

The National Advisory Board
on Health Care Ethics (ETENE)

End-of-life care – memorandum of
the National Advisory Board
on Health Care Ethics

Report of the working group

Members of the working group on end-of-life care appointed
by the National Advisory Board on Health Care Ethics:

Sirkku Eho	Hospital Priest, Lappi Central Hospital, Member of the National Advisory Board on Health Care Ethics
Juha Hänninen	Chief Physician, Terhokoti Hospice
Virpi Kannel	Public Health Nurse, Cancer Society of Northern Finland
Irma Pahlman	Lawyer, Finnish Confederation of Salaried Employees (STTK), Deputy member of the National Advisory Board on Health Care Ethics
Ritva Halila	Secretary General of the National Advisory Board on Health Care Ethics

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1. Introduction

All people die. Most people pass away in institutions. More and more often, death is preceded by a lengthy period of illness and treatment. Dying patients can be young or old, and their situations, life stories and illnesses are all different. How to provide high-quality treatment and humane care for persons who are close to death is one of the most central questions in health care ethics. A society that adopts an indifferent approach to the treatment of the dying is not only inhumane but also violates human dignity.

It is important that the health care and social service units providing treatment have knowledge, experience, and skill in the treatment of the dying. Working, studying, conducting research and sharing experiences form the basis for the quality and development of end-of-life care. Particularly since the 1970s, end-of-life care has been developed as a special area of health care, and in 1982, the National Board of Health issued guidelines for terminal care that proved to be significant.

The National Advisory Board on Health Care Ethics (ETENE) chose as its main theme for 2001 ethical issues related to death and end-of-life care. ETENE also held an internal seminar about this theme in August 2001 and continued to discuss the issue at its meetings the following autumn. Based on this work, a publication entitled "Ethical issues related to death in health care" (ETENE publications 4) was published in January 2002.

In this connection, a report on the guidelines and practices concerning end-of-life care at health care units was made. The variety of practices and the desire for instructions concerning end-of-life care were apparent in the replies. In some places, extensive investigations had been performed about end-of-life care, but there were also many units that had no instructions at all with regard to end-of-life care.

In December 2001, the National Advisory Board on Health Care Ethics appointed a working group to consider questions relating to the provision of instructions about end-of-life care. The members of the working group were: Sirkku Eho, Member of the National Advisory Board on Health Care Ethics, Hospital Priest; Ritva Halila, Secretary General of the National Advisory Board on Health Care Ethics; Juha Hänninen, Chief Physician, Terhokoti Hospice; and Irma Pahlman, Senior Lawyer, Finnish Confederation of Salaried Employees (STTK). At its meeting of 12 February 2002, the National Advisory Board on Health Care Ethics reached a decision about the preparation of ethical guidelines for end-of-life care on the basis of the working group's proposal. At

the following meeting of the Advisory Board, Virpi Kannel, Public Health Nurse, Cancer Society of Northern Finland, was appointed to the working group. The working group has met 11 times.

Rather than compile a detailed set of instructions that could be applied directly in every case, the working group produced a memorandum containing essential ethical and judicial viewpoints and principles concerning the treatment of a dying patient. The memorandum does not discuss details of medical treatment, as material relating to this is available elsewhere. By publishing a memorandum about end-of-life care, the National Advisory Board on Health Care Ethics wishes to stimulate a wide-ranging discussion of the status of a dying patient and his/her right to receive the best possible care. Particular attention should be given to what humane treatment and end-of-life care mean in different situations and with different patients, with due consideration for the patient's family and environment. For instance, dying paediatric patients form a special group, and taking their situations and needs into consideration requires sensitivity, skill, and the ability to work as a team.

The National Advisory Board on Health Care Ethics hopes that this publication will inspire discussion and promote training, development and instruction relating to end-of-life care at both regional and local levels. Principles and guidelines cannot replace presence and interaction in real situations. The quality and ethical standard of end-of-life care are resolved time and again at every encounter between a dying patient and his/her family members. Although caring for dying patients is by no means easy, it is an area that might enrich and diversify the principles and values of health care and make treatment practices more humane in a wider sense.

Helsinki, 17 September 2003

The National Advisory Board on Health Care Ethics

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2. What is end-of-life care?

Doing good and avoiding harm are the cornerstones of ethically good care. Doing good means, among other things, alleviating suffering and promoting well-being. Doing harm means exacerbating pain and suffering. Ignorance or poor knowledge of the diagnosis of suffering often leads to neglect, over-treatment, or incorrect timing of the patient's treatment.

End-of-life care is the treatment of a seriously ill patient in cases where curative treatment has been abandoned and the progression of the illness can no longer be influenced. In end-of-life care it is important to take account of the patient's wishes, to treat the patient's symptoms as well as possible, to prepare the patient for approaching death, and to consider and support the patient's family and friends. End-of-life care means caring for a person at the end of his/her life in the best possible way. Pain and suffering cannot always be eliminated completely, but they can often be alleviated in different ways. The aim of end-of-life care is the alleviation of suffering. The treatment of symptoms is only one part of the care of a dying person. The treatment secures the individuality of the patient and the respect accorded to a human being.

Before end-of-life care is started, a decision must be made about the line of treatment. In some cases, the decision to transfer the patient to end-of-life care can be made in one discussion, while in others it is a continuum of several decisions to refrain from examinations and treatments at various stages of the illness. The decision concerning end-of-life care should be made in mutual understanding with the patient. An end-of-life care decision made too late makes it more difficult for the patient and his/her family and friends to prepare for approaching death. Poor treatment of symptoms and other types of suffering often also impairs the patient's chances of autonomous decision-making. Truthfulness in treatment does not just mean speaking the truth and avoiding telling lies but also communicating clearly and comprehensibly. In order for patients and their families to be able to take part in treatment-related decision-making, they need to receive sufficient, varied, and comprehensible information. Cut-backs in financial resources in the field of health care and the general inequality of society may jeopardise the fairness of the availability of treatment.

In the treatment of a dying person, it is often enough to ensure a sufficiently high standard of symptomatic treatment and basic care. The patient should also be given the opportunity to do the things he/she wants to do and to participate in the monitoring of his/her treatment. Experiencing joy, meaningfulness, tenderness and self-respect may be more important to the

patient than the alleviation of some individual symptom. The patient should be allowed to die in a place he/she feels is safe and to prepare to die in peace without fear or worry about how family and friends will cope.

3. Definitions

End-of-life care, palliative care and terminal care are partly overlapping concepts, all of which are often used to refer to symptomatic treatment at the end of a person's life. However, these concepts differ slightly in terms of meaning.

End-of-life care refers to the active care of a patient who is close to death, coupled with support for family and friends. It is treatment and support in the final stages of illness and during the process of death. A key aim of end-of-life care is to alleviate the patient's symptoms and suffering. End-of-life treatment is based on the fact that the patient has a progressive, incurable illness for which prognosis-improving treatment is either not available or has been rejected by the patient, and that the patient's life expectancy is considered to be short. End-of-life care as such is independent of the patient's diagnosis.

End-of-life care decision is a medical decision made by the physician in full consultation with the patient or the patient's representative. It can be a single decision concerning the line of treatment or the final result of a long process during which it has become clear that the patient's illness cannot be cured.

Palliative care is the comprehensive care of a patient whose illness cannot be cured and where prolonging the patient's life is not the only aim of treatment. Palliative care is not bound to the closeness of death and can last up to several years depending on the illness. Alleviating pain and other symptoms and addressing psychological, social, spiritual and ideological issues are central to palliative care. The aim of palliative care is to ensure the well-being of the patient and his/her family and friends. Palliative care supports life and considers death to be a normal process associated with life. Palliative care helps the patient lead as active a life as possible before death and offers support for the patient's family and friends during the patient's illness and after his/her death.

Terminal care is end-of-life care that directly precedes death.

Symptomatic treatment is the careful monitoring and treatment of symptoms regardless of the prognosis.

Under-treatment in end-of-life care is treatment that leaves some of the patient's pain and suffering unaccounted for. This may be due to the patient's suffering not being noticed, the inability to treat the patient's suffering, or the

underestimation of the patient's suffering. Even in good end-of-life care, the patient's pain or suffering may not always be completely eliminated, but they can be alleviated by various means.

Over-treatment in end-of-life care refers to procedures that prolong the patient's suffering and have only a marginal effect on his/her life expectancy. Over-treatment does not improve the patient's quality of life.

Treatment discussions are a series of talks between the patient and his/her physician. In addition, the patient's family and friends, as well as persons involved in the patient's treatment, may participate in these discussions if the patient so wishes. The number of persons involved in such discussions should be kept sensible so that the patient and his/her family and friends feel that their opinions are heard.

4. Judicial and ethical foundations of end-of-life care

The judicial basis of end-of-life care is stated in the section on the fundamental rights and fundamental regulations of health care in the Finnish Constitution (731/1999). The EC Convention on Human Rights and Biomedicine (ETS 164) complements these and helps with interpreting the regulations. The ethical basis of end-of-life care can be found in the ethical guidelines for health care professionals and in the recommendations and declarations concerning dying patients.

The inviolability of human dignity, equality, an individual's right to life, personal liberty and integrity, and the right to privacy are fundamental human rights. In end-of-life care, respecting human dignity means providing good care, respecting the patient, and observing the patient's opinions and wishes. Respecting human dignity does not end in the individual's death. Equality means equal treatment in similar situations. In health care, this principle means that each patient is treated well regardless of his/her gender, age, health status, handicap, religion, or other issues associated with the individual. The right to life means securing the minimum requirements of life. The right to personal liberty means, in the case of end-of-life care, treatment of the patient in full consultation with the patient until death. According to the Act on the Status and Rights of Patients (785/1992, later the Patient Act), the patient has the right to self-determination and the right to receive good health care and medical care as well as good treatment. According to the law, the patient must be given comprehensible information about the treatment or the examination before it is started.

Each health care professional is under an obligation to provide good treatment for the patient in accordance with his/her training and experience,

to alleviate the patient's suffering, and to continually supplement his/her professional skills (Act on Health Care Professionals (559/1994), obligations relating to professional ethics).

In health care and medical care, the Patient Act is applied in both public and private sectors. The patient's privacy, private life and associated needs must be respected in all treatments and examinations.

Good care has an objective side as well as a subjective side. For each individual patient, good care is finally a subjective and varied concept. When the quality of care is evaluated, the patient's subjective experience is a significant, if not the only, criterion. A dying patient enjoys equality with respect to other patients. However, the treatment of a dying patient involves special characteristics that should be taken into account. The Declaration of the World Medical Association on the rights of the patient (1991,1995) accords more value to this. According to the Declaration, a dying patient has the right to humane end-of-life care and to all assistance so that death is as humane and peaceful as possible.

4.1 Right to self-determination

The patient's right to self-determination means that the patient's consent is required for treatment. The right to decline treatment also applies to situations where, if treatment is not provided, the result could be severe disability or death, provided the patient is able to make decisions concerning his/her treatment. Patients may have the competence and the right to make decisions about their treatment even if they are no longer capable of taking care of, say, their financial affairs. If the patient is unable to make decisions about his/her treatment and has not previously issued a living will, the treatment requires the consent of the patient's legal representative, close relative, or another family member or friend who has been authorised to participate in decision-making concerning treatment in such situations. The main principle should be that the previously expressed wishes of the patient should be observed in such situations unless there are justifiable reasons to conclude that the patient has changed his/her mind about the treatment. The person giving the consent should take into consideration the previously expressed wishes of the patient and his/her personal benefit. The Patient Act will be made more specific in this respect in 2004.

In the case of minors, providing they are able to make decisions concerning their treatment, they may either consent to, or decline, the treatment. Health care professionals will assess the minor's competence to decide about his/her treatment, taking into consideration the patient's age and stage of development. Minors who are unable to make such decisions will be treated in consultation with their guardians or other legal representatives.

4.2 Living will

A person can express his/her wishes about future treatment by making a living will. The patient has the right to decline treatment that has been planned for him/her or already started. A living will comes into effect when the patient is no longer able to express his/her opinions about treatment. In a living will, the patient expresses his/her opinion about important treatment decisions concerning him/her, for example if his/her life as an incurably ill patient is prolonged by means of certain treatment decisions. The living will applies to treatment procedures associated with the closeness of death.

A living will can only be observed in situations to which it applies. A living will is always a person's own subjective decision that should not be assessed from some other, for example medical viewpoint. Everyone's personal living will should be respected. A living will can only be ignored if the physician has a good reason to believe that the will is either not genuine or has not been made in earnest.

A person who is capable of making a living will can also cancel it orally, in writing, by destroying the document and any copies, or by making a new living will about his/her treatment. If the patient is known to have made a living will in writing but the document cannot be found with reasonable effort, it is likely that the patient has destroyed the document. The most recent living will cancels all previous living wills, whether expressed orally or in writing. Health care professionals should make certain that a living will expressed orally, and its cancellation, are recorded in patient documents if the patient makes the living will during hospitalisation.

Section 8 of the Patient Act sets no limits on how long a living will remains valid. In practice, matters need to be resolved on a case-by-case basis, taking into account the fact that a living will concerns a hypothetical situation in the future that can only be predicted in a limited way.

The patient's wishes are particularly significant in relation to important treatment procedures. When a moderately important or important procedure is performed in health care, the consent must be explicit. The patient may be unable to express his/her will orally or in writing but still be able to decide about his/her treatment.

A living will made in earnest may be recurrent or in other ways permanent. A living will is considered to be earnest if the patient expresses it repeatedly, after lengthy consideration or in writing. At present, the most reliable way for a patient to demonstrate the earnestness of his/her wishes is to make a living will in writing and to have it witnessed.

4.3 Non-initiation of treatment and cessation of treatment

The patient has the right to decline all treatment. The patient also has the right to demand that treatment be discontinued. No legal regulations are currently in force concerning the treatment of a dying patient. The National Board of Health spoke for the patient's right to self-determination in several circulars in the 1970s and 1980s. In 1982, the National Board of Health issued instructions about the terminal care of patients. These instructions stated that the purpose of terminal care was to allow the patient to live the rest of his/her life with dignity and to die without pain or other severe symptoms, close to his/her family and friends and in the environment of his/her choice. These instructions were cancelled in 1990 with the abolition of the National Board of Health, but the principles can still be applied in practice. The regulations concerning the patient's right to good treatment, as stated in the Patient Act, also apply to dying patients. End-of-life care is discussed in the document, "Kuolemaan liittyvät eettiset kysymykset terveydenhuollossa" (Ethical issues related to death in health care), published in 2002 by the National Advisory Board on Health Care Ethics. The concept, "cessation of treatment" refers to the abandonment of curative treatment procedures in situations where treatment is no longer in the best interests of the patient. This is part of good treatment practice. The patient is not left untreated.

Treating the patient with respect to his/her dignity as death approaches means the abandonment of treatments that prolong the patient's suffering. When the patient is no longer able to make decisions and assess the situation, treatment decisions are made at the discretion of the doctor. When the doctor is of the opinion that continuing the treatment is not in the best interests of the patient, the treatment will be discontinued even if a person with the authority to give consent demands the continuation of treatment.

5. End-of-life care decision

An end-of-life care decision is preceded by discussions concerning care. Issues relating to the patient's illness and its treatment, different treatment options and future prospects are discussed and decisions relating to the line of care are made. Deciding about the line of care also includes cessation or non-initiation of life-prolonging treatments in accordance with the progression of the illness, the prognosis, and the treatment possibilities. Decisions about the line of care are made on an individual basis, taking into consideration the patient's needs. The need for and the usefulness of fluid and nutritional therapy as well as other examinations and treatments are also discussed in connection with end-of-life care decisions. During the discussions, the patient's thoughts and

feelings concerning everyday routines, experiences concerning the illness, fears, and wishes concerning care are all considered. Decisions concerning care are made by the doctor responsible for the patient's care in full consultation with the patient or the patient's representative.

End-of-life care decisions are made in both special health care and basic health care. If the patient is transferred from one unit to another when end-of-life care is started, the receiving unit should, where necessary, also arrange for the patient's care to be discussed as clearly and in as much detail as possible.

Decisions and their justifications must be recorded in the patient's documents clearly and in detail. It is important that those persons involved in the patient's treatment but who were not able to participate in the treatment discussions also receive up-to-date information about treatment decisions. The decisions made in these discussions are of particular importance in deciding about the treatment in emergency situations.

An end-of-life care decision means relinquishing curative treatment in favour of treatment of symptoms. The decision is often the result of a long process, during which it has become clear that the patient's illness cannot be cured. Decision-making is often supported by consultation between several health care professionals and between patients and their families. The right time to stop, to assess the situation, and to move on to end-of-life care is individual and difficult to define in general terms. Decision-makers, treatment staff, patients and their families and friends often feel inadequate and anxious in such situations. Sometimes the decision to move on to end-of-life care can be delayed because starting the discussion is difficult. However, in such a situation, end-of-life care is the best possible care and sometimes the only medically justifiable treatment option for the patient. If the end-of-life care decision is delayed or, in the worst case, not made at all, the patient is denied the chance to spend the rest of his/her life with dignity and free from suffering.

6. Provision of end-of-life care

Patients receiving end-of-life care are most often treated in basic health care: as in-patients at health centres, nursing homes, institutions for the handicapped, private treatment units, or at the patient's home or in home-like institutions with the support of home nursing and, if necessary, in special health care. End-of-life care is also provided by both private and municipal units specialising in end-of-life care. Resources for end-of-life care must also be available in special health care in the event that transferring a patient from one unit to another would do more harm than good. Once the end-of-life care decision has been made, a treatment plan is drawn up together with the patient

and possibly with the patient's family, friends and treatment staff. This plan also includes the resources for providing the care, taking into consideration the resources of all parties concerned. The care is monitored and assessed regularly.

Care can be provided wherever sufficient resources are available. The patient should have the opportunity to choose between care at home and care in an institution. A patient receiving end-of-life care should always have help and advice available around the clock, if necessary. Units providing end-of-life care should also have close contacts with special clinics and/or units (hospices, pain management clinics). If end-of-life care is provided at home, the patient and his/her family should be able to contact the persons treating the patient at all times.

End-of-life care requires professional skill and teamwork, and units providing end-of-life care must therefore have the resources and the adequately trained professional staff to be able to offer this care. Health centres and hospitals providing end-of-life care should appoint a doctor to be responsible for end-of-life care. This doctor can get enough training concerning the treatment of symptoms, organise resources and time for meetings between dying patients and their families and friends, and train other doctors of the unit in the provision of end-of-life care. The care team should also include a sufficient number of nurses, and it should also be possible to consult a social worker, a psychologist, and a priest, who can also be part of the care team if the patient so wishes. The treatment staff should be capable of treating the patient's symptoms and responding to the emotional reactions and the need for information of the patient and his/her family and friends. If the patient wishes, spiritual questions should also be considered and answered if possible. The starting point is the patient's faith and respect for it. If necessary, a hospital priest or a worker from the patient's church or religious community can be asked to visit the patient at the hospital or at home.

Additional and further training and continuous professional guidance can help to ensure that staff have the necessary skills and the ability to cope. The employer has an obligation to arrange professional guidance and to ensure that staff are able to cope, and in this way maintain high standards of professionalism. More advanced training in end-of-life care should also be included in the basic training of health care staff and social workers.

End-of-life care patients often have a variety of symptoms as well as impaired ability to move around and to function generally. Units providing end-of-life care should have a sufficient number of trained staff members for proper provision of treatment. Occupational safety and patient safety also require sufficient employee numbers. In units providing end-of-life care, the target should be at least one nurse per patient. Enough space, e.g. a private room, should be arranged for a dying patient and his/her family and friends so

that they can be together in privacy and the patient can have the things that are familiar to him/her close by. There should also be enough space around the patient to facilitate basic care. Trained volunteers cannot replace health care professionals, and should not be burdened with the responsibility of caring for the patient. Volunteers play an important role in supporting the family and being available for the patient.

After death, the deceased should continue to be treated with respect and dignity. Units providing end-of-life care should compile instructions about handling and transferring the deceased from the unit and about how the family should be taken into consideration after the patient's death. The family should be given sufficiently detailed instructions about what to do when an end-of-life care patient dies at home according to his/her wishes.

7. End-of-life care at home

The patient's wishes form the basis for end-of-life care and eventual death at home. If this is to happen, a family member or a friend will usually wish to take responsibility for the care. Special attention must be given to the patient's discharge from the unit and to ensuring that the patient receives proper and safe care. It is best to agree about issues beforehand and in as much detail as possible, to put the issues agreed on in writing, and to ensure proper communication between the home and the treatment unit, as well as between persons participating in the treatment. The patient and his/her family member or friend must be able to contact the treatment staff at all times for advice and support at home. The patient should have a support unit in the hospital or health centre to which he/she can be transferred if necessary. The patient's family and friends need to be given guidance, encouragement and respect if they are to care for the patient at home. Voluntary support persons and local congregation employees can play an important role in helping the family to cope. End-of-life care at home should be organised in such a way that expensive medicines, support for the care giver, home nursing fees or other treatment costs do not become an obstacle to the treatment. At home, preparations for the patient's death should be made in advance. Written instructions about practical matters and contacts after the patient has died will be given to the care giver. The patient's family and friends may still be in need of support after the patient's death. Arranging a meeting with the patient's family and friends forms part of good treatment practice.

The principles of end-of-life care at home should also be observed in home-like institutions, e.g. serviced apartments, group homes and nursing homes.

8. Children and end-of-life care

The serious illness of a child and the associated treatment put great strain on the child and his/her family. Accepting the fact that the illness cannot be cured may be extremely stressful both to the persons treating the child and to the child's family. However, moving on to end-of-life care is, at that point, in the best interests of the child and sometimes the only medically justifiable treatment. Good professional skills, wisdom and courage are needed to bring the matter up for discussion with the child and his/her family. A child receiving end-of-life care should be allowed to lead as normal a life as possible right up to the end. Children often wish to stay home as much as possible, and to play, be outside and meet their friends. Treatment procedures should not restrict the child's normal life too much. However, the child's symptoms should be properly treated. Providing support for the parents during end-of-life care and for a sufficiently long period after the child's death is important and forms part of good treatment practice. Directing the child, the parents and other close relatives to peer groups that can provide support for them is often helpful in such a situation.

When a young child is a family member of a patient receiving end-of-life care, he/she may have a very unrealistic concept of the finality of death. If it is the child's mother or father who is dying, the child is about to lose a person who has had a considerable impact on his/her life up to that point. The child should be given the opportunity and the space to express his/her needs, grief and fears. It is also important that the child does not have to worry needlessly about how other family members will cope. Steps must be taken to ensure the well-being and safe development of the child in the event that his/her only guardian passes away.

9. Recommendations of the National Advisory Board on Health Care Ethics

1. Everyone has the right to good and humane treatment even if no curative treatment exists.
2. The patient's right to self-determination should be respected in end-of-life care. The patient's living will can only be ignored if it can be justifiably presumed that the patient has changed his/her mind about the treatment.
3. The end-of-life care decision and the treatment plan are based on mutual understanding between the patient and the persons treating him/her.
4. It is important to ensure the continuity of care when the aims of the patient's treatment change and the patient is transferred from one unit to another. When the change is made from curative treatment to palliative care or end-of-life care, it is also important to make as clear a plan as possible and record it in the patient's documents. The plan should be available for all persons participating in the treatment. Clear expressions that are employed in health care should be used in the patient's documents.
5. Units providing end-of-life care should have the capability to carry out the treatment plan made for a patient receiving end-of-life care. This includes sufficient resources with regard to staff, professional skills and equipment for humane and safe treatment.
6. The patient has the right to die at home or in a place where he/she can be with his/her family and friends if he/she so wishes.
7. Special attention should be given to persons who are not competent to decide about their treatment, whether they are end-of-life care patients or their close relatives.
8. All dying patients are entitled to good end-of-life care regardless of the diagnosis of their illness.

10. Literature

Finnish law:

The Constitution of Finland (731/1999)

Act on the Status and Rights of Patients (785/1992)

Act on Health Care Professionals (559/1994)

Mental Health Act (1116/1990)

Act on Infectious Diseases (583/1986)

Act on Welfare for Substance Abusers (41/1986)

Act on Special Care of Mentally Handicapped Persons (519/1977)

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