## From the USA

Herbert Hendin New York Medical College, NY, USA

Herbert Hendin is Medical Director of the American Foundation for Suicide Prevention and Professor of Psychiatry at New York Medical College. He received a Rockefeller Foundation Scholar in Residence award for his studies of assisted suicide and euthanasia in the United States and the Netherlands.

## An unwise retreat

How disappointing to see the Ethics Task Force of the EAPC retreat from the EAPC's unequivocal opposition to legalizing euthanasia. The Task Force paper appropriately emphasizes respect for autonomy as a goal of palliative care while noting that only a minority of terminally ill cancer patients receive adequate palliative care. Remarkably, the report does not emphasize that the inadequate care results largely from our failure to train physicians in how to provide it.

Patient autonomy is an illusion when physicians do not know how to assess and treat patient suffering and the choice for patients becomes continued agony or a hastened death. The more physicians know about palliative care, the less they favor assisted suicide or euthanasia, the less they know, the more they favor it. Between 1994 and 1998, a decline of 50% in the support of American oncologists in their support for assisted suicide from 44.5% to 22.5% and a decline in their support for euthanasia from 22.7% to 6.5% appeared to reflect their greater knowledge of how to facilitate a 'good death.'<sup>2</sup>

The Dutch experience demonstrates that euthanasia is not a solution to the lack of knowledge of or access to excellent end-of-life care. Given legal sanction, euthanasia, intended originally for the exceptional case, has become an accepted way of dealing with serious or terminal illness in the Netherlands. Palliative care has become one of the casualties, while hospice care has lagged behind that of other countries. The testimony before the British House of Lords, Zbigniew Zylicz, a medical oncologist who is one of the few palliative care experts in the Netherlands, attributed Dutch deficiencies in palliative care to the easier alternative of euthanasia.

The Task Force paper cites authoritatively Dutch government sanctioned studies, <sup>5,6</sup> which have been shown to be flawed and misleading. The report does not cite any of the three independent studies by foreign observers; two of which, conducted after the Dutch government sanctioned studies were completed, highlighted these flaws, while all three were able to demonstrate that guidelines established by the Dutch for the practice of assisted suicide and euthanasia were consistently violated and could not be enforced. <sup>7–11</sup> For example, over 50% of Dutch physicians indicated a willingness to suggest

euthanasia to their patients, which compromises its voluntariness. Sixty percent of Dutch cases are not reported to the authorities, which by itself makes regulation impossible.

The most alarming concern to arise from the Dutch studies has been the documentation of several thousand cases a year in which patients who have not given their consent have their lives ended by physicians. About a quarter of physicians stated that they had 'terminated the lives of patients without an explicit request' from the patient to do so, and a third more of the physicians could conceive of doing so.

The Task Force paper endorses Dutch definitions regarding euthanasia, which have insisted that euthanasia is intrinsically voluntary, that 'voluntary euthanasia' is a redundancy, and that involuntary euthanasia has nothing to do with euthanasia. The evidence indicates that in practice the two are more entwined than the Dutch suggest and the definitions they have adopted serve to conceal that fact.

In addition to the thousand deaths from involuntary euthanasia that the Dutch admit take place each year they do not define or count as either euthanasia or involuntary euthanasia the increasing number of deaths (in their last report close to 2000) where physicians gave pain medication with the *primary intention* of ending the patient's life. When competent patients consent to such a lethal overdose, most investigators regard that as euthanasia. When competent patients do not consent but are given a lethal dose anyhow, most investigators regard that as involuntary euthanasia. It is with good reason that the Dutch Voluntary Euthanasia Society resists pressure to change its name.

Practicing euthanasia appears to encourage physicians to think they know best who should live and who should die, an attitude that leads them to make such decisions without consulting patients. One case presented to me as requiring euthanasia without consent involved a Dutch nun who was dying painfully of cancer. Her physician felt her religion prevented her from agreeing to euthanasia so he felt both justified and compassionate in ending her life without telling her he was doing so.

The Dutch have a stake in justifying their euthanasia polices and have lobbied with some success for them. Before EAPC retreats any further, it should insist on

independent examination of the Dutch data and practices

## References

- 1 Portenoy RK, Coyle N, Kash KM, Brescia F, Scanlin C, O'Hare D, Misbin RI, Holland J, Foley K. Determinants of the willingness to endorse assisted suicide. *Psychoso*matics 1997: 38: 277-87.
- 2 Emanuel E. Ann Intern Med 2000; 133: 527-32.
- 3 Dorrepaal KL, Aaronson NK, Van Dam FSAM. Pain experience and pain management among hospitalized cancer patients. *Cancer* 1989; **63**: 593–98.
- 4 Zylicz Z. The story behind the blank spot. Am J Hospice Palliat Care 1993; July/August: 30-32.
- 5 Van der Maas PJ, Van Delden JJM, Pijnenborg, L. Euthanasia and other medical decisions concerning the end of life. New York: Elsevier, 1992.

- 6 Van der Maas PJ, Van der Wal G, Haverkate I, De Graaf CLM, Kester JGC, Onwuteaka-Philipsen BD, Van der Heide A, Bosma JM, Willems DL. Euthanasia, physician-assisted suicide and other medical practices involving the end of life in the Netherlands. *N Engl J Med* 1996: 335: 1699–1705.
- 7 Gomez C. Regulating death: euthanasia and the case of the Netherlands. New York: Free Press, 1991.
- 8 Keown J. Euthanasia in the Netherlands: sliding down the slippery slope. In J Keown ed. *Euthanasia examined:* ethical, clinical, and legal perspectives. New York: Cambridge University Press, 1995.
- 9 Hendin H, Zylicz Z, Rutenfrans C. Physician-assisted suicide and euthanasia in the Netherlands: lessons from the Dutch. *JAMA* 1997: 277: 1720–22.
- 10 Hendin H. Seduced by death: doctors, patients, and assisted suicide. New York: W.W. Norton & Co. 1998.
- 11 Foley K, Hendin H. *The case against assisted-suicide: for the right to end-of-life care.* Baltimore, MD: Johns Hopkins University Press, 2002.