

The National Advisory Board on
Social Welfare and Health Care Ethics ETENE

January 1st, 2012

HUMAN DIGNITY, HOSPICE CARE AND EUTHANASIA

Background

At the beginning of 2011, the National Advisory Board on Social Welfare and Health Care Ethics ETENE decided to bring forth discussion on euthanasia and its alternatives in Finland. In the background was a lively discussion on the topic carried out in Sweden, among other places. ETENE appointed a working group to make preparations concerning the matter. The working group included the following members of the Advisory Board: Dean Kirsti Aalto, Master of Theology; Irma Pahlman, Doctor of Laws, and ETENE's General Secretary Aira Pihlainen, Doctor of Health Sciences. In addition, Dr. Juha Hänninen, Chief Physician of Terhokoti Hospice and an expert in hospice care, was invited to join the group. In the autumn of 2011 Docent Päivi Topo was appointed ETENE's new General Secretary and she joined the group at that time. The working group met several times over the course of the year and prepared a draft statement for discussion by the Advisory Board. The group reported on its work at the ETENE meeting on 22 September, 2011. The group's draft statement was reviewed in a working seminar on 15 December, 2011. ETENE proposes the following statement on the matter:

Introduction

Death is a secret, unknown to humans. We can take note of the moment of death, but we do not know what happens after death. Discussions on death often express the wish to die with dignity. The thought contains a wish for considerate, skilled care with adequate pain relief and the presence of loved ones – a feeling that one has not been abandoned. It also includes the right to express one's wish concerning the continuance or discontinuance of care and one's burial, and the wish to be treated with respect after death.

Originally, the Greek word for euthanasia meant a good death or peacefully falling asleep at the end of life. Nowadays, euthanasia is considered an active ending of another person's life at his or her request when there is a terminal illness with accompanying unbearable suffering in the background. In Europe, discussions on euthanasia include the concept of suffering and defining what kind of suffering is unbearable to human beings and how it can be detected. In the United States, on the other hand, the thought of self-determination and control of one's own death is emphasized. This is indicative of the cultural connectedness of death and dying. From the ethical standpoint, euthanasia is always associated with conflicting questions.

Euthanasia is a matter of respecting life and human dignity and the actualization of the right of self-determination when death is approaching. The wish to control life and to



possess self-determination regarding one's death has increased. How euthanasia is viewed is linked with political and social values and therefore decision-making on the acceptability of euthanasia requires public debate and will-formation by Parliament.

In practical clinical work, an ethical dilemma is occasionally encountered: would it be right to take active measures to end the patient's life or should he or she be allowed to die naturally? The former is thought to involve less suffering than a slow death. The western view of human nature includes an acceptance of the fragility of human beings and the impermanence of life. Suffering and pain are real but hope and thankfulness for life are equally real.

Another ethical dilemma is associated with the conflict between the patient's will and the physician's professional and ethical conviction. The conflict is alleviated – although not resolved – by the fact that in countries where euthanasia is permissible, implementing it requires the patient's repeated request to end his/her life and adequate cognitive capacity to form an opinion concerning one's treatment. Relatives or other loved ones are not permitted to request euthanasia in any country, and euthanasia is not an option in the case of patients with memory disorders or otherwise impaired cognitive capacity. Euthanasia can never be a solution to the problems in geriatrics or long-term care.

Clarifying the concepts

Hospice care means relieving the symptoms of a terminally ill patient and providing support and a sense of safety to the patient and his/her family at the end of life. Palliative care means symptomatic treatment of a patient with an incurable, progressive disease.

Well-organized hospice care is applicable to the majority of patients approaching death and is useful in supporting the patients' quality of life. Occasionally, a suffering person approaching death cannot be helped by means of well-organized hospice care, even though palliative care medical specialists were consulted. This involves cancer patients at the final stage of life or patients with severe neurological disorders. They are patients with a life-shortening disease who are suffering unbearably, and existing methods are not successful in relieving their suffering.¹

Assisted suicide is not a crime in Finland. Assisted suicide is connected to end-of-life care when the patient takes the deadly dose of medicine himself/herself. Placing the dose of medicine within the patient's reach at the patient's request when he/she has decided to end his/her life, is considered assisted suicide.

Palliative sedation means putting the patient in a sleep-like state when his/her suffering is unbearable and when it cannot be relieved by any other existing means. In palliative sedation, a drug is used to lower the patient's level of consciousness to the degree that he/she can no longer feel the suffering associated with his/her approaching

¹ Pahlman I: Potilaan itsemääräämisoikeus (Patient's right of self-determination) Edita 2003, p. 360



death. In palliative sedation, the medication is not used to cause the patient's death but to alleviate suffering by means of administering the lowest possible dose of medicine required for this purpose. The efficacy and safety of palliative sedation in difficult end-of-life situations causing suffering has been established. An agreement must be reached with the patient concerning the decision on the use of palliative sedation at a stage of treatment when the patient is still capable of forming an opinion on his/her future care.²

Allow natural death (AND) means rejecting measures which in the presence of the patient's imminent death would be directed at pathological changes in the patient's body and which in actuality would be useless. These include giving fluids and nutrients or blood products to the dying patient.

Do not resuscitate (DNR) is a restricted medical decision made by a physician. It prohibits the restoration of heart function. It is applied in a situation where restoring heart function is considered to be more harmful than beneficial to the patient. A person can express the DNR in his/her living will. The abbreviation DNR does not mean that hospice care will be initiated.

A living will is an expression of the patient's will concerning the decision on his/her care, given orally in the treatment situation and recorded in the patient records. A living will can also be submitted in writing. In this way, patients can influence their care even in situations in which they are no longer capable of expressing their will.³

Euthanasia means an intentional, active measure to end the patient's life when he/she requests it repeatedly and deliberately because of an incurable disease and unbearable suffering. Before euthanasia performed, all other possibilities to alleviate the patient's suffering have been considered and utilized. In countries where euthanasia is permissible, it is performed by a physician who has consulted another, independent physician and a psychiatrist, as needed. In such cases, the requests for euthanasia, decision-making concerning it and its implementation must be recorded in detail. The drug administered in active euthanasia produces instant death.

The slippery-slope argument helps in analyzing the debate on the acceptability of euthanasia. The argument is used to indicate that a deed or action which is or can be acceptable as such, leads to another deed or action which is immoral or unacceptable. In the context of euthanasia, the slippery-slope argumentation means that acceptance of euthanasia associated with a person's own firm will would soon result in acceptance of non-voluntary euthanasia as well. This would be expressed in euthanasia not being limited to removing the physical suffering of an inevitably dying patient only. The threatening thought of a gradual descent toward a more widespread use of euthanasia has been avoided, at least according to a Dutch follow-up study. In the Netherlands, euthanasia carried out under strictly defined terms has not been punishable since 2002.

² Pahlman 2003, p. 297

³ Pahlman 2003, 248; Hänninen J, Palliativisen sedaation periaatteet (The principles of palliative sedation) in Hänninen J (ed.), *Elämän loppu vai kuoleman alku* (The end of life or the beginning of death), Duodecim 2006, pp. 92-101



Reflections on euthanasia in Finland

The Act on the Status and Rights of Patients (785/1992, later the Patient Safety Act (1027/2007)) gives patients in Finland the right to refuse treatment that has been planned or already started. The patient's right of self-determination is at its strongest in regard to refusing treatment.⁴ The Act does not afford the patient an opportunity to demand a certain treatment or examination. Hence, the patient cannot demand the implementation of euthanasia.

Previously euthanasia was associated, before anything else, with the thought of safely ending the suffering of a fellow human being through medical assistance. Along with social change, the wish to self-determination and control has been increasingly associated with the wish to decide on one's own death. Euthanasia is being implemented in three European countries (the Netherlands, Belgium and Luxemburg), and a debate concerning euthanasia legislation has been carried out in several countries. In Finland, the Parliament's Committee for the Future stated that the tendency is toward a wider acceptance of euthanasia. According to the Committee, Finland would follow suit in 10-15 years. The matter was touched upon earlier when the Criminal Code was reformed in the 1960s and 1990s. However, the intent was to leave patient care in different situations to good medical practice. If a physician were to end the life of a terminally ill, suffering patient out of pity on the basis of the patient's request following resolute consideration, the deed would most apparently fulfil the essential elements of a homicide.⁵

According to the surveys conducted among Finnish physicians in 1993 and 2003, attitudes toward euthanasia were negative.⁶ In 2007, 19 percent of Finnish general practitioners, specialists in internal medicine and geriatric specialists (N = 661, 32 % response rate) supported the legalization of euthanasia and 17 percent were prepared to perform euthanasia if it were legal. Ninety-six percent of the respondents of the same study said that good palliative care would reduce the need for euthanasia. Only five percent said that palliative care training for physicians was on a satisfactory level⁷ However, the low response rate to the study limits the interpretation of the results.

The two most important ethical obligations of a physician are doing good and not doing harm. Physicians have the obligation to see to it that the patient does not suffer unnecessarily, to protect the patient from disadvantageous effects in treatment situations, and to offer sufficient information to support the patient's decision-making. Physicians must not conduct examinations and provide treatments that are considered to be useless or harmful to the patient. According to good medical practice, symptoms must be alleviated in the final stage of life, even though the methods used to alleviate

⁴ Pahlman 2003, p. 279

⁵ Pahlman 2003, p. 340

⁶ Louhiala P, Hilden H-M, Attitudes of Finnish doctors towards euthanasia in 1993 and 2003, *Journal of Medical Ethics* 2007; 32; 627-628

⁷ Silvoniemi M, Vasankari T, Vahlberg T et al., Physicians' attitudes towards euthanasia in Finland: would training in palliative care make a difference? *Palliative Medicine* 2010;24:744-746



them might shorten the patient's life. The doctor must respect the patient's right to self determination and treat the patient in agreement with him or her.

Euthanasia in other European countries

Euthanasia should be regarded not only as an ethical issue, but also a medical and judicial one. Comparison of the debates and practices regarding euthanasia in different countries is complicated by the fact that the legal systems in the various European countries differ from one another.

The Swedish National Council on Medical Ethics (Statens Medicinsk Etiska Råd) issued an opinion on palliative sedation, the permissibility of euthanasia and ending life in special cases. According to the Council, patients should have increasing opportunities to influence their palliative care and whether palliative sedation can in some instances be used in their care. In the opinion of the majority of Council members an investigation should be conducted as to whether physicians could in some special cases – at the patient's resolute request – prescribe a lethal dose of drugs that the patient would take himself/herself. In these cases, the disease would cause particularly severe physical – and in some cases – mental symptoms before death. The minority of the Council members held the opinion that in some special cases, physicians should be able to be active in helping the patient take the drug. Last year, in one case euthanasia made the headlines in Sweden, even though the case was about a patient's right to refuse treatment that had already been started. In 2011, the Ministry of Health and Social Affairs defined the instructions for life-sustaining treatment that are binding and replace the instructions drawn up in 1992. In Sweden, euthanasia is an illegal act.

In Norway, active euthanasia is prohibited, and participation in one can be judged as an offence against life. The punishment is a minimum of six years of imprisonment. Assisted suicide is also prohibited but penalties have been less severe in cases where providing assistance has been considered to have resulted from compassion, and clear evidence of the patient's own wish has been available. In Norway, a working group considered the decriminalization of the provision concerning assisted suicide, but rejected the proposal in a 5-2 vote.

According to the Danish Act on Patient Safety, active euthanasia and assisted suicide are illegal acts. Participation in active euthanasia may result in a maximum sentence of three years of imprisonment. A great majority of the members of the Danish Council of Ethics (Det Ethiske Råd) oppose active euthanasia.

In Great Britain, euthanasia and assisted suicide are illegal. Assisted suicide may result in a maximum sentence of 14 years of imprisonment. In June 2005, the British Medical Association (BMA) renounced its position of many years of opposing euthanasia and physician-assisted suicide. Nowadays, the Association neither opposes nor supports euthanasia or assisted suicide.

In the Netherlands, a law came into force in 2002 permitting euthanasia and physician-assisted suicide in precisely defined circumstances. The law validated a long-



standing practice in the Netherlands. Ending another person's life at his/her request or assisting in a suicide continues to be criminalized under the Dutch Criminal Code. To avoid becoming guilty of an offence, the doctor must fulfil the criteria of the Euthanasia Act exactly, in which case the act ceases to be an offence against the Criminal Code. The physician is not guilty of an offence when killing on request if two main conditions are met. These are appropriate care and notifying the regional pathologist of the death.

In Belgium, the law permitting euthanasia came into force in 2002. Under the law, euthanasia can be based on a written request by the patient or compliance with the patient's living will.

In addition, legislation permitting euthanasia has been debated in Great Britain, Spain, France, Columbia and Australia. In Finland, assisted suicide is not considered a crime under the Penal Code. In Switzerland, the law permits assisted suicide provided that the assistance does not involve selfish motives, and the physician's position is interpreted to be the same as that of other citizens.

Euthanasia practice in countries where it is permissible

In the Netherlands (1985), Belgium (2002) and Luxemburg (2008), euthanasia is not a punishable act, provided that agreed procedures are followed. In these countries, the emphasis is on suffering as the reason that justifies euthanasia. In the United States, Oregon (1997) and Washington (2009) enacted *the Death with Dignity Act*. It affords patients the opportunity to obtain the assistance of a physician to commit suicide, and emphasizes the patient's right of self-determination and freedom of choice. In countries where euthanasia is permissible, the final decision on its implementation is always made by a physician.

In the Netherlands, euthanasia or assisted suicide was the cause of death in 1.7 percent of all deaths in 1990. In 1995, the corresponding number was 2.4 percent and in 2001 2.6 percent. In 2005, the number turned down and was 1.7 percent in that year. The majority of these patients suffered from metastatic cancer of the gastrointestinal tract or lung cancer (77 %). The four most common reasons for expressing the death wish was the fear of pain (37 %), general deterioration (31 %), hopelessness (22 %) and shortness of breath (15 %). Among requests for euthanasia, the significance of pain has decreased over the past 25 years. Of the euthanasia requests made, 39 % were accepted. In the majority of the cases, euthanasia was carried out by a general practitioner (77 %). Studies have shown the death wish to be strongly and repeatedly associated with hopelessness and depressiveness. According to a survey conducted in the Netherlands, nearly a fifth of the people who requested euthanasia gave having become tired of living as the reason for the request. In the Netherlands, neither this – nor depression – are acceptable reasons for carrying out euthanasia. However, it does reflect the problematic nature of the suffering at the final stage of life.⁸

⁸ Hänninen J, Eutanasia (Euthanasia). Lääketieteellinen aikakauskirja Duodecim (Duodecim Medical Journal) 2011;127:793-9



The sanctity of life and the dignity of the dying

Human life is valuable: according to the Christian-humanistic view of life, each individual has indivisible human value, and each individual has a right to his or her own, unique life. In addition, all international agreements on human rights are based on the principle of inherent human value.

A good death does not mean ending life too soon – it means guiding a person safely to his/her approaching death. Development in medicine begs the question of when is it more merciful to change the treatment policy instead of continuing with the existing treatment. This is at the core of hospice treatment. A death is good when the dying person can depart in peace.

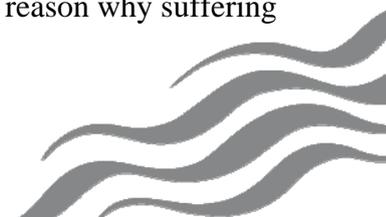
Care that takes into consideration a person's physical, psychological, social and spiritual needs is part of the concept of a good death. The dying person does not need to worry that he/she is burdening relatives and other loved ones or society. Disease and death are part of human life and as such, need not be rejected. Instead, they can be accepted in health and social care and in society as a whole. This acceptance is demonstrated through providing good care and being present – both of which are excellent remedies for reducing the fear of death.

The patient's own view of the quality of his or her life should be kept distinct from that of relatives and other loved ones or professionals. Views on the quality of life may differ from one another significantly, as was found in studies of ALS (Amyotrophic lateral sclerosis) patients who were almost incapable of communicating. The patients saw meaning in their lives in a situation where others no longer did.

A topic contemplated in discussions on euthanasia has been what kind of suffering society should respond to with death. Which conditions a death request should fulfil and when suffering could be viewed as unbearable must be considered. Countries where euthanasia is permissible have withheld it when doctors have considered the suffering to be too minor. This induces one to ponder upon how much must a person suffer to be allowed to die. The quality of suffering must also be considered – is psychological and existential suffering enough, or must there also be physical pain and suffering? Acceptance of the possible use of euthanasia also raises the question how near or far from death must the patient be in order to receive assistance in dying?

One's imminent death may cause existential suffering, characterized by a sense of insignificance and worthlessness, experiencing oneself as a burden to others; a sense of being dependent on others, fear of death or panic; wishing to hasten death and isolating oneself. From the standpoint of a differential diagnosis, treatable conditions such as depression, delirium and anxiety, must be identified. A depressed patient can be helped by psychotherapy. It can also be helpful to the dying person's loved ones in a difficult situation.

Occasionally, the patient wants to die as a result of misinterpretations of suffering and the subsequent inability to help. At times, lack of support from loved ones increases suffering. Sometimes, the difficulty of receiving help may be the reason why suffering



seems unrelieved. Social changes related to receiving and providing care have influenced the ethical and moral choices of individuals and the community as a whole.

Asking for assistance in dying is often considered a human right. In considerations regarding euthanasia, a person's ability to express himself/herself and to form a view of his/her own are primary. The situation where a person is suffering but is unable to ask for assistance in dying must be considered. What is the right way to help in such situations?

Statement

International observations indicate that a harmonious view on euthanasia has not been found. In the background are different views on what kind of measures can and should be part of providing good care and dying with dignity. To define a position that is considered just would require discussing situations in which suffering cannot be alleviated adequately even through good hospice care. It is estimated that in Finland there are a few dozen such patients over the course of a year. This is a small and well-defined group of patients. Therefore, ETENE's view is that a thorough investigation should be conducted to determine how hospice care could be developed in the future to alleviate the suffering of these particular people requesting assistance in dying.

Hospice care and palliative care should be supported and advanced in Finland. Good hospice care must be made available to each patient who needs it at the final stage of life. In this way, human dignity can be respected until death. ETENE's view is that special units are needed for palliative care and hospice care. Basic training in hospice care is also needed for healthcare professionals, and supplementary training is needed for those healthcare professionals who are already caring for a dying patient.

ETENE's view is that the discussion on euthanasia should focus on whether euthanasia is an ethically sound solution for patients who are suffering unbearably, for whom adequate relief cannot be found by using present methods, and who wish to die. ETENE finds that the need for assistance in dying should be assessed time and again as the world changes. Defining those situations in which euthanasia could be considered in practice involves numerous issues, including evaluating suffering, making the decision about euthanasia and taking responsibility for it. Clear answers must be provided to these questions before a commitment can be made to the possible use of euthanasia. ETENE finds that discussion is necessary because in the Advisory Committee's opinion there may be occasional situations where no ethical grounds exist for completely excluding the possible use of euthanasia.

Chairman

Markku Lehto

General Secretary

Päivi Topo



For your information: Pirkanmaa Nursing Home
Terhokoti Hospice
Ministry of Social Affairs and Health/Registry
Minister of Health and Social Services
Department for Promotion of Welfare and Health (HTO)
Department for Social and Health Services (STO)

