Standards of mobile specialized palliative care in the Czech Republic

This material was drawn up in September 2007 using international as well as Czech standards of mobile specialized palliative care (MSPC) and other literature (see Bibliography) and incorporated into it were the comments from all currently working mobile hospice teams in the Czech Republic, which are associated in the Association of Hospice and Palliative Care Providers (Asociace poskytovatelů hospicové paliativní péče), and of MUDr. Ondřej Sláma. This text is still open to comments and discussion – any feedback will be very welcomed.

Contents
- Palliative care
- Target group of palliative care
- Mobile palliative care
- Structure and procedures
- Physical aspects of palliative care
- Social aspects of palliative care
- Spiritual and existential aspects of palliative care
- Cultural aspects of palliative care
- Ethical and legal aspects of palliative care
- Specific aspects of taking care of a patient who is dying
- Requirements
- Volunteers
- Facilities for mobile palliative care
- Documentation
- Other possible activities related to palliative care
- Dictionary of definitions
- Bibliography

Palliative Care

Palliative care means complex, active and quality-of-life-oriented care provided to patients who are suffering from an incurable illness in its advanced or terminal stage. The aim of palliative care is to relieve pain and other physical and psychological suffering, to preserve the patient’s dignity and to provide support to the kith and kin.

Principles of palliative care

- palliative care views dying as part of the human life and is based on the premise that each human being experiences this final stage of their life individually with all its physical, psychological, social, spiritual and cultural aspects
- p. c. closely follows the requests and needs of the patients and their families and respects the values they believe in
- p. c. is based on interdisciplinary cooperation and integrates medical, psychological, social and spiritual aspects
- p. c. strives hard not to uproot the patient from his or her natural social connections; on the contrary it aims at enabling the patients to experience the last stages of their life in the company of their kith and kin in a loving and warm environment
- p. c. offers universal and effective support to the relatives and friends of the patient and helps them cope with their grief even after the patient has passed away
p. c. is based on the assumption that there indeed is a vast difference between bad and
good care of a dying patient and, therefore, it calls for constant monitoring of the quality
of care and it upholds the right of the patient to receive such care

According to the level of the complexity of care necessary for maintaining a good quality of life,
we must differentiate between general and specialized palliative care.

**General palliative care**

General palliative care is taken to mean good clinical practice provided to a patient in an
advanced stage of their illness by medical specialists within the scope of their respective
specialization. The cornerstone of such care is the ability to recognize and influence what is
important for the quality of the patient's life (e.g. treating the symptoms, respecting the
autonomy of the patient, sensitivity and empathic communication with the patient and their
family, helping ensure care and service of other specialists, providing nursing care at home etc.).
All medical personnel should be able to provide such care with view of the specifics of their
respective specialization.

**Specialized palliative care**

Specialized palliative care is active interdisciplinary care provided to patients and their families
by a team of specialists who have been specially trained to provide palliative care and are,
therefore, equipped with the necessary skills and experience. Providing specialized palliative
care is then the main job description of any such team.

**Basic forms of specialized palliative care**

- mobile palliative care facilities
- independent ward facility that provides specialized palliative care
- departments of palliative care that are part of other facilities (i.e. especially hospitals
and asylums)
- consultant palliative care team that operates within hospitals or asylums
- specialized out-patient clinic of palliative care
- day-centers that provide palliative care
- separate facility of specialized palliative care (e.g. consultation service and help lines,
facilities dedicated to specific diagnostic groups etc.)

**Target group of palliative care**

The target group of palliative care comprises patients in the advanced and terminal stages of
incurable diseases.

Diseases and conditions which in their terminal stages require palliative care are the following:

- oncologic diseases
- neurodegenerative diseases such as disseminative sclerosis, Parkinson’s disease,
dementia
- terminal stages of chronic organ diseases: chronic heart, kidney and liver failure
- COPD
- AIDS
- geriatric polymorbid patients
- patients in persistent vegetative state
- certain inborn pediatric syndromes and diseases (e.g. cystic fibrosis)
- critically ill patients with irreversible multi-organ failure in intensive care facilities

According to the degree of changes of cognitive functions and perception, patients that require palliative care can be divided into two groups:

- patients who realize and are aware of the presence of a life-threatening disease and the way in which they mentally process this situation is a very important issue in palliative care
  - they significantly participate in creating the treatment plan, their requests and wishes are the basic framework for providing palliative care
  - When commencing palliative care, the attending physician must find out to what extend the patient understands his or her situation and to what extend s/he is willing to influence the decisions related to the treatment

- the other group comprises patients who have undergone significant changes of cognitive functions and perception
  - such patients have very limited perception and understanding of their situation and they do not participate in the decision-making regarding their treatment plan
  - decisions regarding treatment are taken by the attending physician or the patient’s relatives and they do so in the best interest of the patient
  - the cornerstone of palliative care with patients who belong into this group lies in good nursing care and providing psycho-social support to the kith and kin.

From the perspective of the prognosis of survival and the related possible goals of treatment, the patients of palliative care can be classified into one of the following stages:

1. Compensated disease stage (prognosis of survival in the matter of months, sometimes even years) – the goal of medical treatment is to sustain, for as long as possible, the compensation state, and to preserve the highest possible level of functional ability and the longest possible life expectancy
2. Irreversibly progressing disease stage (prognosis of survival in the matter of weeks and months) – the goal of treatment often shifts towards sustaining the highest possible quality of life.
3. Terminal stage (prognosis of survival in the matter of several weeks, days or hours) – the goal of treatment is to preserve the patient’s dignity in dying. That involves decreasing discomfort, not extending the duration of the process of dying, maximum respect to the uniqueness of each human life.

Mobile palliative care becomes part of the treatment most often in the terminal stage, or in the “irreversibly progressing disease” stage.

**Basic principles of mobile palliative care**

- the patient and their family (or closest friends) are the joint receivers of care and take an important part in creating the treatment plan
- the team that provides palliative care is by its very nature multidisciplinary – it consists of doctors, nurses, a social worker, a psychologist, a coordinator of volunteers, a consultant, personal assistants, orderlies, priests, volunteers and other necessary personnel
- mobile palliative care is complex – it looks after the physical, mental, social and spiritual well-being of the patient as well as of his or her family or friends
professional pain relief and treating other specific symptoms related to dying form an integral part of palliative care and the palliative team has at its disposal experienced professionals who have been trained accordingly

- the palliative team provides care to the family of the patient - at least for the period of one year after the patient has passed away it offers professional help in the period of mourning
- the palliative care team cooperates with general practitioners and attending physicians, agencies that provide nursing at the patient’s home, and other providers of medical and social care
- the team includes volunteers who have been properly trained and who are under the management of experienced professionals

Criteria for admitting a patient into mobile palliative care:

on the part of the patient:

- the patient is suffering from an incurable disease in its advanced or terminal stage
- the patient has been acquainted with his or her medical condition and, with view of his or her mental capabilities, s/he has understood the seriousness and prognosis of his or her disease
- the patient understands the potential and limitations of mobile palliative care and s/he is in agreement with its principles
- the patient wishes to receive care at home
- no reasons (medical, social, or other) have been ascertained that would preclude the patient from the possibility of receiving care at home

on the part of the family and friends of the patient:

- the family have been informed of the medical state of the patient (provided s/he gave permission) and, taking into account their possibilities, they have understood the seriousness and prognosis of the disease
- the family understand the potential and limitations of mobile palliative care and are in agreement with its principles
- the family are willing to take part in the care and at least one family member (or friend) is ready and able to assume the responsibility for providing the patient with continual care

Mobile palliative care – structure and procedures

The mobile palliative care plan is based on:

- the overall interdisciplinary assessment of the patient’s state and capabilities
- the preferences of the patient and his or her family
- the needs of the patient and his or her family
- the support of the patient and his or her family

The introductory assessment, as well as all other following assessments, is carried out on the basis of interviews with the patient and their family, on the basis of medical reports, consultations with other medical specialists and medical and laboratory tests. The assessment includes documentation regarding the state of the illness (including the diagnosis and prognosis of probable future development), regarding the accompanying physical and mental disorders and
symptoms as well as the state of bodily functions and social, spiritual and cultural aspects, including the preferences regarding the treatment plan, and conditions necessary for admitting the patient into mobile palliative care.

As part of the assessment process, the expectations of the patient and their family as regards the aims of the care, the extent to which they managed to understand the disease and its prognosis, the type of care and the place where it is to be provided must be ascertained and documented.

The process of admitting the patient to mobile palliative care is governed by the following scheme:

- introductory interview (either in person or on the phone) that mainly focuses on understanding and clarifying the situation of the patient and their family, and on their needs and preferences as regards the care
- intelligible formulation of the potential and limitations of mobile palliative care
- first meeting between the patient and the doctor and the nurse at the patient’s place
- establishing connection between the palliative care team and the attending physician
- gathering further information regarding the medical and social state of the patient and their family
- admitting the patient into palliative care; drawing up and concluding the contract
- designing the plan of palliative care
- lending the necessary equipment or providing help with obtaining it
- instructing the family in how to look after the patient and how to use the equipment and tools
- mediating contact with out-patient nursing or day care centers, and, if need be, other institutions that provide care; including assistance in coordinating their services

When assessing children or persons with impaired cognitive abilities, it is necessary to take into account their age, the stage of their development and their mental capabilities.

The course of the care

The patient and their family can contact the specialized personnel 24 hours a day, 7 days a week. The assessment of the state, capabilities and preferences of the patient and their family must be updated and documented on a regular basis. At times when important decisions need to be made, proper view must be taken of the benefits and strains of the individual kinds of care.

The members of the mobile palliative care team communicate with other care-providing institutions according to the needs of the patient and their family. Providers of care that are not institutions (i.e. the family etc.) have at their disposal relieving services provided by volunteers who cooperate with the mobile palliative care team.

If the patient is transferred to a bed-ward in an institution that provides palliative care or to another facility, the palliative care team will pass on all experience and information to the team who will be providing subsequent care. At the same time the palliative care team will ensure the continuity of care between the individual facilities and in indicated cases it will provide information to general practitioners and other providers of medical care regarding the accessibility and benefits of mobile palliative care.

Mobile palliative care is terminated if:

- the patient has died
- the patient no longer meets the criteria for being admitted to palliative care because:
  - their medical condition has stabilized or improved, or
the family are no longer able to ensure continual care
- the patient has been transported to a bed-ward where he will be taken care of until s/he passes away
- the family of the patient disagree with the procedures of mobile palliative care and they have suggested a different approach to care

Retrospective interdisciplinary evaluation of the care provided forms a part of the process of terminating mobile palliative care and the results of this evaluation are used to improve the quality of care provided by the team.

Physical aspects of care

Continuous evaluation and pain relief, as well as treating other physical strains, in accordance with the state of development of medical science form the basis of palliative care. The aim is to eliminate pain and other serious symptoms securely and in a timely manner, or to alleviate them to a level that is bearable for the patient throughout the whole period care is provided. In the case of children and patients with impaired cognitive faculties, symptoms are evaluated in an adequate manner.

The most common symptoms and syndromes of diseases in their advanced stage:

- pain
- respiratory symptoms, e.g. asthma, cough, haemoptysis and other
- gastrointestinal symptoms, e.g. nausea, vomiting, diarrhea, constipation, intestinal obstruction and other
- neuro-psychiatric syndromes, anxiety, depression, confused state

From the point of view of nursing care, palliative care focuses mainly on the following areas:

- skin care
- bed-sore prevention and positioning
- nutritional care and consultation in matters of food intake
- care in matters of defecation
- care in matters of fluid intake
- mouth cavity care
- respiratory paths care, especially in cases of respiratory diseases

It is necessary to properly assess the extend to which the patient and their family understand the illness, the limitations it causes, the therapy that best suits the needs of the patient and the possible side-effects of such therapy. If it is necessary, the care of specialist physicians may be recommended to the patient (e.g. radiotherapist, invasive algeziologist, orthopedic specialist, physiotherapist, pediatrician etc.). The family is given proper education and support in providing safe and easing care to the patient. When planning and providing mobile palliative care, certain complications can be predicted, expected and regularly evaluated as to whether they have already begun to appear. The family is also given practical guidelines that have been designed to help them cope with crisis situations.

Psychological aspects of palliative care

The presence of the advanced stages of an illness represents great psychical load on the patients and their families. The patient’s mental state is regularly evaluated – mainly mental reactions
(stress, anxiety about the future, coping with the situation), psychical phenomena (severe depression, suicidal tendencies, states of delirium). The patient’s family, at the same time, is evaluated as regards their main needs (in accordance with Kübler-Rossová), their ability to provide appropriate care and to cope with the new difficult situation. Special attention is given to the communication between the client and their family.

Pediatric patients, their siblings and the children or grandchildren of the patient are provided care adequate to their stage of development.

Psychological care is provided to the family, provided they agree to it, for a period of at least 12 months within the time when the patient passed away, and, if need be, even longer. Support and help in the time of mourning are provided with view of the cultural and spiritual needs, expectations and preferences of the family and its individual members.

Services provided within this area are considered one of the key elements of palliative care programs.

The members of the palliative care team are specialists who possess the necessary knowledge and skills in the area of preventing, diagnosing and treating the psychological effects and psychiatric complications of serious illnesses that may appear in the patients, as well as in the members of their family.

**Social aspects of palliative care**

Specialized palliative care strives to respect the essential social context of the patient’s life. Included in the care is an evaluation of social questions that includes:

- family relations
- social and cultural ties of the patient
- the patient’s communication habits and preferences
- financial and living conditions
- accessibility of other providers of care
- transport possibilities to other facilities
- accessibility of necessary equipment
- legal conditions

Within the framework of palliative care, the patient and their family meet with the members of the interdisciplinary team on a regular basis. The aim of these meetings is to improve mutual understanding, to provide intelligible information and make important decisions, to discuss the aims of the care, to find out about the wishes, preferences, hopes and fears of the patient and their family, and last but not least, to provide them with emotional and social support and improve mutual communication.

The proposed steps in terms of social care are designed to minimize the negative effects of the care-providing process on the family and other non-institutional caregivers.

Ensuring effective respite care forms a significant part of palliative care, and it usually takes the form of admitting the patient to a bed-ward palliative care facility for a short period of time.

The complex care helps the patient and their family to deal with practical social problems that arise in connection with a serious disease (e.g. by means of providing counseling regarding the possibilities of financial support from the state, pension schemes, expert opinions, notarial services).

**Spiritual and existential aspects of palliative care**

Specialized palliative care strives to respect the patient’s opinions, values and religion. Help and care are provided in a way that is appropriate to the patient’s individual, family, cultural and religious values.
Within the framework of palliative care, spiritual and existential views of the patient and their family are carefully ascertained (including their views regarding issues life and death, hopes and fears, decisive attitudes and convictions, feelings of guilt, belief in afterlife, belief in forgiveness and questions related to the end of life), with the aim to identify the spiritual and existential background and related rituals and practices of the patient and their family.

Based on the wishes of the patient or their family, contact can be mediated with the ministers of their religion or with the religious communities. The palliative care team respects and helps perform religious and spiritual rituals observed when a person dies, based on the request of the patient and their family.

**Cultural aspects of palliative care**

The palliative care team ascertains and documents:

- the cultural background of the patient and their family
- the requests and needs of the patient and their family
- cultural traditions
- specifics regarding the communication of information and decision-making.

The program of palliative care is designed to respect a wide variety of cultural, language, nutritional and ritual practices of the patient and their family.

**Ethical and legal aspects of palliative care**

The wishes expressed by the patient or their attorney form, along with the opinions of the family and the multidisciplinary team, the basis for the palliative care treatment plan. Patients whose ability to make decisions has not been impaired can themselves set the extent to which their family are to be included in the treatment plan, and any such decisions are to be respected. The opinions and preferences mainly of older children regarding medical treatment, including whether or not they agree with the treatment, are to be documented and taken into consideration when making decisions about future steps. If the wishes of the child are different from those of their legal guardian, the child has at their disposal suitable specialists. The palliative care team supports long-term planning which makes it easier for the patient (or their legal guardian) to understand and agree on the preferences regarding the services provided throughout the period of care, including its final stage. If the patient is no longer able to communicate, the palliative care program tries to identify the wishes, values and preferences the patient has expressed in the past. The team must be able, in cases where it is necessary, to justify satisfying the previously expressed wishes of the patient or their legal guardian. Support in the area of legal and ethical issues is provided to legal guardians in the decision-making process. Ethical issues that often recur within the framework of palliative care are determined and dealt with in a timely manner so that serious ethical dilemmas can be prevented from arising, or if indeed they do arise, they could be dealt with accordingly. These dilemmas include the issue of the benefit of the individual kinds of care, respecting an individual’s personality and their right to self-assertion, or related legal measures that regard providing truthful information to the patient and their family; the issue of assessing the capabilities, consent and permission in the case of minors and the issue of informed consent; the issue of just distribution of care and of conflict of interests. Care is provided in accordance with professional ethical codices.
The standards and codices of the ethical practice of palliative care have been designed on the basis of the standing professional ethical codices of all related disciplines. The palliative care team tries mainly to prevent certain very serious and complicated ethical dilemmas from arising, tries to identify these dilemmas and to deal with them. That includes mainly ethical dilemmas related to specific procedures, such as refusal or termination of care (including food and liquid administration), fulfilling the orders and requests of the patient as regards prospective resuscitation and the use of sedatives in palliative care. Ethical issues are documented and if necessary discussed with advisors or respective ethical commissions. Persons who provide palliative care are introduced to legal regulations in force that regard medical decision-making, long-term planning of care, the roles and responsibilities of legal guardians; to regulations regarding opiates and other registered substances, certifying death, requirements on the autopsy, on organ donating and on keeping medical records, including personal data protection and medical confidence. The patients and their families are recommended to use the services of the appropriate specialists when modifying the last will and testament, and when dealing with legal guardianship and inheritance.

Specific aspects of taking care of a patient who is dying

The patient and the members of their family should be given instruction regarding the signs and symptoms of coming death in a way that reflects the possibilities of their understanding, age and cultural background. The fears, hopes and expectations of the patient and their family as regards the end of life are openly and honestly discussed and dealt with with view of the social and cultural background of the patient. Symptoms related to the end of life are monitored and documented on a regular basis and, according to the preferences of the family, they are treated. The plan of treatment must be regularly and flexibly updated, so that it would reflect the changing needs of the patient and their family. If, during the terminal stage, the need arises for intensive palliative care, the care provided is immediately adjusted to this need. It is necessary, in cooperation with the patient and their family, to design a plan for coping with crisis situations that can possibly arise. It is useful and acceptable to design a plan of procedure in the case of the patient dying, and also to settle the issue of possible autopsy.

Requirements on the individual members of the mobile palliative care team

The qualification of physicians in mobile palliative care

The physicians who operate as part of the mobile palliative team meet the requirements for obtaining and recognizing professional and specialized qualification for performing the medical profession prescribed under Act no. 95/2004 Coll.

The head physician of the mobile palliative care team should be qualified in the area of palliative medicine and pain treatment, and the other physicians should, in the best case scenario, be qualified in general practice for adults, internal medicine, geriatrics, neurology, clinical oncology, rehabilitation and physical medicine, anesthesiology and resuscitation.

The qualification of nurses in mobile palliative care

The nurses who work as part of the mobile palliative care team meet the requirements regarding the qualification to perform the job of a general nurse prescribed under Act no. 96/2004 Coll.
Head nurses should be specially qualified to perform specialized tasks under government administrative order no. 463/2004 Coll.

The qualifications of the social worker, psychologist, medical assistant are also governed by Act on Performing Non-medical Health Care Professions no. 96/2004 Coll.

**Personality requirements on the members of the mobile palliative care team**

- ability to cope with dying, death and grief
- ability to flexibly and calmly react in unexpected situations
- psychical stability even in crisis situations
- ability to look after own spiritual hygiene and to avoid the burnout syndrome
- dispositions for team work (including tolerance and the ability to deal with criticism and conflict)
- ability to cooperate with other members of the interdisciplinary team, including the volunteers
- ability to communicate with the patient or their family in person or over the phone
- ability to involve family members in the care
- ability to be of sensitive support in mourning and grief

**Requirements on the members of the palliative care team in terms of organization**

**Internal team coordination**

- interdisciplinary cooperation, taking part in creating and maintaining communication procedure within the team
- regular exchange of information with other members of the team and with team management
- orientation in the organizational structure of mobile palliative care, proactive cooperation on developing it
- regular attendance at supervision sessions

**Administration**

- proper keeping of medical records with view of data protection
- help in gathering data and compiling comprehensive statistics

**Public relations**

- cooperation on designing educational and media materials for the public
- cooperation with the management on communication with the public (e.g. with the media)
- help in organizing and carrying out informative events, charity events etc.

**Requirements on the members of the palliative care team in the area of education and improving the quality of care**

- regular further education and increasing specialized knowledge (reading specialized literature, participation in courses and training seminars etc.)
- ability to apply obtained knowledge and to pass on such knowledge
• participation in regular quality of care evaluation and the ability to apply the results in clinical practice

Volunteers

Volunteers form an integral part of the multidisciplinary palliative care team. Involving volunteers is necessary not only for economic reasons, but mainly because it enriches palliative care for the spirit of mutuality, without which this form of care loses one of its most important dimensions. The selection of volunteers, their specialized training, supervision and involving them in the process of palliative care is managed by the volunteer coordinator. Volunteers are people who decided to devote part of their free time to helping, to the best of their ability, in the area of palliative care.

Personality characteristic of the volunteer

• suitable motivation
• ability to cope with disease, dying and death
• empathy
• good communication skills
• tolerance towards age, cultural, religious and personality differences
• ability to define and respect limits of responsibility for individual areas
• ability to work as a part of a team
• ability to take care of oneself
• psychological stability and flexibility in crisis situations
• ability to increase the level of knowledge and to improve

Job description of volunteers in mobile palliative care

• support and help in the families of clients
• support in mourning for the survivors
• support on the phone
• getting involved in all areas of mobile palliative care
• transporting equipment to the families, if necessary assembling the equipment and instructing the family on how to use the equipment
• administrative and editorial work
• other activities (promotion, help in organizing cultural, educational and charity events: concerts, exhibitions, public collections etc.)

Facilities of mobile palliative care

The environment of mobile palliative care and its equipment is appropriate to the size of the facility (i.e. number of employees, number of patients).

The facility and its basic equipment enables

establishing the first (and all subsequent) contacts with the patients, their families and the survivors in an accessible, loving and secure environment

• phone consultations
• team meetings
keeping records in accordance with appropriate legislation
• storing drugs and other medical equipment
• storing opiates and other registered drugs in accordance with legislation
• do administrative work, take care of mail

Mobile palliative care includes an equipment storage room

• hygienic storing of tools and equipment
• lending and giving back the equipment
• cleaning and disinfecting the equipment

The type and number of tools and pieces of equipment in mobile palliative care depends directly on the number of patients and their diagnoses. Tools and equipment are inventoried on a regular basis, and they are maintained by authorized servicing companies according to the specifications of the manufacturer.

• positional bed
• active and passive anti-decubitus mattress
• linear drug dispenser
• pulse oxymeter
• mobile EKG
• inflatable bath tub
• lifter
• anti-decubitus tools
• toilet chair, wheelchair, walker
• trolley for the shower, bath tub chair
• signaling device and other tools

Documentation

Part of medical reports is the treatment plan in the area of health, nursing, psychological, social and spiritual care. The documentation is continuously updated and at the time when the care is terminated it contains a written interdisciplinary evaluation of the provided care, the results of which are use to improve the quality of care.

The medical records for the purposes of palliative care are kept in two copies – one at the family and one at the office.

What is rather specific about medical documentation is the fact that it captures social ties of the patient and that it contains information regarding how the patient (and the family) coped with the disease and with impeding death. Included in the documentation is written informed consent of the patient with the proposed treatment plan.

The access of the patient and other persons to the documentation, and other aspects of keeping and storing the records are governed by the legislation in force.

Activities that can complement the services of mobile palliative care

• palliative day care clinic
• counseling in the area of the field of operation of mobile palliative care
• social clubs (for families who are taking care of a terminal patient, or for those who have lost a member of family)
- cultural events and lectures for those who lost a relative, for volunteers and for the general public
  - educational activities for staff and volunteers
  - educational activities for specialists (lectures, internships)
  - a library of specialized, general and consoling literature
  - charity events and collections (concerts, exhibitions, tea house, etc.)

### Dictionary of definitions

<table>
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<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Accompanying</strong></td>
<td>is an important part of mobile palliative care in which the team members (usually in cooperation with trained specialist) provide support to the families of deceased patients in the time of their mourning, usually for the period of one year. It is considered and indispensable part of palliative care.</td>
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<tr>
<td><strong>Burnout syndrome</strong></td>
<td>is a set of symptoms that appear with caregivers and that are caused by long-term non-compensated pressure that taking intensive care of other people may bring. It is a state of mental, or sometimes overall, exhaustion that is accompanied by feelings of hopelessness, anxiety, by a decrease in self-confidence, or even feelings of anger – in worst cases it may lead to depression. To prevent this syndrome from developing it is necessary to maintain an optimal level of work load, to balance work and personal life, to take care of spiritual hygiene and to provide appropriate spiritual support and supervision.</td>
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<td><strong>Day care centers</strong></td>
<td>usually operate alongside specialized bed-ward departments of palliative care, mobile palliative care departments or as independent facilities. The patients can visit the clinic once or more times a week. The services these clinics provide can be described as medical (blood transfusions, pain relief and treatment of symptoms etc.), social (shower, bath), rehabilitative (physiotherapy, ergotherapy), relaxation (massages) or hobby (arts and crafts). Another aim of day care is to provide the person who is responsible for nursing care with some time to relax.</td>
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<td><strong>Department of palliative care</strong></td>
<td>is a department that provides specialized palliative care within other bed-ward facilities (i.e. mainly hospitals and clinics). It treats patients who require complex palliative care as well as other medical services they can obtain only in hospital (or clinic etc.). Departments of palliative care strive to carry out the ideal of hospice care within the possibilities of the particular medical facility. Such departments often serve as a bed-ward base for the palliative care consultant team. Departments of palliative care in teaching hospitals also play an important role in education and research.</td>
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<tr>
<td><strong>Family</strong></td>
<td>For the purposes of palliative care, family is taken to mean all the non-professional caregivers who participate in the care on the basis of previously existing emotional ties. In terms of palliative care, it is often said that it is received by the whole family. Even though this is not to be taken literally (as it is the patient who is at the center of attention of palliative care and who is the main recipient of this care), it gives expression to the specific role and importance of the family. If the family is to play its unique role of a specific palliative caregiver, it must be given complex support, and in this sense it becomes a co-recipient of palliative care.</td>
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<td><strong>General palliative care</strong></td>
<td>is good clinical practice carried out in the advanced stages of an illness that is provided by medical personnel within the scope of the respective specializations. The basis of such care is monitoring, discovering and influencing whatever aspect of the patient’s life that can have an effect on quality of life (e.g. treating the most common symptoms, respecting the patient’s autonomy, sensitive and empathic communication with the patient and their family, managerial skills in organizing the care and in using the services of other specialists, providing in house nursing care etc.). All medical personnel should be able to provide general palliative care, with view of the specifics of their specialization.</td>
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<td><strong>Hospice care</strong></td>
<td>There is no single satisfactory definition of hospice care. Originally, this term was...</td>
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used for the form of care that developed as a counterpart to regular medical care. Hospice care emphasized comfort, psychological and spiritual aspects of care and a large part of work was done by volunteers. Nowadays, in most counties, this term is gradually being used as a synonym to palliative care.

**Hospice** exists in the form of a bed-ward, or of mobile palliative care. A bed-ward hospice is an independent bed-ward that provides specialized palliative care. Mobile palliative care provides specialized palliative care in the patient’s household, where the patient is looked after mainly by their family and friends.

**Interdisciplinary** denotes such kind of team work in which care is provided by a team that consists of professionals of various specializations and that acts as one entity. To emphasize this fact, we sometimes differentiate between interdisciplinary and multidisciplinary cooperation – in the case of interdisciplinary team cooperation the borders between individual specializations and their areas of operation are less important than in the case of multidisciplinary work.

**Pain relief**, along with the treatment of other specific symptoms that accompany the process of dying, represents the cornerstone of palliative care, as it in most cases has a fundamental effect on the quality of the patient’s life. Included in the palliative care team must be medical professional who specialize in pain relief and in treating other symptoms that accompany the process of dying. Continuous evaluation and documentation of the amount of pain the patient has to suffer and of the effects of the therapy form an integral part of palliative care. If possible, verified tools should be used to evaluate and measure the effectiveness of pain relief.

**Palliative care** can be defined in various ways. This text uses the definition based on that published by the WHO in 1990 and 2003. Palliative care means complex, active and quality-of-life-oriented care provided to patients who are suffering from incurable illness in its advanced or terminal stage. The aim of palliative care is to relieve pain and other physical and psychological suffering, to preserve the patient’s dignity and to provide support to the kith and kin.

**Palliative care consultant team** provides consultations in the area of specialized palliative care within the particular medical facility (a hospital or a clinic), or within its area of operation in the case on mobile palliative care.

**Palliative medicine** is specific medical care provided to patients in the advanced stages of a progressing illness whose prognosis is limited and it focuses predominantly on quality of life. It is a part of palliative care.

**Quality of care** should be the result of interdisciplinary cooperation and it should be evaluated on a regular basis. Feedback mechanisms are part of palliative care which allows the patients, their families, the medical personnel and communities to make an effective contribution to evaluating and improving the quality of care. Quality evaluation (by the patient and their family) of the palliative care provided should form an essential part of the standard documentation and it should be put to effective use.

**Quality of life**. The basic aim of palliative care is to ensure the highest possible quality of life. However, it is immensely difficult to define this claim and even more complicated to perform relevant measurements in the case of patients in advanced stages of disease. It is usually impossible to apply evaluation methods used in the case of disease-modifying treatment for the purposes of palliative care, particularly because these methods are unable to take into consideration the attention paid to existential, spiritual and social aspects towards the end of the patient’s life. Such criteria are most suitable for evaluating the quality of palliative care that are based on the preferences of the patient or of their family.

**Respite care** is a form of care the aim of which is to give the family a chance to take a break from taking care of the patient, which might be necessary if the family members require medical attention themselves, or if they just need to take a holiday. Respite care can be provided in hospitals, nursing homes, homes for seniors or in in-patient palliative care facilities. The border between respite care, day care clinics and a short-term hospitalization is not always entirely clear.

**Specialized palliative care facilities** are such facilities that specialize in providing specialized
palliative care. This care is provided by an interdisciplinary team who have been properly trained and who work under the leadership of a palliative care specialist who has appropriate education and experience.

**Specialized palliative care** is active professional interdisciplinary care provided to patients and their families by a team of specialists who have been educated in the field and who possess the necessary experience. The team consists of a physician, nurses, a social worker, and, if necessary, of a psychologist, a physiotherapist, a priest, a volunteer coordinator and other specialists. Providing palliative care is the main part of the job description of this team.

**Specialized palliative care outpatient clinic** provides outpatient care to patients who live at home or in social care institutions. There is usually very tight cooperation between general practitioners, in house care and specialized palliative care institutions. Palliative care outpatient clinics sometimes operate alongside hospices or palliative care departments of bed-wards.

**Spiritual care** focuses on the issues of the meaning of life and existential religious questions that often trouble the patient and their relatives when they are facing the terminal stages of a disease. This care is not limited to religious patients only – it is available to all patients and their relatives (regardless of their religion or whether they even believe in God) before the patient passes away as well as after.

**Supervision** is the qualified attendance that focuses on the quality of care, that takes the form of group or individual interviews, and that allows the members of the team to reflect on the positive as well as negative experience and aspects of their operation under professional leadership. Supervision is an important tool that can help improve the quality of care as well as minimize the negative effects of palliative care on the members of the team and on the volunteers. It provides emotional and psychological support and can help prevent the burnout syndrome.

**Treatment plan** is a document designed and regularly updated by the palliative care team in cooperation with the patient and their family that states the needs and preferences of the patient and their family, the expected development and the tasks assigned to the individual professional and non-professional home nurses. The treatment plan tries, to the maximum extend, to anticipate the future development and it focuses on avoiding crisis situations.

**Volunteers** are nursing personnel who devote a part of their time to providing palliative care to patients without getting paid or without having had any previous relationship towards the patient. In the context of mobile palliative care, these volunteers are managed and coordinated by a volunteer coordinator. Paramedical workers and other specialists may also work as volunteers.

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