HCLU on Euthanasia

Dilemmas related to ending life have come to the forefront of interest in many parts of the world in recent decades. Modern medicine can lengthen the dying of patients even by years, which means that health-care professionals, patients and their relatives occasionally have to face decisions that were not known in the past. Public perception of death underwent changes as well: there are many people today who do not believe it to be inevitable that they should bear the pains attendant on dying and therefore expect health-care professionals to assist them in making their dying shorter.

The right to die in dignity and the right to euthanasia entailed by it are emerging these days as fundamental human rights. The Hungarian Civil Liberties Union (HCLU) has taken the following position on this issue:

- *terminally ill pepole have the right to make a decision about their fate;*
- *when a patient with decision-making capacity requests that his[*] life-sustaining treatment be withdrawn, his request must be honored;*
- *when a patient who is suffering from unbearable pains requests analgesics, his request must be honored even if such drugs may cause his death;*
- *a terminally ill patient has the right to ask for medical assistance to end his life.*

What is euthanasia?

A physician helping his patient who suffers from an incurable (and lethal) disease, to die, (for example, by withdrawing life support measures or by refraining from taking such measures), performs euthanasia, provided that he acts in the best interest of the patient. Euthanasia may be performed at the patient's request (*voluntary euthanasia*) of without the patient's consent if the patient is not in a state to be consulted (*non-voluntary euthanasia*). Experts often distinguish active from passive euthanasia. Such distinction is not based on whether or not the physician brings about euthanasia by action or by omission. In the case of *passive euthanasia*, the physician refrains from giving treatment to his patient (for instance, he does not apply resuscitation) or withdraws a treatment (unplugs the patient from the mechanical respirator), and thereby lets his patient die. In the case of *active euthanasia*, the patient's death is caused by an act of the physician, which would cause the death of a healthy person as well (for instance, administering a lethal injection). A third case is when the physician *assists* a patient in suicide (for instance, by giving the patient the lethal drug).

A most important condition for an act to qualify as euthanasia is that a physician must act *in the best interest of the patient*. Opponents of euthanasia occasionally mention under the heading of euthanasia the eugenics programs applied in Hitler's Germany. The eugenics program, however, was pursued against the interests of those killed, and aimed at eliminating certain categories of people. It is not justified to speak about euthanasia when a patient dies because the health care

[*] For the case of simplicity, *he* and *his,* always include *she* and *her.*

facility concerned did not possess the equipment to prolong his life (for instance, there were two mechanical respirators for three patients).

Do we have the right to refuse life-sustaining treatment?

The right to self-determination in the context of health care means that patients have the right to make decisions on questions related to their treatment: whether or not they make use of health care, which medical interventions they consent and which they refuse.

According to the HCLU's position people have the right to self-determination even in the state of terminal illness. The presumption is that the life of all patients has to be sustained and, that, patients must receive effective treatment. However, the purpose of medicine cannot in all cases consist in postponing death – in other words, in prolonging the dying of patients – at any price. In case a patient does not want to delay his death, it is not necessary to apply all measures. It follows from the recognition of the right to self-determination that even the life-sustaining and life support measures may only be taken with the consent of the patient concerned.
Besides the right to self-determination, freedom of conscience must be taken into account in this respect. Not everybody consider life to be a value in absolute terms. Many people are unwilling to prolong their lives temporarily at the price of suffering and defenselessness. Instead, they would opt for an "easy death" in exchange for reducing the length of their lives. The state must acknowledge that people have different conceptions about the meaning of life.
By accepting the right to refuse life-sustaining treatment, we accept *the right to voluntary passive euthanasia*. According to that right, it is not permitted forcibly to apply the mechanical respirator to a patient who opposes that; it is not permitted to amputate the leg of a patient who opposes that; it is not permitted to apply a treatment that temporarily lengthens a patient's life in case he asks for the withdrawal of such treatment because of his pains.
The HCLU position is that any patient with decision-making capacity may refuse life-sustaining treatment. A patient has decision-making capacity if he

- is capable of understanding information that is necessary for the decision;
- is capable of weighing his options according to his values and objectives;
- is capable of understanding the possible consequences of the decision;
- is capable of informing the persons who give him treatment about his decision.

A patient with decision-making capacity will pass a decision about his treatment on the basis of his own moral values. Decision-making capacity is different from competence in the legal sense. Persons who do not have full competence in the legal sense might still be capable of making informed decisions about their medical treatment. It cannot be ruled out that a person who is slightly disabled mentally or suffers from a psychiatric illness and is incapable of making decisions about his financial situation, can make a valid decision about the withdrawal of his treatment. Furthermore, 16 or 17 years old young people are not fully competent in the legal sense but cannot be excluded from the opportunity of meeting autonomous decision in the state of terminal illness.
It often occurs that a patient does not have decision-making capacity because in the course of his treatment, he has received an overdose of tranquilizers or analgesics. In such cases, health-care providers must aim to restore the patient's decision-making capacity as much as possible.

Ever since the 1970s, an increasing number of court decisions in the United States recognize that the right to self-determination of sane adults includes the right to reject life-sustaining treatment: if a patient requests so, he must be taken from a mechanical respirator, a paralytic person may refuse to receive tube-feeding, and Jehova's Witnesses may reject receiving blood transfusion. According to a precedent-setting decision of the Supreme Court, medical treatment may only be terminated provided the patient's intentions are unequivocal and can be convincingly established. Following the example of the United States, it has become generally accepted in Western Europe that even people who are dying may not be treated without their consent, in other words, that, they too have the right to reject life-sustaining treatment. Acting in the capacity of Supreme Court in the United Kingdom, the House of Lords made a decision in a concrete case that the life-sustaining treatments of a man called Anthony Bland – who had suffered incurable brain damage – may be withdrawn because that is dictated by the patient's best interests. In Ireland, where the influence of the Catholic Church is very strong, the Supreme Court ruled that the interests of a woman who was comatose for over 23 years were served best by withdrawing tube-feeding.

Do we have the right to make an advance directive about the refusal of life-sustaining treatment?

There are several diseases and injuries which result in a loss of consciousness or decision-making capacity. A patient in this state is incapable of making a statement on whether or not he accepts treatment. However, the right to self-determination entails the need in legislation to ensure that citizens should be able to make *advance directives* for such occasions. An advance directive is a written document in which a patient makes a statement in advance about his intentions related to future medical care he is supposed to receive. The advance directive may take any of two possible forms:

- *Advance directive about the forms of treatment:* a person makes a statement on that, should he irreversibly lose decision-making capacity because of a disease or an accident, he refuses receiving life-sustaining treatment; which means then that he should let die. In addition, it is also possible to define in advance those forms of treatment which the patient making the statement would not accept under any conditions (for instance, the application of mechanical respirator, dialysis, or the refusal of resuscitation).
- *Advance directive on a proxy decision-maker*: in such a statement, the patient names a person who makes a decision in his stead in case he loses his decision-making capacity. Rather than making his decision on the basis of what *he* believes is the best choice for the patient, he proxy decision-maker is supposed to rely on what he believes *the patient* would consider as the best choice, taking into consideration the patient's assumed intentions and interests.

Legislation must make it clear that patients have the right to withdraw or amend their advance directives at any time. A proxy decision-maker also has the right to change his opinion as long as such a change does not run contrary to the advance intentions of the patient. The life-sustaining treatment of a patient may only be withdrawn or omitted provided the patient's intentions have been proven unequivocally.

What is to be done when a patient lacking decision-making capacity did not made an advance directive in the past? The HCLU position is that in such cases, decision-making should be vested in the legal representative of the patient (in a parent or a guardian). We regard it indispensable

that, in such cases, the directive given by the proxy decision-maker to withdraw the life-sustaining treatment is approved by a court. Life-sustaining treatment may only be withdrawn provided that such a move conforms to the intentions and best interests of the patient as far as they can be known.

May patients request medical assistance to terminate their lives?

Occasionally, a patient's request that his dying be shortened cannot be met simply by the discontinuation of his treatment. That can occur in the following cases:

- Numerous terminal diseases take a long time before they end the patient's life, while applying life-sustaining treatment is of no help and, therefore, it is not experimented with.
- In other cases, life-sustaining treatment would be possible, but its discontinuation would result in shorter or longer periods of unbearable sufferings. For instance, when a mechanical respirator is switched off, the patient's death by asphyxiation may take hours; and when an operation is refused, the terminal stage of a dying person can be rather lengthy.

It is the conviction of the HCLU that patients have the right to die in dignity also in cases when they cannot achieve that by refusing treatment. In such cases, a physician may assist a patient in ending his life fast and in a painless manner by giving the patient a drug that causes the patient's death. We are in favor of a regulation which allows a physician to give such a drug for the patient along with adequate information. In support of this position, one can appeal to three constitutional rights of the individual:

- *The right to human dignity* requires that the physician gives assistance to his patient to avoid unbearable physical and spiritual sufferings.
- A patient with decision-making capacity exercises his *right to self-determination* when he requests for the assistance of the physician and when, making use of that assistance, he puts an end to his life at his own decision.
- It is a part of the *right to life* to exercise the right to end one's life. A patient must have the freedom to dispose of his own life and it is not permissible to force him to remain alive in case it has become impossible to continue his life in a meaningful manner.

In case a patient – after thoroughly weighing the pros and cons of the case – makes the decision that his final days would not mean a life for him that is worthy of a human person, he is justified in requesting assistance for suicide. *In other words, he has a justified claim for medical assistance to suicide.*

We regard it essential that legislation ensures safeguards against abuses. Only patients who have decision-making capacity should have the right to request assistance for suicide, and such request should be appropriately documented. The physicians have to establish whether or not the patient who applied for assistance for suicide is in possession of the necessary informations, whether or not the request was based on the patient's considered decision, and whether or not the patient appropriately considered the pros and cons of such a decision. The patient must get information about the use of the drug concerned. Another physician, who does not take part in the treatment of the patient, must confirm that the patient's state justifies his receiving a lethal drug, and that the latter must make sure that the assistance to suicide takes place on the basis of the patient's autonomous decision. It goes without saying that physicians also protected by freedom of conscience and, therefore, no physician can be obliged to take part in such an action if that runs contrary to his conviction.

In certain countries of Europe, for instance, in Germany, Switzerland and Sweden, there is no clear distinction between withdrawal of treatment and the handing over of a lethal drug. Even in those countries, it is not allowed for physicians to give lethal injections, but in case a physician writes a prescription about, or hands over a lethal drug, he does not commit a crime.
In the United States a device produced by Dr. Kevorkian injected into the patient's organism a lethal dose of a drug after a button was pressed. In all those cases, the device was activated by the patients themselves. Dr. Kevorkian assisted over a hundred persons to die in that manner. For a long time, no court was available to convict Dr. Kevorkian for such action. However, there was a case when Dr. Kevorkian himself gave a lethal injection to one of his patients. In that case, he committed active euthanasia, for which he was imprisoned. In the State of Oregon, USA, terminally ill patients have the legal right to seek physician-assisted suicide. The law on death in dignity was enacted in Oregon in 1994 but owing to constitutional objections, its application only started two years ago. Those patients above 18 years of age may apply for assistance from a physician to suicide who are assumed to die within six months.

Is a physician who does active euthanasia guilty of a crime?

The HCLU has taken the position that a physician who performs active euthanasia at the request of his terminally ill patient is not guilty of a crime. The majority of the dying are afraid of pains more than death. Most patients need that their sufferings should be alleviated, and it is the duty of the physician to apply such therapy. Patients must receive information about the techniques of pain relief, and narcotics or other means must be used at the request of the patient even if that involves the risk of causing death. In order to alleviate the sufferings of the dying, the destruction of nerve tracks by the application of the injected drugs is acceptable and so is giving addictive narcotic drugs. The HCLU is of the view that if need be, a terminally ill patient may even receive such a dose of narcotics that is likely to shorten the life of the patient by impeding his breathing.
It must be made clear in the penal code that a physician does not commit homicide or any other crime when a patient dies of a large dose of narcotic if:

- the patient suffered from a incurable disease and he experienced unbearable pains;
- a patient who has decision-making capacity, or his proxy decision-maker, has given informed consent to applying high-risk analgesics;
- narcotics given in smaller doses would not have alleviated the sufferings of the patient;
- it was the sole purpose of the physician to alleviate the patient's sufferings.

Provided these conditions are jointly met, no criminal procedure should be initiated against the physician. It is sufficient that the physician makes preliminary consultation with another physician, and afterwards he writes a report about the case. A physician should only be called to account if he violated the above requirements.
The HCLU is of the conviction that there are no grounds for legal action unless the physician acts with the aim to bring about the death of the patient rather than to alleviate pain. In medical practice it is conceivable that a physician brings about the death of a patient with such a method that cannot qualify as pain relief: after examining the state of the patient he concludes that prescribed dose of the narcotic is insufficient to alleviate the growing pains of the patient. Therefore, at the request of the patient, he gives him a greater dose of the narcotic with the aim of

allowing the patient to die within a short time and without pains. Such action is *active euthanasia*, which is usually considered by law as homicide.
The HCLU accepts the view that there should be court procedure covering all cases when a physician brings about the death of his patient deliberately by giving a lethal injection or in some other manner. However, the courts should be given the legal opportunity to *relieve* the physician *from punishment*. This is because the court might find that the physician had to face an insolvable dilemma: he ran out of the means to alleviate the sufferings of his patient but the patient was no more in a state to end his own life and, therefore, he asked for a lethal dose of narcotic. In case the physician refuses to fulfil that request, he robs his patient from the opportunity to die in dignity. Conversely, if he fulfils the request, he takes the life of his patient. When a physician opts for active euthanasia, he has to be prepared to stand for a trial and defend his decision in public. Courts must have the option of not applying punishment.

Active euthanasia gets a milder court sentence in, among other countries, Germany, Poland, Italy, Denmark and Switzerland, where there is a separate legal provision for "killing at the patient's request".
The Netherlands is the only country where active euthanasia is widely exercised and officially accepted. In 1994, a Dutch Supreme Court ruled that when a physician who is confronted by the dilemma of "thou shalt not kill" and "alleviate the patient's pains", at the request of the patient helps a patient to die, he is acting in an emergency and is therefore not punishable. Unwilling to legalize euthanasia, the Dutch parliament regulated the physicians' duties in this regard in a 1993 law on funeral procedure. According to that law, no criminal procedure is initiated against a physician provided he abides by the following rules: (1) Euthanasia shall not place unless it is requested repeatedly by the patient, and there is no doubt that the patient indeed wants to die. (2) The patient shall be fully informed about his disease and the opportunities for further treatment. (3) The patient undergoes unbearable physical and spiritual sufferings and no treatments whatsoever that would be acceptable for him can alleviate his pains. (4) The physician shall make preliminary consultation with another physician.
Experience shows that the majority of Dutch physicians consider euthanasia an accepted part of their profession. According to surveys, active euthanasia is occasionally applied in the absence of the request of the patient. This usually happens when a patient undergoes incurable and unbearable sufferings and he is not in a state to be able to respond to questions. In such cases, the physicians make consultation prior decision with the relatives and other physicians.
The first law on euthanasia was adopted in May 1995 when the Parliament of the Northern Territory of Australia enacted the law on the rights of terminally ill patients. According to that law – provided strict rules are abided by – a physician has the right to prescribe, prepare and hand over as well as inject himself a lethal drug to his patient. Soon after that law was made operative, it was annulled by the Federal Parliament of Australia.

The recognition of the right to die in dignity in Hungary

Before 1998, there was no comprehensive law in Hungary to protect the rights of patients. Provisions covering the welfare of terminally ill patients were also incomplete. As a rule, all forms of euthanasia were generally considered forbidden. The only legal provision that covered this field was as follows: "A physician is obliged to treat with utmost care even that patient

whom he considers incurable." The consent of the patients was only requested before non-life-saving operations, and the question what treatment to apply was always decided by the physician. Depending on the conduct of the physician, euthanasia was considered either as homicide, assistance to suicide or omission of giving help.

It goes without saying that euthanasia occurred in Hungary notwithstanding. Matters related to the welfare of terminally ill patients were decided without consultation with the patients. It was solely within the discretion of the physicians to decide whether or not to omit resuscitation or withdraw a patient from a mechanical respirator, and often physicians injected analgesics in such as dose that hastened death. In that period, the patient was the object rather than the subject of the treatment.

The new Health Act, which came into effect in 1998, broke with that attitude, clarifying the rights patients have in the course of their treatment. The Health Act stipulates that medical treatment is subject to the consent of the patient, and the patient has the right to refuse health care. A patient even has the right to refuse life-sustaining treatment in case he suffers from an incurable disease which – even if he receives appropriate medical treatment – is assumed to cause death within a short period of time. Verbal expression of a refusal of treatment – except some cases - is not valid, though. It is legally required that the patient makes a written statement duly signed. The new Health Act also makes it possible for individuals to make an advance directive about the medical procedure to be followed in case they suffer an accident or develop a serious disease. Such a statement can be made at a notary public.

It is undoubted that the present law foresees a complicated procedure for the exercise of such rights and, that, it fails to ensure the right to use their self-determination for all patients capable of making decisions about themselves. For instance, those patients who suffer from an incurable and painful disease but could be kept alive for some time with aggressive life-prolonging measures do not have the right to refuse life-sustaining treatment. Neither can those patients use their right of self-determination who are not incurable by present-day medicine but whose disease is likely to cause endless and unbearable sufferings. Despite all these shortcomings, Hungary has taken the initial steps towards a regulation that is similar to those of the Western states.

In order to promote and widen the rights of the patients, the HCLU pursues the following objectives:

- to ensure that the patients could exercise their right to refuse medical treatment in abidance by the new Health Act;
- to ensure that the various forms of advance directive become known as widely as possible;
- to ensure that every patient with decision-making capacity can exercise his right of self-determination;
- to create conditions for the humane care of terminally ill persons;
- to promote legislation recognizing the right to die in dignity;
- to promote legislation defining the conditions of physician-assisted suicide;
- to ensure that physicians who carry out active euthanasia at the request of patients should go unpunished in the eye of the law and according to court practice.