

To

Joint Select Committee on End of Life Choices
The principal research officer, Dr. Jeannine Purdy
Legislative Assembly
Government House
PERTH WA 6000

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Consultation on legislative options for Assisted Dying
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As former CEO of the Dutch Right to Die Society NVVE (retired) and now Executive 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 in later evaluations. As Chairman of the Registration and Education Commission of so called SCEN-doctors (the specialized doctor that can act as the legally obligatory second independent doctor) I am currently intensely involved in the quality aspects of our Dutch law.

I have long been in the position to explain to great extent the ins and outs of our law in many countries in the world, amongst which in South Australia and New Zealand in 2015. My thus built experience has learnt me to understand on one side the impossibility to export Dutch Law to other countries one-to-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 30 years of tolerated and legalized practice) forms a sound basis and even may provide valuable concrete contributions for other jurisdictions to design their own laws; 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 when (medical) aid in dying is legal, the patient have 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 and unfortunately still is the (deliberate?) misuse of the figures on the end-of-life practice in The

Netherlands, as 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 2015 for the last time. These figures include amongst others also figures on doctors actions at the end of life of persons, which are against our law then as now (the number of euthanasia cases without request, happily misused by opponents); but, these figures have decreased largely since our law was put into force (0.8% to 0.1%).

In many countries now Palliative Care (PC) in general and Palliative (terminal) Sedation (PS) in particular is brought forward as alternative to Euthanasia or Physician Assisted Dying. Euthanasia and PS are two possibilities at the end of a process of dying guidance / palliative care; each has its own properties, the one never can be replaced by the other as if they are full alternatives.

Euthanasia (in the Netherlands) is termination of life on request by the person involved; if the doctor performs the euthanasia and complies with the criteria of the law, (s)he will be free of prosecution. Major criterion – next to there being a request - states there must be a situation of *unbearable and hopeless suffering*.

Palliative sedation is possible when there is a terminal situation (dying is to be expected within 1 - 2 weeks) and there are what is called *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 those refractory symptoms; while being in this state food and fluid are withheld. It is a medical decision and is considered 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 just 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** (*since 2002 in NL*) and **guideline** (*recognized by Royal Dutch Medical Association in 2009 and updated later*) gives more guarantees 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 West Australia and everywhere in the world) 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 unbearable and

hopeless and thus futile suffering. The Dutch have since the legalization seen

- a. no unexplainable increase in numbers,
- b. no increase in misuse (if at all in substantial numbers),
- c. no decrease in trust in doctors
- d. and all that despite internationally recognized high level of Dutch palliative care!

A human being 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 life (of proper quality!) 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, 2010 and 2015 (Onwuteaka, van der Heijden) are statistically sound and show no signs of a slope downwards, let alone a slippery slope:
 - a. the absolute numbers of euthanasia and physician assisted suicide have shown to be rather stable with a gradual rise caused by the acceptance of the legal situation by doctors and individuals: a yearly rise of some 10%, the total percentage growing from about 2% of all death cases per year to 4% last year;
 - b. the percentage of *reported* euthanasia cases has grown from 18% in 1990 to over 80% in 2015;
 - c. the same reports even showed the decisions without requests (also in our eyes to be incorrect!) also to dramatically go down from 0,8% in 1990 to 0,1% in 2015
 - 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. As is recognized now by the European Association for Palliative Care (EAPC), even the best Palliative Care (PC) will never be able to take away all complaints and therefore requests for euthanasia. The best PC should offer 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. The lessons from the Netherlands can be that legalisation of assisted dying 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 Executive 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 influence an honorable and proper debate about a bill that is supported by a majority of West-Australians. It is in the interest of patients to have real choices at the end of life and those are only feasible 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 further oral evidence (or by Skype) on the matter in a discussion with your Committee if you see the benefits of such evidence.

I wish you wisdom in your decisions.

Rob Jonquière MD
WF Executive Director