

Code of Ethics and Rules of Procedure

Hungarian Hospice Palliative Association

The Community of Hungarian Hospices

The Code of Ethics and Rules of Procedure of the Hungarian Hospice Palliative Association (HHPA)

Introduction

The *purpose* of this Code of Ethics is to define and promulgate the common set of ethical norms and values shared by the member organizations of HHPA. To this end, it comprises the ethical rules pertaining to the provision of holistic hospice care, in full compliance with all relevant laws, statutes and regulations. In line with these, it upholds the principle of providing high-quality hospice care to those in need and their families without any kind of discrimination. The member organizations of HHPA voluntarily accept the values and principles set out in this Code of Ethics, and they commit themselves to following and representing these values and principles in their operations.

This Code of Ethics *comprises* the ethical values and moral norms accepted by the member organizations of HHPA. It sets out the moral and practical considerations which follow from the hospice philosophy, and it also includes a detailed description of ethical duties.

This Code of Ethics *assists* the management and general workforce of its member organizations in reaching ethically sound decisions, and it defines the appropriate conduct in situations where the ethical provision of care is at risk of being compromised.

This Code of Ethics *facilitates* the preservation of a common set of professional and ethical principles of hospice care providers. Thereby, it also facilitates the internal cooperation of hospice care providers, as well the efficient advocacy of the hospice community on the professional, societal and policy-making levels.

This Code of Ethics *defines a standard* of conduct for hospice care workers, thereby reinforcing the trust invested in hospice care providers.

This Code of Ethics serves as the basis for quality control with regard to the member organizations of HHPA.

The Effect of this Code of Ethics

This Code of Ethics has effect over the member organizations of HHPA, their management, their employees, their volunteers, as well over all such providers of care, which, in their name and their activities, profess and declare an adherence to the philosophy of hospice. (In addition to this Code of Conduct, these persons and legal entities are also subject to all the relevant laws, statutes and regulations, as well as, if applicable, to the Codes of Conducts relevant to their professional subfield.)

The Validity of this Code of Ethics

This Code of Ethics is valid from its passing by the General Assembly of HHPA until its revocation by the same body.

The Legal and Ethical Background of the Formulation of this Code of Ethics

This Code of Ethics complies with the spirit of laws, statutes and regulations of Hungary. The stipulations of this Code of Ethics are compliant with the laws and regulations pertaining to hospice

care, and they provide a solid basis for the compliance of the member organizations with the spirit of hospice care. (Appendix 1: Legal references, Professional Guidelines, Professional Minimum Conditions, The Code of Ethics of the Hungarian Medical Chamber, The Code of Ethics of the Hungarian Chamber of Health Professionals)

Shared responsibilities

HHPA declares that all persons and legal entities involved in hospice care are bound by the ethical norms set forth in the Codes of Ethics of the following organizations: HHPA, the Hungarian Medical Chamber, the Hungarian Chamber of Health Professionals and all other relevant professional organizations. (Appendix 1: The Code of Ethics of the Hungarian Medical Chamber, The Code of Ethics of the Hungarian Chamber of Health Professionals)

In order to ensure the acceptance of and adherence to the ethical norms, one has to build an appropriate relationship with:

1. patients, relatives of patients, member organizations and supporters,
2. funding, regulatory, supervisory and controlling agencies,
3. suppliers and contractors,
4. organizations and communities which cooperate with HHPA and its member organizations, or otherwise support their activities.

The Values Promulgated in this Code of Ethics

The principle of bioethics and hospice care

During the provision of hospice care to patients, the following bioethical principles must be upheld: autonomy, beneficence, nonmaleficence and justice, as well as the patient rights set forth in the Law on Health (1997, CLIV). (Appendix 1: Legal references)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (Appendix 2: Palliative care WHO 2002)

Hospice providers, both individually and as a community, follow and embody the principles of palliative care. In their work, appearance, behaviour, public pronouncements and publications, they protect and strengthen the professional and societal prestige of hospice care in Hungary, as well as the trust of patients and supporters.

Ethical provisions pertaining the operation of member organizations of HHPA

1. Personal duties pertaining to employees

Employees of member organizations of HHPA are responsible for following and abiding by the ethical rules of conduct in the course of providing hospice care to patients.

All employees are duty bound to report to the Ethics Committee all observed incidents of unethical, illegal, unprofessional, harmful, unscientific, corrupt or otherwise problematic behaviour.

2. Data protection regulations

The member organizations, in their capacity of data managers and data providers, must handle and store all the personal data of their patients, relatives of patients, employees, volunteers, clients and partners in strict compliance with GDPR (general data protection) regulations both from a data protection and an information technology perspective. (Appendix 1: Legal references)

3. The acceptance and rejection of donations and gifts

The acceptance of any irregular or informal payments is antithetical to the spirit of hospice care.

Member organizations of HHPA, as organizations, may accept donations: both monetary and non-monetary. Any such grants or donations must be fully voluntary and unconnected to the provision of care. Grants or donations offered by a patient or a relative of a patient must not in any way be reciprocated by offering advantages or special treatment with regard to the patient concerned. (Appendix 1: Legal references)

4. The safeguarding of copyright and intellectual property

Member organizations of HHPA must fully respect copyright and intellectual property. For educational, training and research purposes, the materials of presentations, published articles and books may only be used in adherence to the rules of scientific citation. (Appendix 1: Legal references)

5. The ethics of supplier relations

The board and the membership of HHPA commit themselves to the principle of fair competition. Any tenders, procurement processes, and potential supplier contracts are managed following this principle.

6. Sales activities and fundraising

Member organizations involved in fundraising must comply with all laws, statutes and regulations pertaining to sales activities and fundraising. (Appendix 1: Legal references)

In the course of their information campaigns, sales activities and advertising, member organizations of HHPA represent the whole community of hospice providers in Hungary, and they are bound to protect the shared values of values and interests of this community in all their public appearances. They must provide full and transparent information, in keeping with the spirit of hospice care, to patients, to their relatives, to the general population and to professional forums.

In the course of their fundraising activities, member organizations of HHPA follow the principles of authenticity, legality, transparency and openness. They emphasise the values of the philosophy of hospice and of the hospice community, both when organizing events which emphasize social responsibility and solidarity within the context of hospice care, and also when recruiting employees and volunteers.

In the case of fundraising, the concrete use of the funds collected must be defined and made public. Likewise, the sum of the collected donations must also be made public.

Trust in **hospice care** is a fundamental and common value. It is the defining factor of the general acceptance and societal role of hospice care, and it is also a key determinant of the success of fundraising and the recruitment of volunteers. All member organizations of HHPA enjoy this trust together, and they also commit themselves to actively seeking to preserve and deepen this trust in all their public activities.

Any pronouncements by member organizations, whether oral, print or electronic, must always convey truthful, complete and non-manipulative information; and they must never be aimed at be financially or morally detrimental to any other member organization. (Appendix 1: Legal references)

7. The ethics of invoicing

Member organizations of HHPA are committed to the ethical and honest practice of invoicing, based on full compliance with accounting regulations. (Appendix 1: Legal references)

8. The ethics of care provision

Member organizations of HHPA commit themselves to cooperation with regard to the acceptance and referral of patients. The acceptance, placement and referral of patients is carried out based solely on clinical need and on the actual capacities of HHPA member organizations. Member organizations must not solicit nor accept any quid pro quo arrangements.

Rules of Ethics Procedure

The Ethics Committee is fully independent from the member organizations of HHPA. In questions falling within its scope, it reaches its conclusion independently from the Board of HHPA and from its Scientific Advisory Board.

Initiation of an ethics procedure: an ethics procedure may be launched ex officio, or upon notification, or upon the basis of a request to investigate.

An ethics complaint may be launched by any affected person or legal entity.

Limitation period: any ethics notification must be lodged no later than within 3 months of gaining knowledge of the potential ethics breach.

How to lodge an ethics notification: Ethics notifications or requests to investigate must be sent in written format (print or electronic) directly to the Ethics Committee or to HHPA (in which case, the notification will be forwarded to the Ethics Committee). Alternatively, a request to investigate may be voiced during the general assembly of HHPA: such requests must be entered into the general assembly minutes and forwarded to the Ethics Committee.

Mandatory contents of an ethics notification:

1. Basic information on the person lodging the identification (for purposes of identification and access).
2. A detailed description of the event concerned, including the identification of the ethical principle that has potentially been breached.
3. A clear identification of the participants (persons or legal entities) involved in the case.
4. The date and place of the event concerned.
5. Information on whether any steps have already been taken in connection with the event or in order to remedy the event concerned.

The course of an ethics procedure: the Ethics Committee initiates the investigation of the notification no later than 15 days from the lodging of the notification, and concludes the ethics procedure no later than 60 days from the start of the investigation.

The Ethics Committee sends an official notification to all parties concerned, as well as the Board of HHPA, informing them that an ethics procedure has been launched.

The following forms of evidence are admissible in the procedure: oral testimony, written documents, photographs and audio recordings.

The course of procedure: the course of the procedure must be recorded in the minutes of the Ethics Committee. This includes: informing the parties concerned of the relevant data protection regulations, the hearing of the complainant, the reaction of the person/entity against whom the complaint has been lodged, the introduction of evidence, the questions of the commission into the circumstances of the case and the answers provided, the attendance sheet related to the case and the written or audio recordings of statements. The Ethics Committee takes its decision on the basis of the available information, data, known facts and the hearing of the parties, independently, appraised in a discretionary manner, in a closed session. In reaching its decision, the committee takes into account the relevant legal, professional and ethical regulations, mitigating and aggravating factors, the degree of wilfulness or negligence, and the magnitude of the material or moral damage caused.

The Ethics Committee issues its conclusions in one of the following formats: a decision, a note or a memorandum.

The decision of the Ethics Committee may be of the following nature: a decision of condemnation, a decision of termination of the process, and a decision of material rejection of the complaint.

The decision of the Ethics Committee

In its decisions, the Ethics Committee may issue the following sanctions:

1. a caution,
2. a reprimand,
3. the suspension for two years of the membership of HHPA,
4. in the case of an egregious ethical breach: the expulsion from HHPA,
5. in case of a serious ethical breach, especially in case of suspected illegal activity, the Ethics Committee takes the necessary steps of notifying the relevant authorities (either by notifying the regulatory authority or by lodging a criminal complaint)

The conclusion of the ethics procedure

The Ethics Committee sends an official notification about the conclusion of the procedure, which includes the original complaint, the main documents of the process, a description of the events and measures taken, and the reasoning behind the decision reached. The decision of the Ethics Committee cannot be appealed. The Ethics Committee must ex officio send a notification about the conclusion to the following: the parties of the procedure (the complainant and the person/entity against whom the complaint has been lodged) and the Board of HHPA.

Voluntary publication

A properly authorized member of the Ethics Committee must give a detailed summary to the annual General Assembly of HHPA of all ethics procedures in progress or concluded in the past year.

Resolutions of the Ethics Committee

In order to prevent or address ethical issues which are frequently arising or otherwise topical and affect hospice care and its participants in a general manner, the Ethics Committee may, on its own initiative or upon request by the Board of HHPA, issue resolutions on rules of procedure to follow

and/or on expected or desirable behaviour. These resolutions are to be published on the website of HHPA and/or in a circular.

Date of Effect:

This Code of Ethics and Rules of Procedure takes effect on the day of its acceptance by the General Assembly of the Hungarian Hospice Palliative Association.

Budapest, April 12th, 2019

Appendix 1

Legal references and other references

Appendix 2

Palliative care (WHO 2002)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.