design their own law; to design a system in which – this turned out in The Netherlands to offer the most important effect – the quality of end of life care could be improved, also because the patient, once assisted dying is legalized, has a real choice at the end of his/her life.

One of the ever returning discussion points when in debate with “opponents” of this choice possibility was the (deliberate?) misuse of the figures on the end-of-life practice in The Netherlands, presented by The Netherlands self. Since 1995 we have produced regular scientifically sound (world renowned statistics!) figures about our practice, repeated more or less every five years, in 2010 for the last time. These figures include amongst others also figures on doctors actions at the end of life, which are against our law then as now: the number of termination of life cases without request, happily misused worldwide by opponents; but now have decreased by more than 50% since our law was put into force.

In many countries Palliative Care (PC) in general and Palliative (terminal) Sedation (PS) in particular is brought forward as ‘alternative’ to Euthanasia or Physician Assisted Dying. But the principal differences between the two are such that never the one can be replaced by the other as if it were a choice. Euthanasia and PS are both possibilities at the end of a process of dying guidance / palliative care, each with its own properties.

Euthanasia is termination of life on request from the person involved; if the doctor performs the euthanasia and he complies with the criteria of the law, he will be free of prosecution. One, maybe the strongest, of those criteria says there should be a situation of unbearable and hopeless suffering.

Palliative sedation is according to international protocols only a real option when there is a terminal situation (dying is to be expected within 1 - 2 weeks) and there are refractory (untreatable) symptoms (pain, shortness of breath for example). The sedation is given to have the patient in a deep sleep in order for him not to notice the refractory symptoms. It is a medical decision and seen as a normal medical treatment for which no reporting is required.

Yes of course there is a grey area between the two methods, but that area is not bigger because euthanasia is legalised; both proponents of euthanasia and of palliative sedation wants this area to be as small as possible. The existence of both **law** and **guidelines** gives more guarantee for transparent treatments by doctors in order for patients to have the right to co-decide with the doctor which way they prefer.

To summarize:

1. People in The Netherlands (as in Australia) rather live than die, but want to have (and in The Netherlands now are lucky to have) the possibility to ask for medical support when they find the end of their life is inhumane because of futile, unbearable and hopeless suffering. The Dutch have since seen some increase in numbers (to be explained by 'getting used' to the existence of the possibility), certainly no increase in misuse (if at all not in substantial numbers), no decrease in trust in doctors (Belgium and the Netherlands come out of surveys as countries where the trust from patients in their doctors is among the highest in the world) and all that despite internationally recognized high level of Dutch palliative care (now number 4 of Europe list)! An individual does not ask easily for help to die; the legal possibility to do so facilitates the asking, facilitates the civilized conversation about this last phase of someone's life and – in my experience – sooner prolongs (quality of) life than shortens it; prevents ill-considered decisions from desperate humans and leads to better end-of-life care for all, palliative care included!
2. In no country in the world there is so much openness on medical decisions around the end of life as in the Netherlands. The scientifically well renowned reports of 1990, 1995, 2001, 2005 and 2010 (Rommelink, Van der Wal, Onwuteaka, Van der Heijden) are statistically sound and show no signs of a slope downwards, let alone a slippery slope:
 - a. the relative numbers of euthanasia and physician assisted suicide have shown to be rather stable, being about 2% of all death cases per year;
 - b. the percentage of *reported* euthanasia cases has grown from 18% in 1990 to 80% in 2005;
 - c. the same reports also showed the terminations of life without requests (also in our eyes to be improper) also to dramatically go down from 0,8% in 1990 to 0,2% in 2010 (some of them being termination of the life of severely multi-handicapped new-borns; now separately reported and assessed)
 - d. since 2001 there was a significant rise in percentage of Palliative Sedation (PS), a development in the opposite direction of that of Euthanasia.

3. Even the best of Palliative Care (PC) will never be able to take away all requests for euthanasia. The best PC offers a free choice to patients as to how and when they die. One of those should be Euthanasia, another PS. Good communication between the dying patient (and his/her family) on the one side and the acting doctor on the other side, long before the final moments turn out to be crucial for a humane death for the patient and a soothing bereavement for the relatives.
4. Presenting the Dutch system abroad I have discovered that the core of our law and practice lie in
 - a. the principle of termination of suffering (a Hippocratic dedication) rather than in termination of life
 - b. the real decisions are those that are taken by the patient who asks and the doctor who is prepared to help together, within a framework of general due care criteria (such as obligatory request and suffering unbearably and hopelessly).
 - c. The more (in my opinion see above useless) due care criteria are built in, the lesser the real choices for individuals are possible, and the lesser security doctors feel when giving help to dying patients (which already also happens in Australia as everywhere in the world and through all ages), resulting in actions to be performed in secrecy.
5. The lessons from the Netherlands can be that legalisation of Euthanasia turned into a better quality of all end-of-life care, a higher level of Palliative Care and a continued high level of trust between doctors and patients.

Now, as WF Communications Director and as webmaster of its website www.worldrtd.net, I regularly see those false arguments reappear, and my big fear is that wrongly used statistics from The Netherlands might be the reason for NOT openly consider new legal challenges, where the public as everywhere has grown to larger majorities to do so. It is in the interest of patients to have real choices and those are only there where and if a legalized possibility is in existence.

Knowing the complexities in this and realizing the limitations of written evidence, I will be happy to give oral/electronic evidence on the matter in a discussion with your Committee if they see the benefits of such evidence.

I wish you wisdom in your decisions and hope for a positive outcome for the citizens of Victoria.

Amsterdam, July 31, 2015