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Non-Voluntary and Involuntary Euthanasia in the Netherlands: Dutch Perspectives¹

RAPHAEL COHEN-ALMAGOR University of Haifa

During the summer of 1999, twenty-eight interviews with some of the leading authorities on the euthanasia policy were conducted in the Netherlands. They were asked about cases of non-voluntary (when patients are incompetent) and involuntary euthanasia (when patients are competent and made no request to die). This study reports the main findings, showing that most respondents are quite complacent with regard to breaches of the guideline that speaks of the patient's consent as prerequisite to performance of euthanasia.

Introduction

In November 1990, the Dutch Ministry of Justice and the Royal Dutch Medical Association set out Guidelines for the performance of euthanasia based on the criteria established in court decisions relating to the conditions under which a doctor can successfully invoke the defense of necessity. The substantive requirements are as follows:

- The request for euthanasia or physician-assisted suicide must be made by the patient and must be free and voluntary.
- The patient's request must be well considered, durable and consistent
- The patient's situation must entail unbearable suffering with no prospect of improvement and no alternative to end the suffering.² The

¹ The author is most grateful to Evert van Leeuwen and Martine Bouman for facilitating the research and to the interviewees for their kind cooperation.

² The Medical Association Executive Board emphasized that there are only limited possibilities for verifying whether suffering is unbearable and without prospect of improvement. The Board considered it in any case the doctor's task to investigate whether there are medical or social alternatives that can make the patient's suffering bearable. John Griffiths, Alex Bood and Heleen Weyers, Euthanasia and Law in the Netherlands (Amsterdam: Amsterdam University Press, 1998), 66.

Euthanasia must be a last resort.³

The procedural requirements are as follows:

- No doctor is required to perform euthanasia, but those opposed on principle must make this position known to the patient early on and help the patient to get in touch with a colleague who has no such moral objections.
- Doctors taking part in euthanasia should preferably and whenever possible have patients administer the fatal drug themselves, rather than have a doctor apply an injection or intravenous drip.⁴
- A doctor must perform the euthanasia.
- Before the doctor assists the patient, the doctor must consult a second independent doctor who has no professional or family relationship with either the patient or doctor. Since the 1991 Chabot case, ⁵ patients with a psychiatric disorder must be examined by at least two other doctors, one of whom must be a psychiatrist.
- The doctor must keep a full written record of the case.
- The death must be reported to the prosecutorial authorities as a case of euthanasia or physician-assisted suicide, and not as a case of death by natural causes.⁶

In 1990, the Dutch government appointed a commission to investigate the medical practice of euthanasia. The Commission, headed by Professor Jan Remmelink, Solicitor General to the Supreme Court, was asked to conduct a comprehensive nation-wide study of "medical decisions concerning the end of life (MDEL)." The following broad forms of MDEL were studied:

Non-treatment decisions: withholding or withdrawing treatment in situations where treatment would probably have prolonged life;

Alleviation of pain and symptoms: administering opioids in such dosages that the patient's life could be shortened;

Euthanasia and related MDEL: the prescription, supply or administration of drugs with the explicit intention of shortening life, includ-

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ing euthanasia at the patient's request, assisted suicide, and life termination without explicit and persistent request.⁷

The study was repeated in 1995, making it possible to assess for the first time whether there were harmful effects over time that might have been caused by the availability of voluntary euthanasia in the Netherlands. It is still difficult to make valid comparisons with other countries because of legal and cultural differences, and also because similar comprehensive studies are quite rare.⁸

The two Dutch studies were said to give the best estimate of all forms of MDEL (i.e., all treatment decisions with the possibility of shortening life) in the Netherlands as approximately 39% of all deaths in 1990, and 43% in 1995. In the third category of MDEL, the studies gave the best estimate of voluntary euthanasia as 2300 persons each year (1.9% of all deaths) in 1990, and 3250 persons each year (2.4%) in 1995. The estimate for physician-assisted suicide was about 0.3% in 1990 and in 1995. There were 8900 explicit requests for euthanasia or assisted suicide in the Netherlands in 1990, and 9700 in 1995. Less than 40% were actually undertaken. The most worrisome data is related to the hastening of death without the explicit request of patients. There were 1000 cases (0.8%) without explicit and persistent request in 1990, and 900 such cases (0.7%) in 1995.

In 1990, 30% of the general practitioners (GPs) interviewed said that they had performed a life-terminating act at some time without explicit

³ John Keown, "The Law and Practice of Euthanasia in the Netherlands," The Law Quarterly Review, 108 (1992), 56.

⁴ The Royal Dutch Medical Association's refinements of the 1984 Guidelines (August 25, 1995). Cf. Marlise Simons, "Dutch Doctors to Tighten Rules on Mercy Killings," The New York Times (September 11, 1995), A3.

⁵ Supreme Court of the Netherlands, Criminal Chamber (June 21, 1994), no. 96.972. For translation, see John Griffiths, Alex Bood and Heleen Weyers, Euthanasia and Law in the Netherlands, op. cit., Appendix II (2), 329-340.

⁶ http://www.euthanasia.org/dutch.html#remm. See also Marcia Angell's Editorial, "Euthanasia in the Netherlands—Good News or Bad?," New Eng. J. of Medicine, Vol. 335, No. 22 (November 28, 1996); Adriaan Jacobovits, "Euthanasia in the Netherlands," Washington Post (January 23, 1997), A16; General Health Council, "A Proposal of Advice Concerning Careful Requirements in the Performance of Euthanasia" (The Hague, 1987).

⁷ Cf. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medical Decisions Concerning the End of Life, Health Policy Monographs (Amsterdam: Elsevier, 1992).

⁸ Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate et al, "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," New Eng. J. of Med., Vol. 335, No. 22 (November 28, 1996), 1699-1705. For further discussion, see Johannes J.M. van Delden et al., "Deciding Not to Resuscitate in Dutch Hospitals," J. of Medical Ethics, 19 (1993), 200-205; Tony Sheldon, "Euthanasia Law Does Not End Debate in the Netherlands," BMJ, Vol. 307 (December 11, 1993), 1511-1512; Henk Jochemsen, "Euthanasia in Holland: An Ethical Critique of the New Law," J. of Medical Ethics, 20 (1994), 212-217; Chris Ciesielski-Carlucci and Gerrit Kimsma, "The Impact of Reporting Cases of Euthanasia in Holland: A Patient and Family Perspective," Bioethics, 8 (1994), 151-158; J.K.M. Gevers, "Physician Assisted Suicide: New Developments in the Netherlands," Bioethics, 9 (1995), 309-312.

⁹ P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medical Decisions Concerning the End of Life, 41.

sia and Other Medical End-of-Life Decisions and the Euthanasia Notification Procedure," in David C. Thomasma, Thomasine Kimbrough-Kushner, Gerrit K. Kimsma, and Chris Ciesielski-Carlucci, eds., Asking to Die (Dordrecht: Kluwer Academic Publishers, 1998), 171. See also Bill Mettyear, "advocating legalising voluntary euthanasia" (February 1997), http://www.on.net/clients/saves/South Australian Voluntary Euthanasia Society. In his comments on the first draft of this study, Van der Maas wrote that in 1990 the decision had been discussed with a patient in 46% of the cases, and in 14% there had been an expressed wish. Because explicit request is defined very strictly in our studies, these were not counted as euthanasia on request. Van der Maas noted

up to one week.16 period by which life was shortened. 15 In 67% of the cases, life was shortconsultation because the situation was clear.14 Van der Maas and colassisted suicide cases). In 68% of the cases, the physician felt no need for consulted in 72% of the cases (as compared with 94% in euthanasia and assisted suicide. A colleague was consulted in 48% of the cases (as comenough to make the treatment worthwhile. 13 It should be noted that the explicit request of the patient. The physician did not use these alternarequest (as compared with 25% of specialists and 10% of nursing home ened by fewer than 24 hours. In 21% of the cases, life was shortened by leagues note that this should be considered in light of the very brief pared with 84% in euthanasia and assisted suicide cases). Relatives were out patient's explicit request than in cases of euthanasia or physicianlevel of consultation was significantly lower in life-termination acts with-"only would prolong suffering," or because the expected gain was not tives when the patient indicated a desire to stop treatment because it in 8% of cases in which a life-terminating act was performed without or physician-assisted suicide. 12 There were still treatment alternatives formed with older patients more, on the average, than were euthanasia physicians). $^{\rm II}$ Life-terminating acts without explicit request were per-

small number of cases (approximately 15) involved babies who were sufall of those cases, and death was hastened by a few hours or days. A voluntary euthanasia. 17 The patient was no longer competent in almost the doctor's decision, in consultation with the parents, to hasten the end fering from a serious congenital disorder and were barely viable; hence About a quarter of the 1000 patients had earlier expressed a wish for

number of active cases involving ending of life among newborns in the Netherlands to be 10-15 cases per year. Personal communication on September 18, 2000. frequencies of ending of life without explicit request of over 3%. He estimated the an interesting comparison: Replication studies in Australia and Belgium both found

Medical Decisions Concerning the End of Life, 58. $^{
m II}$ P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other

- ¹² Ibid, 61
- ¹³ Ibid, 62
- worker. Cf. G. van der Wal, J.Th.M. van Eijk, H.J.J. Leenen and C. Spreeuwenberg, they did not ask for a second opinion before administering euthanasia or assisted "Euthanasia and Assisted Suicide. II. Do Dutch Family Doctors Act Prudently?," Family suicide, and 12% of the GPs had no kind of consultation with any professional health ¹⁴ In another study among family doctors, one quarter of the physicians said that
- Medical Decisions Concerning the End of Life, 65. 15 P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other
- ¹⁶ Ibid, 66
- Academia Nacional de Medicina, Tomo CXII (Madrid, 1995), 429. 17 Henk A.M.J. ten Have, "Euthanasia: The Dutch Experience," Annals de la Real
- of life in the Netherlands," Foreign Information Department, Netherlands Ministry of Foreign Affairs ¹⁸ See 1996 Study Findings, "Euthanasia and other decisions concerning the end

practice failed to help and, in any event, death would have occurred within fied because the patients' suffering was unbearable, standard medical mination of life as "providing assistance to the dying." They were justi-The Remmelink Commission regarded these cases of involuntary ter-

with policy makers. centers of medical ethics as well as some research hospitals, and to speak end, in the summer of 1999 I went to the Netherlands to visit the major euthanasia policy and practice conceive this worrisome data. To that The aim of this study is to explore how leading figures in the Dutch

Methodology

explicitly declined my request for an interview.²⁰ social sciences and ethics, asking to meet with them in order to discuss perts in their respective fields: medicine, psychiatry, philosophy, law, Before arriving in the Netherlands, I wrote to some distinguished exthe Dutch policy and practice of euthanasia. Only one—Dr. Chabot—

and analyzed.²¹ together comprise some 200 dense pages. Later the interviews were typed series of questions. During the interviews I took extensive notes that for more than two hours during which I asked more or less the same lands. They lasted between 1 to 3 hours each. Most interviews went on The interviews took place during July-August 1999, in the Nether-

use of the Dutch efficient train system. Groningen in the north to Maastricht in the south, making extensive Amsterdam. To have a sample of different locations I traveled from able to me at the Department of Medical Ethics, Free University of taurants. Two interviews were conducted at the office kindly made availoffices. Four interviews were conducted at the interviewees' private homes, and four interviews in "neutral" locations: coffee shops and res-The interviews were conducted in English, usually in the interviewees

tions but did not insist on all of them when I saw that the interviewee questionnaire. With a few interviewees I spoke only about their direct preferred to speak about subjects that were not included in the original The interviews were semi-structured. I began with a list of 15 ques-

¹⁹ Remmelink Commission, Rapport Medische Beslissingen Rond het Levenseinde (The Hague: SDU, 1991), 37. See also Henk A.M.J. ten Have, "Euthanasia: The Dutch

some specific questions relating to his conduct that brought about the charges against not to make an appointment with you." He, however, agreed to answer via e-mail the final court judgement (1991-1995) and discussing the case with many people from abroad, I hope you will understand that I prefer to remain in the background now and ²⁰ In his letter dated June 5, 1999, Dr. Chabot wrote: "After four years waiting for

of Pennsylvania Press, 2002). done in R. Cohen-Almagor, Euthanasia in the Netherlands (Philadelphia: University ²¹ For limitation of space I cannot possibly report the entire study here. This is

who wanted to know my own opinion on the subject matter before conlink report. This line of questions disturbed some of the interviewees, view to a close tinuing to answer my questions. Others seemed eager to bring the interquestions I addressed the troublesome aspects reiterated in the Remmethe problematic aspects of the euthanasia practice, after some general involvement in the practice of euthanasia. Because I was interested in

The Interviewees' Responses

Hastening of Death without the Patients' Explicit Request

and 900 cases (0.7%) in 1995. What is your opinion?" were 1000 cases (0.8%) without explicit and persistent request in 1990 of the most worrisome data in the two Dutch studies are concerned with the hastening of death without the explicit request of patients. There The question that opened the critical line of the interviews was: "Some

erlands and that it is not a specifically Dutch problem; there is a similar saw no problem in this, arguing that the balance favors termination of with beneficence in such severe circumstances. Some of the interviewees strive to alleviate the pain of very sick patients at the end of their lives policy in hospitals all over the world.²² tice was common long before euthanasia became available in the Nethlife in such instances. Many interviewees also emphasized that this prac-In essence, what they are saying is that it is right to replace autonomy would die within a matter of days or even hours. By so doing, physicians borns with severe health problems, and patients who are suffering that They said that this group includes cancer patients, PVS patients, new-Most of the interviewees had similar interpretations of this finding

sponsibility to verify what patients want. the options at the beginning of the dying process. It is a physician's remination of treatment early on with these patients. Physicians know indicate a slippery slope, and they occur in every country. Nevertheless these suffering, dying patients with the last push. Such cases do not that they were no longer competent. Their physicians sometimes help lives, who were suffering greatly and who had had so much medication sia. Nearly all of them involved cancer patients in the last phase of their the consequences of increased doses of medication and should discuss Leenen is worried that the physicians did not discuss the option of ter-Leenen, on this matter. He argues that these are not cases of euthana-Consider the view of one of the foremost euthanasia activists, H.J.J

of Metamedicine, Free University of Amsterdam, recommend ethical and practical training as well as open discussions to overcome this problem in Amsterdam, and Evert Van Leeuwen, Chairperson of the Department Bert Thijs, Director of the Medical Intensive Care Unit, VU ziekenhuis

cians to reflect on their decision-making process among themselves and sultation sessions. These discussions would make it possible for physi-Physicians should discuss and debate this issue by holding regular con-

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out having an opportunity to consult the patients regarding euthanadrugs. The doctors were then forced to act upon their own initiative withhours left to live and had been rendered incompetent from painkilling of whom were in the advanced stages of cancer. They had only days or doctors wanted to alleviate the pain and suffering of their patients, most effect"), while the drugs used for euthanasia are muscle paralyzers. The unclear. Most of the patients died from large doses of morphine ("double Wal also notes that the doctors' intentions regarding these patients were open and to exchange views between physicians and patients. Van der Therefore, it is important to make the climate around euthanasia more cases, the issue of euthanasia was not sufficiently discussed beforehand. rigid, honest, straightforward"). He further argues that in most of these more Calvinistic" (I asked what this meant, and he answered "more open, would be called double effect. In the Netherlands, "we are more explicit, countries, Van der Wal maintains, ending a patient's life in such cases keep the patients alive and who wanted to stop their suffering. In other comatose patients whose families asked whether it was necessary to tients, who did not make an explicit request for euthanasia, includes at the Free University, Amsterdam explains that this category of paions. Van der Wal of the Institute for Research in Extramural Medicine van der Wal and Paul van der Maas, express remarkably similar opinwith paramedics in their teams. The two most productive researchers in the field of euthanasia, Gerrit

tions. Half of the patients had given no indication of what they wanted.²⁴ past that they would prefer to hasten death under such terrible condiof these patients had living wills, but about half had indicated in the three days, and they actually died from opiates (double effect). Very few in their agonizing condition. Most of them would have died within one to extremely, vomiting, unable to express themselves, and totally immersed cer patients in the advanced stage of the disease. They were suffering lost consciousness or their ability to communicate. Two-thirds were canthe data. In nearly all of the cases in question, the patients suddenly Erasmus University of Rotterdam, reports that he is not worried about Van der Maas, Professor of Public Health and Social Medicine at the

does not believe that the data reveal the existence of a slippery slope. fect," rather than euthanasia, given that the opiate doses were increased Dick Willems, a philosopher and physician who works with Van der Wal Similarly, Heleen Dupuis calls the deaths of this group "double ef

Willems, Bert Thijs, A. van Dantzig, Heleen Dupuis, Margo Trappenburg, Henri Wijsbek, and Arie van der Arend ²² Interviews with John Griffiths, Evert van Leeuwen, Govert den Hartogh, Dick

Life: Is It Permissible?" Bioethics, 7 (1993), 330-339. ²³ For further deliberation, see Gerrit van der Wal, "Unrequested Termination of

tients had living wills. In contrast, van Delden claimed that a very small number of Jaap Visser argues in answering this question that in many of these cases, the pa-²⁴ See Herbert Hendin, Seduced by Death (New York: W.W. Norton, 1997), 88-89.

reiterating that the two major studies indicate more or less similar numbers of such deaths (1000 and 900).

Johannes van Delden provides the most interesting answer to the question regarding this worrisome data. He said that that these findings were in part artifact, the creation of the researchers in the construction of the categories, which included clear-cut expressed wishes, cases of no explicit request, and cases with some remarks. Of the 1000, 56% expressed some view. However, the authors of the research "decided to have a clear-cut euthanasia group, and this group emerged from the way we chose to analyze." Van Delden explained that "you need autonomy and beneficence to perform euthanasia." There might be very extreme cases in which doctors decide to conduct euthanasia without the patient's explicit request, but these cases are few in number. It is hardly conceivable to act in this way, "maybe in pediatrics." Van Delden did recognize that most of these cases were insufficiently justified and insisted that the autonomy requirement be maintained.²⁵

Henri Wijsbek argues that most of these cases involve situations in which patients are unconscious, suffering greatly, and would have died within two hours. ²⁶ This practice occurs in many countries, and Wijsbek sees no problem with it. He adds his hope that under such circumstances, his doctors would do the same for him. When there is hopeless suffering, and doctors cannot alleviate the pain, the option of euthanasia should be available. Similarly, Van der Arend, who teaches at the Health Ethics and Philosophy Department of Maastricht University, explains that there

earlier time have expressed a general wish for euthanasia but who in the final stages severely defective newborn babies, long-term coma patients, and persons who at some Assisted Suicide, and Other Medical Practices Involving the End of Life in the Nethcal Decisions Concerning the End of Life, 69. Van der Wal, Van der Maas et al. report David C. Thomasma et al., eds., Asking to Die, 98. "The Slippery Slope: Are the Dutch Sliding Down or Are They Clambering Up?" in of the process of dying are no longer capable of expressing their will. John Griffiths, John Griffiths argues that this category of patients is highly heterogeneous, including erlands, 1990-1995," New Eng. J. of Med., Vol. 335, No. 22 (November 28, 1996), 1701 J. van der Maas, Gerrit van der Wal, Ilinka Haverkate et al., "Euthanasia, Physicianearlier in the illness or the patient had expressed a wish for euthanasia if suffering that in about half of all these cases, either the decision was discussed with the patient P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medipatients had been previously "indicating something" regarding life termination. Cf these patients had a living will. The 1990 study reports that about one-quarter of the became unbearable. In the other cases, the patient was deemed incompetent. Cf. Paul

²⁵ In another forum, Van Delden explained that the type of patients involved were cancer patients with brain metastases and, consequently, were rendered incompetent. It would give "a false picture of Holland if one thought that we put away demented people or the weak ones in society. It really is the patient dying and already fading away." Proceedings of Euthanasia and Assisted Suicide in the Netherlands and in Europe, Maastricht, June 10-11, 1994 (Luxembourg: Office for Official Publications of the European Communities, 1996), 47.

²⁶ According to Van der Wal, Van der Maas et al., life was shortened by 24 hours at most in 33% of these cases, and in a further 58% it was shortened by one week at most. Cf. Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate et al., "Euthana-

are situations in which patients are suffering, unconscious or half-conscious, in the last stage of disease, and physicians then do not have any other choice but to end the patient's life. He is not worried about the numbers, saying that he could not imagine that termination of life was the result of careless medical practice. Van der Arend added: "There will always be cases like these."

Rob Houtepen, who teaches in the same department in Maastricht, also sees no reason for alarm in regard to this data. He testifies that he is quite liberal about termination of life when people are suffering, even if they are incompetent. He believes that compassion is the primary consideration for euthanasia. Autonomy is a secondary consideration. It is unjust that people be denied the option to end their suffering, an option that is available to competent patients. In his mind, we should not make strict distinctions between competent and incompetent patients. Hence, Houtepen is "not shocked" by the figures, though he does recognize the need for stricter notification procedures so as to make more data available about the circumstances of each and every patient who did not make an explicit request.

Ron Berghmans, also from Maastricht, supports the need for more information about these cases and the circumstances involved in each case, particularly when the patient could have expressed an opinion about the issue. In addition, the issue of advance directives needs to be discussed further. The new law stipulates that ADs have the legal force of the patient's voluntary explicit request. Berghmans reiterates the problem of how to evaluate suffering in cases of dementia and expresses doubt about whether we should honor the ADs of dementia patients.²⁷

In his comments on the first draft of this study, Govert den Hartogh wrote that my implicit assumption is that the worrisome data is the result of the lax Dutch rules. He thinks that probably the opposite is true: In other countries, this figure would probably be much higher, precisely because euthanasia is forbidden and hence cannot safely be discussed with patients. Accordingly, the result of the Dutch rules, on this account, is that the figure is unusually low. This, however, does not mean that the data are not worrisome.

To substantiate his point, den Hartogh referred to the recent research project in Flandres, which is a replica of the Van der Maas/Van der Wal

sia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," 1702. The 1990 study reports that in 21% of the cases, life was shortened by one to four weeks; in 7% of the cases, life was shortened by one to six months; and in a small number of cases, life was shortened by more than half a year. These patients were not in the terminal stage of their illness. Cf. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medical Decisions Concerning the End of Life, 66, 183. See also Loes Pijnenborg, Paul J. van der Maas, J.J.M. van Delden and Caspar W.N. Looman, "Life-terminating Acts without Explicit Request of Patient," Lancet, 341 (May 8, 1993), 1196-1199.

²⁷ For further deliberation, see R. Berghmans, "Advance Directives and Dementia," in R. Cohen-Almagor, ed., Medical Ethics at the Dawn of the 21st Century, 105-110.

studies. Belgian law forbids euthanasia and assisted suicide, nor is there an equivalent of the Dutch judge-made law. According to this research, the overall percentage of deaths as a result of euthanasia or assisted suicide in Belgium is somewhat lower, but not very much lower, than it is in the Netherlands. However, the percentage of deaths from "euthanasia" without explicit request is five times as high (3.5%). Den Hartogh's interpretation of these data is not that Belgian doctors, any more than Dutch doctors, "get rid of unwanted patients." Although they believe themselves to be acting in the best interests of the patient and fulfilling the wishes of the patient, they are simply reluctant to discuss the matter

A minority of interviewees did express concern in regard to this data. Margo Trappenburg says that when patients are suffering and on the verge of death, she does not view it as problematic if the doctor provides morphine to ease the pain and the patient dies. However, in cases where the patients were competent and the doctor took their lives without asking them, this is worrisome. Some of the reasons given by the doctors for euthanizing these patients were invalid in her mind, as was the apparent unwillingness of some doctors to consult a colleague. Indeed, according to the 1990 report, among the considerations by the physician in performing a life-terminating act without explicit request of the patient were the patient's low quality of life (31% of the cases), inability of the patient's relatives to cope (32%), and economic considerations (1%). 30

Egbert Schroten, who has served on many medical committees, says that the findings are worrisome but that the discussion about their seriousness is exaggerated. Such medical behavior always existed before the invocation of the euthanasia policy, and a good doctor needs to help patients who are in great pain. Suffering of body and spirit is the most important consideration, and here we speak of incompetent patients in the very last days of their lives, who suffer miserably.

Ruud ter Meulen, Director of the Institute for Bioethics and Professor at the University of Maastricht, indicates that the issue worries him. He would like to have in place an explicit policy on termination of life, with no room for interpretation. The policy should insist on the explicit request of the patient and on strict medical criteria. There is also a need to define the concept of suffering. Ter Meulen expresses a critical view of the existing practice of passive euthanasia and the use of morphine to shorten life. He argues that it is not clear on which criteria decisions for

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passive euthanasia are based and what role the patient has in the decision-making process.

The three most critical voices in the present survey did not justify the existing situation. Both Chris Rutenfrans and Henk Jochemsen express concern about the lack of control mechanisms and the freedom that physicians have to decide the fates of their patients without consulting them. Jochemsen acknowledges that some were probably cases of double effect, but in others patients were competent and were still not apprised of the situation. This is not morally justifiable. The major consideration for physicians must be the suffering of the patient. Autonomy gives an additional justification, but does not constitute the major reason. While recognizing that the termination of life took place in the last stage of the disease, Jochemsen emphasizes that there was no preference expressed by patients in a significant number of cases.³¹

Most outspoken was Frank Koerselman, who is worried by the phenomenon and contends that junior doctors readily make Do Not Resuscitate (DNR) orders without much thought, especially when patients are old. Young doctors often evaluate a patient's quality of life without even knowing the patient, and many of them do not find compelling reasons for working to save a 90-year-old patient. Koerselman testifies that he has seen many cases in which DNR orders were taken by phone or given by a junior physician without consulting a senior colleague.³²

Fears of Elderly Patients

The next inter-related question was: "Some Dutch studies appear to indicate that some elderly people fear their lives will be ended without their consent³³ and that, in fact, families in the Netherlands request euthanasia more often than the patient.³⁴ Is this true?"

A study in thirty nursing homes showed that when medical indications for hospitalization of elderly patients arose, nursing home physicians decided not to transport the patient to the hospital in 12% of cases,

²⁸ Personal communication on August 27, 2000. Cf. Luc Deliens, Freddy Mortier, Johan Bilsen, Marc Cosyns, Robert Vander Stichele, Johan Vanoverloop and Koen Ingels, "End-of-life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey", Lancet, 356 (November 25, 2000), 1806-11.

²⁹ Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate et al., "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," 1704, Table 4.

 $^{^{30}\,}PJ.$ van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medical Decisions Concerning the End of Life, 64.

³¹ According to the 1990 report, the patient had given some indication about terminating life in 28% of cases. Interestingly, this consideration is mentioned by physicians in only 17% of cases. Apparently, it was not so much the wish of the patient but the circumstances that made the physician appreciate the patient's wish. Cf. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medical Decisions Concerning the End of Life, 64.

³² C.I. Dessaur and C.J.C. Rutenfrans wrote that a young doctor expressed objections to the use of pacemakers in people older than seventy-five years and declared that society may not be burdened with the duty of keeping old people alive. Cf. "The Present Day Practice of Euthanasia," Issues in Law and Medicine, 3 (1988), 402.

³³ J.H. Segers, "Elderly Persons on the Subject of Euthanasia," Issues Law Med., 3 (1988), 429-437; R. Fenigsen, "A Case Against Dutch Euthanasia," The Hastings Center Report, Vol. 19, No. 1, Special Supp. (January/February 1989), 24-26.

³⁴ R. Fenigsen, "Mercy, Murder and Morality: Perspectives on Euthanasia. A Case Against Dutch Euthanasia," Hastings Center Report, Vol. 19, No. 1 (Supp.) (1989), 22-30. In another essay, "A Case Against Dutch Euthanasia," 24, Fenigsen argued that spouses have coerced their husbands or wives to undergo 'voluntary' euthanasia.

particularly when there was a life-threatening emergency. In a considerable number of cases, the decisions were made without consulting the patients or their families. In a study done in Dutch hospitals, doctors and nurses reported that more requests for euthanasia came from families than from patients. The family, the doctors, and the nurses often pressured the patient to request euthanasia. ³⁶

Herbert Cohen, one of the country's leading practitioners of euthanasia, said in an interview to John Keown that he would be put in a very difficult position if a patient told him that he really felt a nuisance to his relatives because they wanted to enjoy his estate. Asked whether he would rule out euthanasia in such a case, Cohen replied that in the end he wouldn't because "that kind of influence—these children wanting the money now—is the same kind of power from the past that ... shaped us all." Cohen maintained that the same thing goes for religion, education, family of origin, "all kinds of influences from the past that we can't put aside."³⁷ It is unclear how this view could be seen as an acceptable interpretation of the Guidelines that speak of free and voluntary request of the patient as well as of unbearable suffering.

where the motivation is sincere. However, the patient needs to express a as propaganda of the anti-euthanasia lobby. Cases that include bad relaand demented patients receive treatment. There is no room for fear, and are afraid of having no option at the end of life and that in any event, old nasia was requested in his/her living will. She maintains that most people euthanize a patient who cannot express his/her will to die, even if euthacians is to cease treatment, not to perform euthanasia. Doctors will not when the patient is incompetent, the only available option for physiliving will, then the living will should be respected. will to die. If the patient does not express such a will and does not suffer tions in a family should not prevent euthanasia in the many other cases it is ridiculous to be afraid. In turn, van Dantzig dismissed the question for the existing policy and practice of euthanasia. ** Dupuis explains that then it is not an appropriate case for euthanasia. If the patient had a Heleen Dupuis and A. van Dantzig expressed the most supportive voices A minority of the interviewees dismissed the question as "ridiculous

Likewise, Van der Wal dismissed the question, saying that Segers was speculating, and that the articles I cited are "nonsense" and "scien-

tifically unsound." In one of the articles he co-authored, Van der Wal wrote that Dutch studies do not provide any evidence for the elderly being in danger of becoming "victims" of euthanasia or assisted suicide. ³⁹ Furthermore, Van der Wal did not know of any study on the role of families (according to Henk Leenen and Govert den Hartogh, no research has been done on the role of the family), and he and his research team were exploring the issue of conducting such research at the time of the interview. Van der Wal knows of only one opinion poll designed to investigate the issue, which, in his opinion, was conducted by a biased fundamentalist organization and was scientifically unsound. He further notes that euthanasia and assisted suicide among the elderly are rare. The age of most patients requesting euthanasia varies between 55 to 75.⁴⁰

Having said that, although Van der Wal dismissed the issue as "non-sense," he acknowledges that sometimes families find the suffering of their loved one unbearable and that there has been incidental anecdotal evidence of family pressure being brought to bear in the termination of a patient's life. That is to say that family pressures do exist, but doctors testify that they are not affected by such pressures, and that most of the time they resist those pressures. Van der Wal emphasizes that, unlike other countries, there are no financial incentives for requesting euthanasia in the Netherlands because the costs of maintaining patients are not borne by their families.

H.J.J. Leenen says that he has never heard of patients who are afraid of euthanasia. On the contrary, one hears more about patients who fear that they will ask for euthanasia when their time comes, but their request will not be honored. J.K. Gevers and Govert den Hartogh do not think that families request euthanasia any more than patients do, or that physicians act on the wish of the family more than on the wish of the patient. In his comments on the first draft of this study, den Hartogh wrote that in all of the cases reported, the doctor acted on the request of the patient, and that in almost all instances the family supported the request of the batient. There is hardly any evidence of undue influence of the wishes of the family on the decision of the doctor, either from the reported cases or from other sources.

On the other hand, some physicians and consultants are insufficiently aware of the possibility of subtle forms of psychological pressure exerted on patients by their families. They routinely allow the family to be present at all discussions with the patient. This is one of the ways in which the

³⁵ Richard Fenigsen, "Physician-Assisted Death in the Netherlands: Impact on Long-Term Care," Issues in Law & Medicine, 11 (1995), 293-294.

³⁶ Herbert Hendin, Seduced by Death (New York: W.W. Norton, 1997), 93.

³⁷ John Keown, "The Law and Practice of Euthanasia in the Netherlands," The Law Quarterly Review, 108 (1992), 63; idem, "Euthanasia in the Netherlands: Sliding Down the Slippery Slope?," Notre Dame J. of Law, Ethics and Public Policy, 9 (1995), 412.

³⁸ In his comments on the first draft of this study, van Dantzig wrote succinctly: "I do not wholeheartedly support the existing system." Personal communication on July 6, 2000.

³⁹ Martien T. Muller, Gerrit K. Kimsma and Gerrit van der Wal, "Euthanasia and Assisted Suicide: Facts, Figures and Fancies with Special Regard to Old Age," Drugs & Aging, 13 (1998), 185.

⁴⁰ Cf. P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg. Euthanasia and other Medical Decisions Concerning the End of Life, 44, 137. In both tables, the first age category is 0-49; the second 50-64, not 55. The same age categories are used in Table 3 of the 1995 study. Cf. Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate et al., "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," 1703.

SCEN-project⁴¹ may lead to substantial improvement, as SCEN-doctors are trained to be alert to this possibility.⁴²

Some interviewees⁴³ argued that even if such fears on the part of patients exist, they are unfounded. Opinion polls show that the public thinks it is unacceptable for the family to request euthanasia because they cannot cope with the patient's condition. Families may request euthanasia for the patient because they might become exhausted by dealing with the patient's suffering and illness, but such a request would not be granted because testimony of a relative does not constitute sufficient grounds for euthanasia. Schroten and Wijsbek have heard that elderly patients fear their lives might be terminated prematurely without their consent. They believe that these fears often arise from religious convictions and are totally unrealistic.

Parenthetically, let me refer to Bert Keizer's exchange with a nephew of one of his patients, who assured him that "this is not at all what he [the patient] wanted, ending his days in a place like this." Keizer, who practices medicine in a nursing home in Amsterdam, writes: "it always annoys me, that tone of voice in which people say, Uncle would never have wanted this. What they mean is, he's not as stupid as those other 56,000 Dutch people staying in nursing homes who have 'let things go ton for '"'44

Van Delden, one of the authors of the 1990 comprehensive study, based his answer on this study. The study shows that relatives made an explicit request to hasten the death of the patient in 14% of the cases, and others (physician, nurse or someone else who is not a relative) made the request in 1% of cases. 45

Van der Arend tells of arguments he witnessed between relatives over financial affairs, even about an inheritance while the patient was still alive. Therefore, families should be engaged in the decision-making, but should not be given the last word. All parties should be involved in the euthanasia decision: the patient, the physicians and nurses, and the patient's family. If members of the family are not involved, they might end up going to court. Van der Arend added that patients usually trust physicians not to terminate their lives without their consent. When the patient is rendered incompetent and has not prepared a living will, the

family assumes a larger role in the decision-making process, but still does not have the last word.

George Beusmans and Gerrit Kimsma, both physicians who practice euthanasia, testified that they always provide information to the patient as well as to the family. It is irrelevant if the family wants to take a certain course of action when the patient does not share the same preference. It is only the patient's request that counts. When they practice euthanasia, it is done in the open with the consent of the patient, who must voice repeated requests and sign a written document. Kimsma asserts that his patients' families have always been satisfied with the euthanasia procedure. He has never had a family meetings to resolve differences of opinion. At the same time, Kimsma declares that euthanasia is an individual matter of the patient and that he always resists family pressures for euthanasia when the patient does not want it.

Evert van Leeuwen argues that there are elderly people in nursing homes who fear that their lives will be ended without consent. However, euthanasia is rarely conducted in nursing homes. Indeed, studies show that Dutch nursing home physicians together receive an average of 300 requests for euthanasia and assisted suicide annually, of which they comply with only 25.46 In comparison to general hospitals, nursing homes have a less permissive policy on euthanasia.47 Bert Keizer writes that most of the patients in nursing homes belong to the generation that still associates "euthanasia" with "mass murder."48

Van Leeuwen maintains that there might be cases of inadequate care and, as a result, patients may die earlier than expected. Van Leeuwen further testifies that he once heard a physician describe how he and his colleagues could have improved a patient's situation, but did not do so because the patient had no family to care for him were his condition to improve, thus leaving him alone in a difficult situation.⁴⁹ In addition, when some families request that the elderly die peacefully, they are indirectly exerting their influence on the decision makers.

Rob Houtepen, Ron Berghmans and Dick Willems argue that families do exert pressure for, but also against, euthanasia. Most physicians

⁴¹ In May 1999, the government initiated the organization of consultancy teams all over the country. Consultants travel to small villages to examine medical files and to see patients. Cf. Bregje Onwuteaka-Philipsen, Consultation of Another Physician in Cases of Euthanasia and Physician-assisted Suicide (Amsterdam: Department of Social Medicine, Vrije Universiteit, 1999), Doctoral Thesis, esp. 91.

 $^{^{\}it 42}$ Personal communication on August 27, 2000.

 $^{^{\}rm 43}\,Egbert$ Schroten, Margo Trappenburg and Henri Wijsbek.

⁴⁴ Bert Keizer, Dancing with Mister D (London: Black Swan, 1997), 301-302. See also 306, 312.

⁴⁵ P.J. van der Maas, J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medical Decisions Concerning the End of Life, 134.

⁴⁶ Martien Tom Muller, Death on Request (Amsterdam, Vrije Universiteit Thesis, 1996), 18. See also Table 3 in Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate et al., "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," 1703, and Table 2 in Gerrit van der Wal and P.J. van der Maas, "Empirical Research on Euthanasia and Other Medical End-of-Life Decisions and the Euthanasia Notification Procedure," in David C. Thomasma et al., eds., Asking to Die, 172.

⁴⁷ Dick J. Hessing, John R. Blad and Roel Pieterman, "Practical Reasons and Reasonable Practice: The Case of Euthanasia in the Netherlands," J. of Social Issues, 52 (1996), 155.

⁴⁸ Bert Keizer, Dancing with Mister D, 258. Keizer also testifies that only a small percentage of his patients really want to die (emphasis mine, RCA). Ibid., 268.
⁴⁹ In his comments, van Leeuwen asked me to emphasize that he heard this once, and only once. Personal communication on August 30, 2000.

sist it. The common procedure is to inform and to speak with family tained in a later communication that this problem is in no way limited to euthanasia rather than to provide adequate pain relief. Griffiths mainsituation might exert pressure on doctors and influence them to opt for sue of family pressure as one of the problems that needs to be addressed 90% of the euthanasia cases. 50 In turn, John Griffiths identified the ismembers. Willems estimates that families are consulted in more than are aware of the pressure on them to perform euthanasia, and they retively in connection with abstention decisions. euthanasia. His impression is that it is far more important quantitaby effective regulation. Families that can no longer cope with the patient's

request for euthanasia. However, in his comments on the first draft of as a solution to a pressing problem, and ter Meulen adds that this is sources, cuts in the nursing staff and a larger number of the elderly who burden on their families. This consideration may play a role in their especially true with respect to elderly patients who do not want to be a wish to be in nursing homes. We can expect that the quality of care for homes and for home care. The Netherlands is facing a shortage of reposition of elderly people, given that there are waiting lists for nursing the most critical voices on this matter. Ter Meulen is worried about the ing a role in the practice of euthanasia at this point. this paper, ter Meulen added that there is no evidence of this issue playthe elderly will deteriorate. Euthanasia may be a promising alternative Ruud ter Meulen, Henk Jochemsen and Frank Koerselman voiced

it is often the case of the family, rather than the patient, asking for euessary treatment. beyond the necessary point. Jochemsen also objects to providing unnec-He adds that patients sometimes also fear that treatment will continue thinks that some elderly patients indeed have good reason for this fear. thanasia when the patient has become a burden. Hence, Jochemsen Henk Jochemsen, professor of Christian medical ethics, contends that

ence. He argues that such fears on the part of the elderly do exist. In his ascertain that families who find it difficult to cope with the suffering of view, families have informal influence on doctors, and it is impossible to the studies of Segers and Fenigsen, and testifying about his own experi-As usual, Koerselman expresses the most critical view, agreeing with

R. Cohen-Almagor, Non-Voluntary and Involuntary Euthanasia

dition, both mentally and physically. ment and was eventually discharged from the hospital in very good contry to be a healthy 85-year-old man. The patient then agreed to treatpression, two perfectly treatable conditions, and that he might as well Koerselman explained to him that he suffered from pneumonia and detreatment and that he did not want to become a burden on his family. patient. The patient said at first that there was no reason to continue move the family from the room so that he could speak privately with the response was negative. Koerselman had to order security guards to rethe patient's GP whether he had spoken with the patient alone. The and said that if he had not taken an active role in this case, they would ment. Koerselman was invited to consult on the patient's depression him, and the GP agreed with the family that there was no point in treatboth of which are treatable conditions. His family did not wish to treat told the story of an 85-year-old patient with pneumonia and depression their loved ones do not influence the decision-making process. Koerselman physically wanted to prevent me from treating him." Koerselman asked humanely and would receive a nice bottle of wine from the family who have taken the easy way out: "He would die, all would say that I acted

Conclusions

lives are terminating without their consent. cations to show that there is no real cause for alarm even when patients' voluntary and non-voluntary euthanasia, recruiting an array of justifiauthorities in the field of medical ethics are quite complacent about inperceptions of some of the worrisome data revealed in the Remmelink Report. The present study reveals that most of the interviewed Dutch The aim of this essay was to provide account of Dutch policy makers'

ening the scope of the practice. advance more bills that would legitimize euthanasia further, while broadwithout seeing much difference between the two, and whose legislatures policy and practice of both euthanasia and physician-assisted suicide, mains the only country in the liberal world that generally accepts the tempts to legalize assisted suicide and euthanasia. The Netherlands rewas declared void. The legislatures of Canada and England resist atallowed terminally ill patients to commit suicide with a doctor's help cide is facing a challenge. In Australia, the Northern Territory Bill that In the United States, Oregon's Measure 16 that allows assisted sui-

nasia without compelling reasons. They argued that, of course, crimidoctors' motives, and saw no reason why doctors would perform euthawhich it is the role of doctors to help patients. They didn't question the tioned the system as such. Many of the experts depicted a society in ion regarding specific questions and issues, but only a minority quesafter all, we are dealing with life and death. There were variants of opinsystem that suffers from serious flaws while the stakes are very high; nals exist in every society, in every sphere of life, but policy is not built I found it troublesome that scholars and decision-makers support a

erlands, 1990-1995," 1704. Interestingly, another study shows that patient's relatives others" were consulted only in 70% of euthanasia and assisted-suicide cases. Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate et al., "Euthanasia, Physiciancerning the End of Life, 47. According to the 1995 death-certificate study, "relatives or J.J.M. van Delden, and L. Pijnenborg, Euthanasia and other Medical Decisions Con-Notification Procedure for Physician-Assisted Death in the Netherlands," New Eng van der Wal, Paul J. van der Maas, Jacqueline M. Bosma et al., "Evaluation of the were "contacted" in more than 90% of the euthanasia and assisted-suicide cases. Gerrit Assisted Suicide, and Other Medical Practices Involving the End of Life in the Nethcases, and specialists consulted with relatives in 85% of cases. Cf. P.J. van der Maas, J. of Med., Vol. 335, No. 22 (November 28, 1996), 1709 ⁵⁰ According to the 1990 study, GPs consulted with patients' relatives in 97% of the

voluntariness of the request is thus compromised. On occasions, the euthanasia or physician-assisted suicide. Often the doctor proposes euand time again. It is not always the patient who makes the request for not work because all the Guidelines, without exception, are broken time abuse. Many of the interviewees failed to recognize that the system does emphasized that the two major reports of 1990 and 1995 indicate there system's rationale is good—to help people in their time of need. They install control mechanisms against the possibility of abuse, but that the around this small number of criminals. They believed there is a need to with no prospect of improvement. Sometimes nurses, instead of doctors patient's medical condition does not always entail unbearable suffering patient's request is not always durable and persistent as required. The request was made and patients were put to death. Furthermore, the patient's request is not well considered. There were cases in which no thanasia to his patient. Sometimes the family initiates the request. The is no slippery slope, yet ignored the fact that there is already too much independent colleague and/or euthanasia cases are reported as natural perform euthanasia. In quite a few cases, physicians fail to consult an

Interviews in the Netherlands (summer 1999)

Professor John Griffiths, Department of Legal Theory, Faculty of Law University of Groningen (Groningen, July 16, 1999).

dam (Amsterdam, July 19, 1999). Professor J.K. Gevers, Professor of Health Law, University of Amster-

University of Amsterdam (Amsterdam, July 19, 1999; Haarlem, July Professor Evert van Leeuwen, Department of Metamedicine, Free

Dr. Dick Willems, Institute for Research in Extramural Medicine Department of Social Medicine, Amsterdam (Amsterdam, July 20

Amsterdam (Amsterdam, July 20, 1999). Professor Bert Thijs, Medical Intensive Care Unit, VU Hospital

July 20, 1999). Professor A. van Dantzig, retired expert in psychiatry (Amsterdam

dam (Amsterdam, July 21, 1999) health law, Medical Faculty and Faculty of Law, University of Amster Professor H.J.J. Leenen, formerly professor of social medicine and

dam (Amsterdam, July 21, 1999) Medicine, Department of Social Medicine, Free University of Amster-Professor Gerrit van der Wal, Institute for Research in Extramural

ics, The Hague (Amsterdam, July 21, 1999). Dr. Jaap J.F. Visser, Ministry of Health, Department of Medical Eth-

of Leiden (Leiden, July 22, 1999). Professor Heleen Dupuis, Department of Metamedicine, University

of Leiden (Leiden, July 22, 1999). Dr. Margo Trappenburg, Department of Political Science, University

sity of Rotterdam (Rotterdam, July 23, 1999). Dr. Henri Wijsbek, Department of Medical Ethics, Erasmus Univer-

University (Maastricht, July 26, 1999). Dr. Arie J.G. van der Arend, Health Ethics and Philosophy, Maastricht

Dr. George Beusmans, Maastricht Hospital (Maastricht, July 26

(Amsterdam, July 27, 1999). Professor G.F. Koerselman, Sint Lucas Andreas Hospital, Amsterdam

ningen, July 27, 1999). Professor Henk Jochemsen, Professor Lindeboom Institute (Ede Wage-

sity of Amsterdam (Koog 'aan de Zaan, July 28, 1999). Dr. Gerrit K. Kimsma, Department of Metamedicine, Free Univer-

dam (Amsterdam, July 29, 1999). Visiting Research Fellow at the Institute for Social Research, Amster-Dr. James Kennedy, Department of History, Hope College, Michigan.

of Medicine, Erasmus University, Rotterdam (Amsterdam, July 29 Professor Paul van der Maas, Department of Public Health, Faculty

Dr. Chris Rutenfrans, Trouw (Amsterdam, July 30, 1999)

Amsterdam (Amsterdam, July 30, 1999; August 8, 1999). Dr. Arko Oderwald, Department of Metamedicine, Free University of

Ms. Barbara de Boer and her three children (Amsterdam, August 2.

Law, Utrecht University (Utrecht, August 5, 1999). Professor Egbert Schroten, Director, Center for Bioethics and Health

Amsterdam (Amsterdam, August 10, 1999). Professor Govert den Hartogh, Faculty of Philosophy, University of

ics and Health Law, Utrecht University (Utrecht, August 10, 1999). Dr. Johannes JM van Delden, Senior Researcher, Center for Bioeth-

versity (Maastricht, August 11, 1999). Dr. Rob Houtepen, Health Ethics and Philosophy, Maastricht Uni-

(Maastricht, August 11, 1999). Dr. Ron Berghmans, Institute for Bioethics, Maastricht University

fessor at the University of Maastricht (Maastricht, August 11, 1999) Professor Ruud ter Meulen, Director, Institute for Bioethics and Pro-