

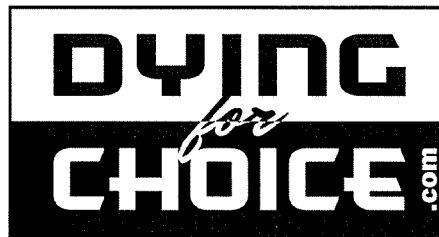
Supplementary Submission

to the

Parliament of Western Australia
Joint Select Committee
on
End of Life Choices

from

Neil Francis



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18th April 2018

Ms Amber-Jade Sanderson
Chair, Joint Select Committee on End of Life Choices
Parliament of Western Australia
Harvest Terrace, Perth, 6005

18th April 2018

Dear Ms Sanderson,

It was a pleasure to appear before the Committee on 9th April. I thank you for the opportunity to contribute and hope my testimony was of some assistance to the Committee in its deliberations on end of life decision making law reform in Western Australia.

I am providing this supplementary submission to the Committee in further answer to a question raised by the Hon. Mr Goiran during my appearance, in relation to medical practice in jurisdictions where assisted dying is now lawful. I would be grateful if you would circulate it to Committee members.

If the Committee has any further questions, I would be happy to do my best to answer them.

Yours sincerely

Neil Francis
DyingForChoice.com

Question about changes in medical practice

During my appearance, the Hon. Mr Goiran asked about improvements in medical practice surrounding end of life decisions and assisted dying in jurisdictions where it is lawful.

I report here some supplementary data that adds to the replies I provided at the time.

Mr Goiran opined that improvements in palliative care are not relevant to this question. I disagree. Assisted dying decisions are *not* made in a vacuum: they are another form of end-of-life decision making, particularly when usual medical interventions including palliative care have been determined by the patient to have been insufficiently effective.

Indeed, it is only after reasonable interventions — that are acceptable to the patient — have been tried and failed, that the patient is likely to request and the doctor likely to consider, a hastened death. Therefore, the quality of those interventions ought to be high.

Thus, in jurisdictions like the Netherlands, Belgium, Oregon, Canada and Victoria (Australia) where assisted dying is lawful, careful attention has been paid to the funding and quality of palliative care. Either statutory or Government initiatives have been promoted to improve the funding and practice of palliative care.

Palliative care professional development in Belgium

Belgium provides an important exemplar of what happens when its Palliative Care professional body is not opposed to assisted dying law reform. Indeed, the Belgian reform was in part sponsored and supported by the Flanders Palliative Care Association. Government funding of palliative care was doubled at the time the Euthanasia Act was legalised.

For at least the four years from the Euthanasia Act, data shows that Belgian physicians attended professional development conferences/courses in palliative care at a far greater rate than similar countries (Figure 1). In fact, the Netherlands and Belgium were two of the top three countries in terms of this palliative care professional development.

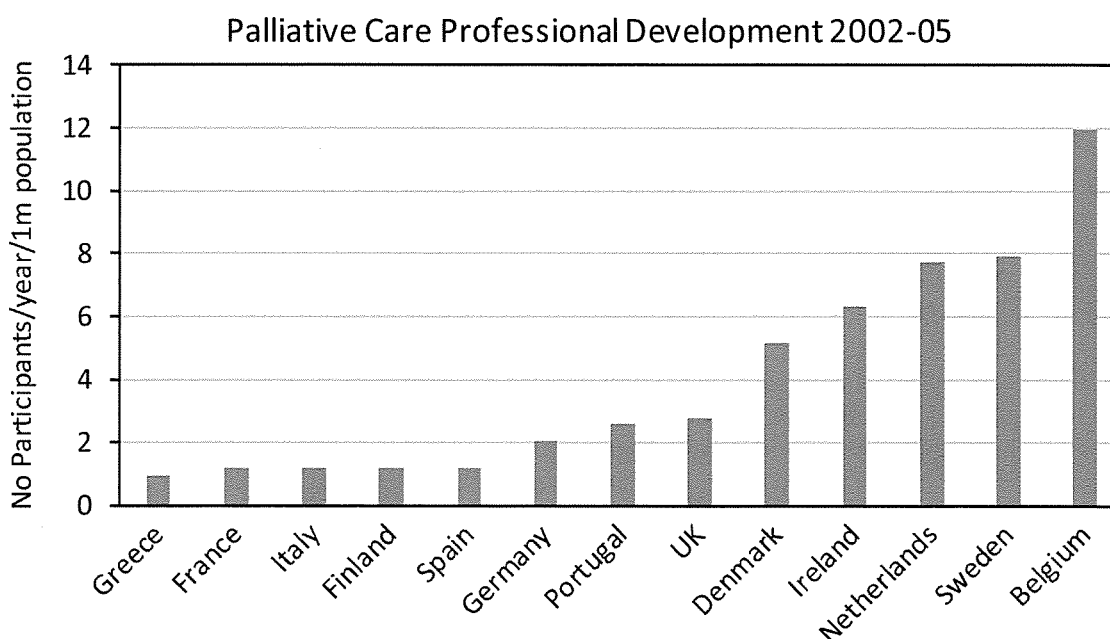


Figure 1: European physician attendance at palliative care professional development courses, 2001-05

Source: Prof. Jan Bernheim, End-of-Life Care Research Group, Vrije Universiteit, Brussels.

Dutch physicians attended professional development events at more than twice the rate of physicians in the UK (the origin of and world's gold standard for palliative care) per head of population, while Belgian physicians attended at four times the rate of UK physicians.

End-of-life care decisions in Belgium

Figure 2 shows the frequency of end-of-life care decisions in Flanders, Belgium as percentages of all deaths. Intensive alleviation of symptoms increased significantly after the Euthanasia Act came into effect in 2002. This practice is considered good medical care as it can diminish the patient's suffering.

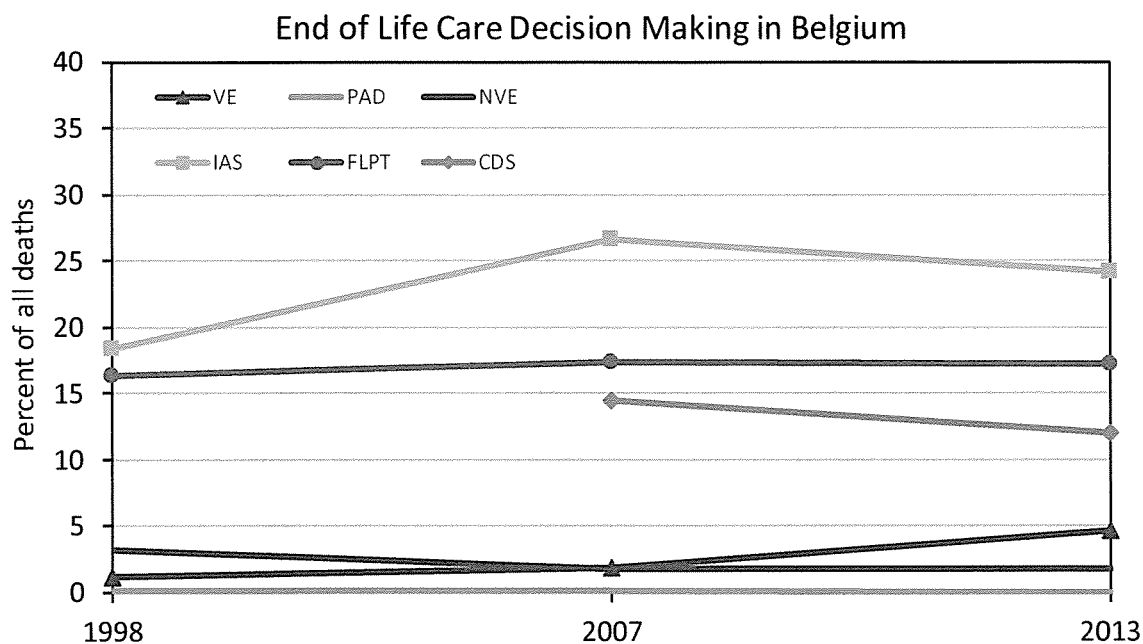


Figure 2: End-of-life care decision making in Flanders, Belgium before and after the 2002 Euthanasia Act
Source: Chambaere et al 2015¹

Notes: VE=voluntary euthanasia (physician administration), PAD=physician-assisted death (patient administration), NVE=non-voluntary euthanasia, IAS=intensified alleviation of symptoms, FLPT=foregoing life-prolonging treatment, CDS=continuous deep sedation (not measured in 1998).

Over the same period, an undesirable physician behaviour decreased: non-voluntary euthanasia (NVE) — the act of hastening a patient's death without an explicit request from the patient. The rate of NVE was considerably higher when Belgium had no euthanasia law, but dropped significantly after the law came into effect and has remained at the much lower level since then.

Figure 3 shows the drop in the Belgian NVE rate in more detail. The drop from 1998 to 2007 is highly statistically significant.

Belgium provides a clear example of how medical practice has improved in an environment that includes assisted dying as a lawful choice, where end of life decisions need not be feared, avoided or taken in secret, and where additional conversation and scrutiny is brought to bear. The desirable practice of symptom alleviation has increased at the same time the undesirable practice of hastening death without an explicit request has decreased.

¹ Chambaere, K, Vander Stichele, R, Mortier, F, Cohen, J & Deliens, L 2015, 'Recent trends in euthanasia and other end-of-life practices in Belgium', *N Engl J Med*, 372(12), pp. 1179-1181.

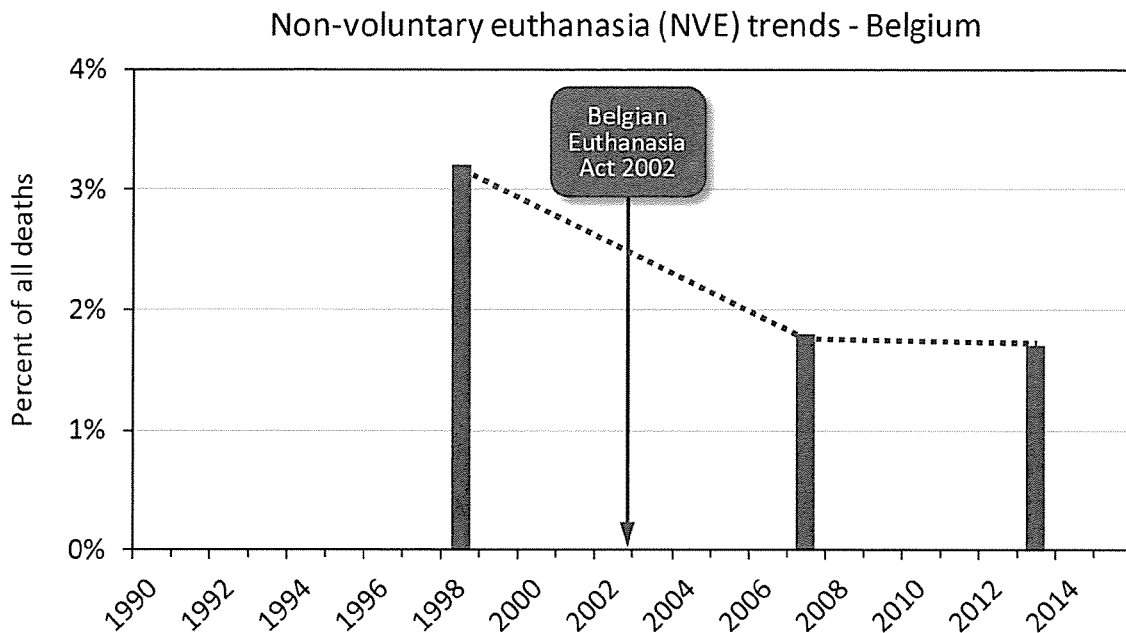


Figure 3: Belgian non-voluntary euthanasia rates before and after the 2002 Euthanasia Act

Source: Chambaere et al 2013¹

End-of-life care decisions in the Netherlands

Figure 4 shows the frequency of end-of-life care decisions in the Netherlands as a percentage of all deaths. After the Euthanasia Act came into effect in 2002, intensive alleviation of symptoms practice greatly increased, providing much greater relief to patients.

The practice of continuous deep sedation also increased, keeping the patient comfortable but unconscious until death, a practice that is accepted as good palliative care including under the doctrine of double effect, if the sedation were to unintentionally cause any shortening of the patient's life.

At the same time as a very substantial increase in the rate of intensified alleviation of symptoms for the patient's comfort and benefit, and a much smaller increase in the assisted dying rate, there has been a small decrease in the rate for forgoing life-prolonging treatment. However, it is unclear from the research whether the decrease is statistically significant or not.

Over the same period, there has been a significant drop in the non-voluntary euthanasia (NVE) rate in the Netherlands (shown in more detail in Figure 5). There is no statistically significant difference between the three NVE rates prior to the Act, nor between the three rates after the Act. However, the drop from before to after is highly statistically significant.

Figure 5 also shows the NVE rate in the UK, the home of and gold standard for palliative care worldwide. The Dutch NVE rate after the Act is similar to the UK, which has never had an assisted dying law.

Conclusion

This supplementary report furnishes direct evidence of, post the introduction of assisted dying laws in Belgium and the Netherlands, significant increases in desirable behaviour and decreases in undesirable behaviour in relation to end-of-life care decisions.

End of Life Care Decision Making in the Netherlands

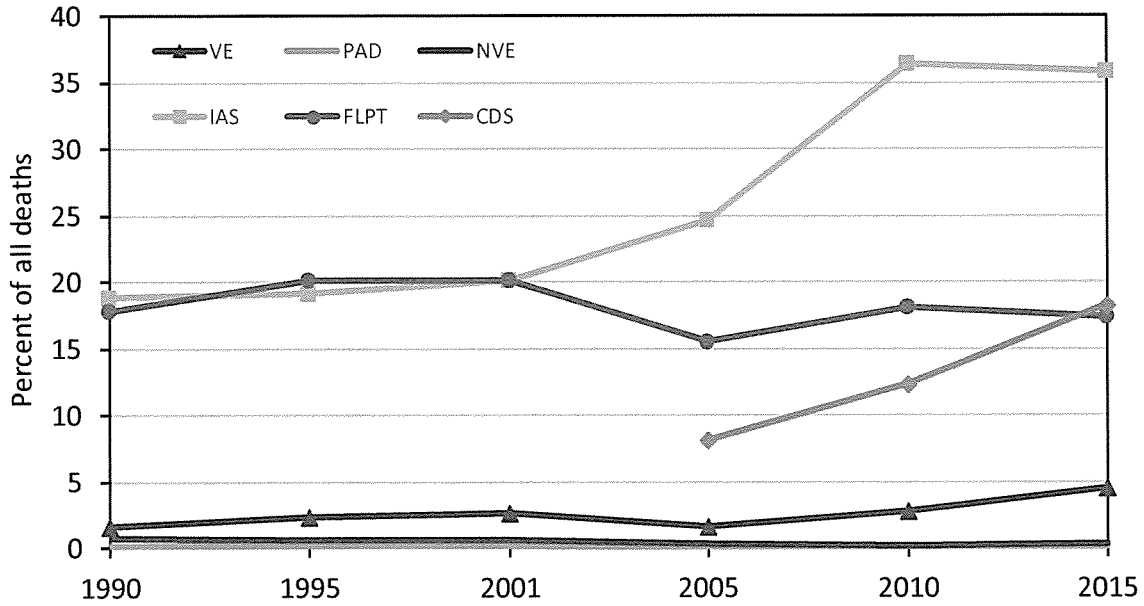


Figure 4: End-of-life care decision making in the Netherlands the 2001 Euthanasia Act (in effect from 2002)

Source: van der Heide et al 2017²

Notes: VE=voluntary euthanasia (physician administration), PAD=physician-assisted death (patient administration), NVE=non-voluntary euthanasia, IAS=intensified alleviation of symptoms, FLPT=foregoing life-prolonging treatment, CDS=continuous deep sedation (not measured in 1990-2001).

Non-voluntary euthanasia (NVE) trends - The Netherlands & UK

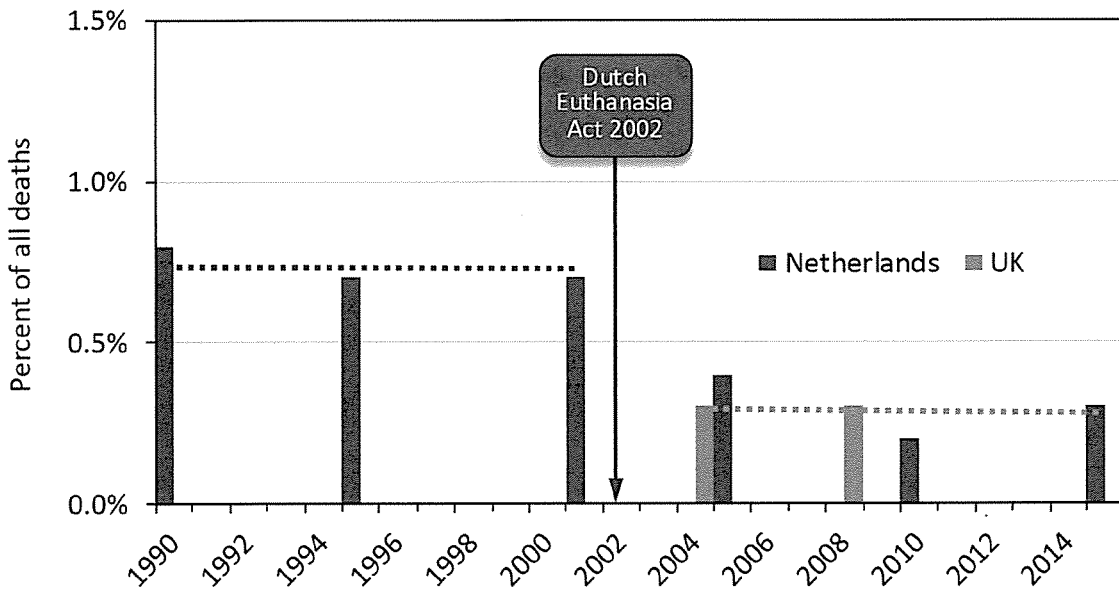


Figure 5: Dutch non-voluntary euthanasia rates before and after the 2002 Euthanasia Act, UK rates

Sources: van der Heide et al 2017,² Seale 2012³

² van der Heide, A, van Delden, JJM & Onwuteaka-Philipsen, BD 2017, 'End-of-life decisions in the Netherlands over 25 years', *N Engl J Med*, **377**(5), pp. 492-494.

³ Seale, C 2009, 'End-of-life decisions in the UK involving medical practitioners', *Palliat Med*, **23**(3), pp. 198-204.