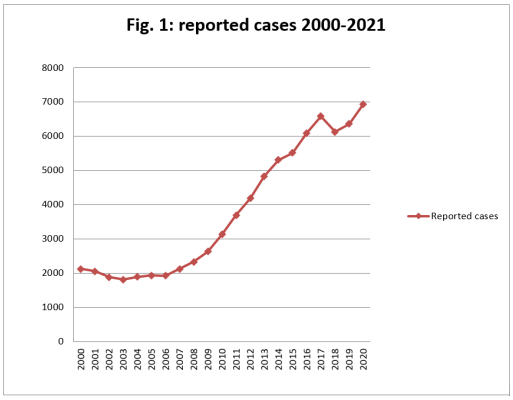
Written evidence submitted Professor Theo Boer (ADY0484)

What to expect when you permit assisted dying: some comments from the Netherlands

It has come to my attention that an inquiry is currently being undertaken by the House of Commons Health and Social Care Select Committee into assisted suicide in the United Kingdom. In order to be as best informed as possible, the Committee invites individuals and institutions to provide their viewpoints and experiences on this topic. Although I am not a British citizen and in full recognition of the expertise and responsibilities of British citizens and lawmakers, I nevertheless decided to send you my submission. The main reason is that your *Call for evidence* contains two questions about which I think I am qualified to provide an informed opinion, namely questions 2 ("What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?") and 5 ("What protections could be put in place to protect people from coercion and how effective would these be?"). In what follows – and towards the end of my submission – I will specifically address these two questions, but I will start by sharing some general information from the Dutch situation, as the Dutch were the first globally to legalise euthanasia and assisted suicide. The numbers that I refer to are not contested by anyone, which is the reason for me to refer to sources where needed. What may be contested, is my interpretation of the numbers.

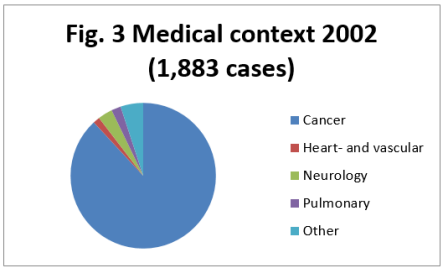
After euthanasia was legalised in 2002, I supported the Dutch legislation and worked for the authorities reviewing euthanasia cases between 2005 and 2014. I was convinced that the Dutch had found the proper balance between compassion, respect for human life, and respect for individual liberties. Over the years, however, I have become increasingly concerned about some developments. After an initial stabilisation we saw a dramatic increase in the numbers, which went from 2,000 in 2002 to 7,666 in 2021(Regional Euthanasia Review Committees 2022; 2003) and the expectation is that the numbers will be well beyond 8,000 in 2022 (fig. 1).

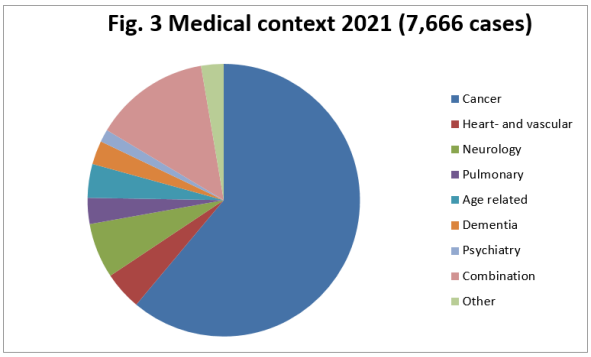
Fig. 1: reported cases 2000-2021



On top of this, the 2017 governmental evaluation found that an additional 15% of cases are in a grey zone and go unreported. Whereas euthanasia and assisted suicide nationally now account for 5% of all deaths, the regional numbers vary considerably. Based on data provided by health insurance companies we found that in some urban districts in the Netherlands, between 12 and 14% of all deaths are the result of assisted dying. In 2019, the then outgoing director of the Euthanasia Expertise Centre – which provides assisted dying to about 1,100 patients yearly – expressed his expectation for the euthanasia numbers to double again in the near future(Wier 2020).

The Dutch law on euthanasia and assisted suicide has in essence remained the same since the first, 'makeshift' law of 1994, which was followed by the current euthanasia law that was enacted in 2002. What has happened, then, are shifts in the way the legal criteria are interpreted. In the pioneering years of Dutch euthanasia, it was found almost exclusively in terminally ill mentally competent adults. As can be seen from figs. 2 and 3, the pathologies have shifted significantly.





Presently, the practice includes those with chronic conditions, disabled people, those with psychiatric problems, incompetent adults with an advance directive, and euthanasia in young children 1-11 years. Expansion is under debate for elderly persons without a medical diagnosis(Adviescommissie Voltooid Leven 2016).

It is well known that British advocates of assisted dying argue for a more restricted law than is found in the low countries. Here is my prediction: any law that allows assisted dying will come to be experienced as an injustice and will be challenged in the courts. Why only euthanasia for terminally ill patients, who have access to an ever widening array of palliative care and whose suffering will be relatively short, whereas chronic patients may suffer more intensely and much longer? Why exclude psychiatric patients, many of whom are suffering most heartbreakingly of all? Why only an assisted death for people suffering from a disease, and not for those suffering from irremediable meaninglessness, alienation, loneliness, from life itself? We are presently seeing how in the years 2016-2023 Canada's Medical Assistance in Dying (MAiD), from being euthanasia for terminal patients only, has evolved into an assisted death for patients whose chronic disease has become unbearable due to shortage of healthcare(Douthat 2022).

There is not one jurisdiction in the world with some form of legal assisted dying where the practice over the years did not expand into a direction (both in terms of numbers and in terms of pathologies) that was neither originally envisaged by the lawmakers, nor was part of the original campaigns towards legalisation. There is merely a difference in speed: in countries where euthanasia is possible the developments go at a much faster pace than in countries that have legalised only assisted suicide. Clearly, when a doctor performs the procedure the demand is higher and increases faster than when a patient is the primary actor of their death. But in *both* varieties of legal assisted dying we see the developments that I named.

The logic of many is that assisted dying will bring down the numbers of violent and traumatizing suicides. If true, this would be a powerful argument in favour of changing the law. Violent suicides may be heavily traumatizing for all those involved. However, the Dutch statistics speak another language. Whereas the percentage of euthanasia of the total mortality went from 1.6% in 2007 to 4.6% in 2021 – a period in which euthanasia became available for people with psychiatric illnesses and dementia –, the suicide numbers also went up: from 8.3 suicides per 100,000 inhabitants in 2007 to 10.6 in 2021, a 28% rise(CBS 2022). If in these numbers we would include the deaths through assisted suicide in patients commonly considered to be at risk of committing suicide (psychiatric patients, people with chronic illnesses, dementia patients, elderly and lonely people), the total increase in self chosen deaths over the past decade would be closer to 50% than to 28%. Meanwhile in Germany, very similar to the Netherlands in terms of religion, economy and population, but with no option of assisted dying, the suicide rates went down by about 10%. I conclude that euthanasia can be a welcome alternative to suicide for some patients and their loved ones, but overall, it does not lead to a decrease in the suicide numbers.

To come back to the first of the two questions mentioned above: I am convinced that legalising any form of assisted dying – be it euthanasia or assisted suicide – will have greater cultural impact than just granting individual patients who are in extreme suffering the liberty to end their lives or to have it ended. In countries where it has become legal, the availability of assisted dying has had a bigger impact than that. To make a comparison: legal assistance in dying may influence a nation in ways similar to how flying has impacted friendships, trade, tourism and ecology – even for those who will or would never fly. To use another example: legal assistance in dying may influence a culture in ways similar to how smartphones have impacted friendships, journalism, the economy, and even people's self-understanding. I would describe this wider impact of the legal availability of assisted dying – again, besides the undeniably positive effects for some individuals – as follows: it pushes us in the direction of despair, in which death is increasingly seen as a serious solution for enduring and irresolvable care-dependence, loneliness, aging, and meaninglessness. In that process the human resolve to endure or cope with serious and seemingly unbearable hardships, so much stressed by philosophers through the ages, becomes undermined. In the longer run it will affect us all, both those who have a direct death wish and those who haven't, and both those who are in serious suffering and those who aren't. The definition of what constitutes a liveable and dignified life becomes narrowed down.

Besides as a liberty, this availability will increasingly become a responsibility: citizens who are eligible for aid in dying will not only have the liberty to choose, but they will also *have* to answer to themselves and others: "Do I want to avail myself of this way out, or do I choose to go on living under the present problematic circumstances, thereby asking others to take care of me?" In the Netherlands, this has become known as 'stress to choose.' I have seen literally hundreds of euthanasia reports in which the wish to shield one's relatives from the agony of witnessing their suffering and carrying the burden of long-term care was one of the reasons, if not the essential reason, to ask for an assisted death. In a society where it has been legalised, people are confronted with one of the most dehumanizing choices possible: do I want to live on, or do I want to effectuate my death?

This brings me to the second question: how to protect vulnerable citizens? Different from what is presently going on in Canada, I do not yet see a specific risk for citizens who by many are considered vulnerable – homeless, underinsured, people on welfare, people with disabilities. Although these groups are present in those who get euthanasia in the Netherlands, it is not my impression that they are overrepresented. If any group is well represented in the euthanasia numbers, it is the better-off,

the healthy-aging population, the higher educated. In our research on practice variation, we found that in regions where the average experienced health is higher, the euthanasia numbers are also higher. In places where people on average are better off, obviously serious threats to their wellbeing tend to be more often a reason for a euthanasia request than in places where people are more used to dealing with life's different hardships. This leads me to adopt a different definition of vulnerability, a vulnerability that may be found in all social and economic groups, from top to bottom: one of despair, meaninglessness, social isolation, feeling redundant. It may apply to wealthy citizens in a villa with woodblock floors and a grand piano, whose children have their businesses elsewhere and whose friends are either dead or institutionalized, just as much as to a single disabled woman on welfare. *Anyone* under this shadow of despair may make a euthanasia request, and there is no way a government can prevent this kind of vulnerability to motivate a euthanasia request, since the autonomous citizens are not under any other pressure than their own, that is, their own incapacity to face life's harder episodes. "Life has always been a feast for me," an elderly man whose euthanasia I assessed, "and that's how it should end for me."

Thus, as the House of Commons looks at this issue, please take seriously the experiences from the Netherlands and other countries that have legalised assisted dying. Looking at our countries may provide an insight into what other countries may look like in 2040. Like those currently arguing for a change in the law in Great Britain, I once believed it was possible to regulate and restrict killing to terminally ill mentally competent adults with less than six months. (Paradoxically, I doubt whether my country would have legalised assisted dying if we had had the level of palliative care in 1994 that we have now.) Moreover, by taking this bold step I believed we could regulate suicide and death in this way that would curtail those all too familiar cases where someone ends their own life. I was wrong. If even the most well-regulated and monitored system worldwide cannot guarantee that assisted dying remains a last resort, why would Great Britain be more successful?

Theo Boer is Professor of Health Care Ethics at Groningen Theological University and member of the Dutch Health Council. From 2005-14 he assessed a total of 4,000 euthanasia cases on behalf of the Dutch Government, and from 2019-2022 he was a Visiting Professor of the History of Ethics at the University of Sunderland. This piece was written on his personal title.

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