The Dutch Euthanasia Law: good example or signal for danger?

Ladies and Gentleman,

Thank you for the invitation to meet your esteemed Committee to give evidence in relation to the citizen's initiative concerning Euthanasia KAA 2/2017 vp. It gives me the opportunity to fall in with a citizen's initiative that so much deserves and earns my support and respect, and to shed a better light on sort like developments around the world in general and in the Netherlands in particular.

I consider myself an expert in the field because of my professional history: I have practised euthanasia (long before we had a law) as a family doctor, have trained family doctors, have, as CEO of the Dutch Right to Die Society NVVE, been intensely involved from the start of the parliamentary debate since end of 1999 and so witnessed the first steps towards the Dutch law and helped nationwide with the practical implementation of the new law. Since 2008, after my retirement from NVVE, I now am the Executive Director of the World Federation of Right to Die Societies, an umbrella organisation for 51 national societies (the Finnish Society Exitus Ry being one of them) from 26 countries around the world. In those capacities I have given many presentations around the world, from the USA and Mexico to New Zealand, Japan and Australia, explaining the matter, as I hope to do so to you today.

Before all I want to I explain to you what I imply when I use the term Euthanasia, mainly to avoid a major misunderstanding and source of many pointless discussions.

Yes indeed, euthanasia originates in ancient Greek and literally translated means 'good death'. Worldwide we see the term used with prefixes in order to distinguish a number of actions, ranging from merci killing to using double effect. There are many ways to die well and never did or will I suggest that applying euthanasia according to the Dutch Law is the only way to have a good death.

When I use euthanasia it is defined as the "deliberate termination of life by someone else, on the explicit request of the person involved".

We also legalised physician assisted suicide in which the doctor provides the medication that is used by the concerned individual himself. Since the criteria and practice – apart from who administers the deadly substance – are fairly identical, I will from here onwards use only euthanasia.

It is good to realise that in the Dutch concept a number of choices at the end of life are not euthanasia (such as palliative sedation, termination of life without request and non-treatment decisions), and thus fall outside the euthanasia law.

Euthanasia is still present in our penal code (articles 293 and 294). This implies that in the Netherlands Euthanasia still constitutes a prosecutable crime, unless – and that is the core of our legalisation – it has been performed by a doctor who complied with the criteria. That doctor is free from prosecution – the case will be closed as "careful".

This law has not been changed since it became affective in 2002, and up till today more than 99% of all euthanasia cases are strictly within the legal boundaries. No prosecutions for wrongful euthanasia has taken place yet.

The criteria (of good care) are presented here. The request must be made by a competent adult (> 18 years), though in Dutch law the age criterion has been adapted to that of the Patients' Rights Act (from 1998): a competent individual/child from 12 till 16 is allowed to ask or decide but needs *the consent* of the parents, a 16 and 17 year old may ask or decide while the parents have *to be informed*.

Such a request must be voluntary and well considered. Dutch law suggests that durability of the complaints and request must be seen as included in the "well considered".

Essential in our law is that there must be unbearable (the patient's input) and hopeless (doctor's input) suffering. Because the criteria are derived from 20 years of caselaw, the actual cause (physical or psychological) of the suffering is not decisive.

Since euthanasia is to be considered as the final step in a longer process. An initial request seldom is made "out of the blue", patients are ill, diagnosed and in treatment and thus "seen by doctors". After that request there mostly is ample time to talk with patient and family; to try and make the suffering bearable, offering alternative treatments.

The doctor who is going to comply with a request must ask a second independent doctor to assess if all the criteria of the law have been met. This has been translated in the Netherlands in a scheme of specially trained doctors, so called *SCEN-doctors* (**S**upport and **C**onsultation with **E**uthanasia in the **N**etherlands), which I consider to be one of the crown jewels of our law.

And of course the application must be made in a professional way in conformance with a protocol.

Last of all – each case of euthanasia has to be reported to the Review Committee (consisting of a lawyer, a doctor and an ethicist), which after assessment of all details will consider the case as having been careful. If not, the case will by them be referred to the Prosecutor and the Health Inspection.

If we look at the practice we see that a vast majority of diagnoses in which euthanasia had been practiced concerned malignity (> 75%), chronic neurological, cardiological and pulmonological conditions (together >10%).

The debate in Finland, like in practically all countries, and as was the case in the Netherlands in the 80-ies, revolve around the criteria to prevent misuse and abuse and guarantee safety for individuals (the vulnerable): proponents want as few as possible (choosing for autonomy and human right as leading principle), where opponents suggest that never enough safeguards will guaranty safety for specific vulnerable groups. Argumentations not seldom are based on a number of returning data, many of those derived from Dutch research and surveys, produced since 1990 (famous Remmelink Report), providing scientifically sound figures about the end-of-life practice in the Netherlands. These surveys are repeated more or less every five years, in 2015 for the last time. These data indeed show a small rise in percentages for euthanasia (in 2017 to some 4%), but it all stays within limits.

The surveys also show that the patient-doctor relationship is not injured. My own experience – and that of many colleagues – is even that the relationship often is improved!

With me many others find the way these figures are used by opponents has to be considered as (deliberate?) misinterpretation of figures on the end-of-life practice in the Netherlands, figures derived mostly from the large scientific Dutch Surveys.
These misinterpretations give rise to ever returning misconceptions on the Dutch practice, some of which I will address here.

One is that in the Netherlands old and incapacitated people are afraid of going to hospitals or nursing homes. Sometimes it is even reported that people carry "credit card sized" cards saying that they do NOT want euthanasia (I have never seen one!).
It can be proved that this interpretation is completely wrong by studying the facts shown in the annual Review Report: if the application of euthanasia would be 'normal' in hospitals or nursing homes, why then is only < 20% of all assisted dying taking place there. As in most countries around the world, people want to die at home, and that is also where most euthanasia's are applied!

Another misconception is that legalizing euthanasia constitutes a major danger for vulnerable members of society: the old, the socially weak, the handicapped and the poor people.

Two studies performed in Oregon USA and in the Netherlands has shown that this 'vulnerable' group seldom is found in the groups that use the choice for medical aid in dying. The individuals that do make use of the law are predominantly white, well to do and highly educated (T. Quill, and M. Battin e.a.:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1995535/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2652799/)

An often heard and misused argument is that in the Netherlands euthanasia legalization was started because there was insufficient palliative care available. Separate from the fact that palliative care at that moment in NL (debate on Euthanasia since the 80-ies) was not recognized as a separate specialism like in UK, the development of it occurred more or less parallel to that of the euthanasia. The minister that was responsible for the Euthanasia law, also started a very well-funded national wide program for integrated palliative care.

The misconception also is that availability of palliative care makes the necessity to terminate suffering by terminating life redundant.

In many countries now Palliative Care in general and Palliative (terminal) Sedation in particular is brought forward as alternative to euthanasia or medically assisted dying. But Euthanasia and PS must be seen as two different possibilities at the end of a process of dying guidance, whether it starts from an euthanasia request or from a palliative care trajectory; each has its own properties, the one never can be replaced by the other as if they are full alternatives.

The misconception that palliative care is a good alternative, can in my opinion also be falsified by showing the these figures: those factors that typically belong to the physical PC domain (treatment of pain and suffocation) are far below on the list of reasons to ask for aid in dying.
In recent research into Quality of PC provisions in the World (EAPC, 2017) we see that the Netherlands and Belgium (both with legalized euthanasia practices!) are in the top of the list; Netherlands being on 5th place in Europe (Finland nr. 12)

One of the most frequently heard opposing arguments is the development of a so called slippery slope, that would be evident in the Netherlands. The threat of misuse by doctors of the legal option to terminate life (‘once they are used to terminating life *on* request, they will start doing it *without*) can be falsified by

looking at the numbers of cases of *life-termination <u>without</u> request* (part of the National Surveys!): these numbers have decreased by > 80% since our law was put into force.

Finally, if we again look at the illnesses and diseases for which requests are made, we do not see changes in the general pattern: still a majority of cases concern (terminal) cancer (85%); the rise in numbers for more complex situations like dementia, old-age and psychiatry are only marginal.

Dutch experience and numbers make clear that legalisation does not cause such a slope to develop. If there is one country in the world where such a slope would have happened, it would have been the Netherlands; no country in the world after all has a longer existing practice of tolerated and legalised medical aid in dying (now over 35 years).

If you allow me I would recommend in your future debates to take into consideration two of the lessons we in the Netherlands have learnt:

Talking about termination of life – as the formal definition of euthanasia is – may prompt opponents to substitute these actions as “killing”, while what a suffering patient wants and a doctor intends to do when complying with the request, is termination of *suffering*. Presence of legal options, such as euthanasia, at the end of life, sometimes turns out to prolong life rather than prolonging it. And it adds quality to the last period: knowing that if the suffering is really not longer acceptable, a humane solution is available.

Thank you