

Palliative Care

Medical-ethical Guidelines and Recommendations

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Palliative Care

Medical-ethical Guidelines and Recommendations

I. Preamble

Palliative care has been discussed in various guidelines published by the SAMS over the past few years. The definitions are not uniform, the understanding of palliative care can differ and its importance in medical practice remains controversial. The SAMS therefore decided to draw up separate medical-ethical guidelines especially for this particular topic.

Besides the successes, the developments and advances that have been made in medicine also lead to an increase of various complex medical situations. Increasing specialisation sometimes leads to a fragmented view of things as well as of modes of treatment. This involves the risk that one in fact loses the focus on the patient's quality of life and his or her suffering. Primarily, quality of life is not a medical concept only. It should be understood and defined in the context of the patient's case history; this means that it is the patient's point of view, which is decisive. Without losing sight of the mental, social and spiritual aspects, the aim of palliative care is to give patients with incurable, life-threatening or chronically progressive diseases as good a quality of life as possible throughout the course of their illness, until they die. This principle applies particularly in neonatology, intensive-care medicine, geriatrics and psychiatry.

The aim of the following guidelines is to encourage palliative care in everyday medical practice, in all fields of medicine, but also in situations were therapeutic options are still practicable. Their objective is not to establish a new medical speciality, but mainly to encourage an attitude, which recognises the limitations of medicine and helps to face an inevitable death as well as the feelings of helplessness, often associated with this.

II. Guidelines

1. Definition¹

Palliative care is understood to mean the complete treatment and care of patients with incurable, life-threatening or chronically progressive diseases. The aim is to give the patient as good a quality of life as possible throughout the course of his² illness, until he dies, to alleviate his suffering as much as possible and also to consider the social, spiritual and religious aspects, according to the patient's wishes. High-quality palliative care depends on the professional knowledge and the working procedures of those responsible for the care of the patient. As far as possible such care should happen at the place the patient wishes to be. Palliative care is most important during the period when the dying process and the patient's impending death are seen as inevitable, but it is often useful to start palliative care with foresight and at an early stage, possibly already parallel to the therapeutic measures.

In detail, this means that palliative care

- respects life and accepts mortality;
- respects the patient's dignity and autonomy and places his priorities at the centre of the caring process;
- is provided for all patients who are suffering from an incurable, progressive disease, irrespective of age;
- aims to achieve optimal alleviation of symptoms that are difficult to bear, such as pain, respiratory difficulties, nausea, fear or confusion;
- also facilitates rehabilitative, diagnostic and therapeutic measures that can contribute to the patient's quality of life.

2. Area of application

Palliative care should be integrated into the overall treatment of all incurable diseases, complementary to the therapeutic measures, in situations where the ultimate outcome is uncertain:

- irrespective of the patient's age (from premature babies and newborns to the elderly);
- in home care (e.g. outpatient services) as well as in hospitals and institutions;
- in all fields of medicine as well as in nursing;

Unlike in the definitions of the SGPMP and the WHO (see details of sources in the Appendix), this paper's definition does not focus on the care and support of the patient's relatives as a main task of palliative care. Although care of the relatives is desirable and important in practice, it is not specific to palliative care. The focus of these guidelines is on the patient. In the sense of comprehensive care of the patient, the care and support of the relatives is mentioned in different chapters.

 $^{^{\}rm 2}\,$ For the sake of simplicity, the masculine prepositions are used when both sexes are intended.

In these guidelines, the term *relatives* is used for persons who are close to the patient, especially spouses or partners as well as close relatives or particularly close friends. Cantonal laws may define the term *relatives* differently.

- integrated into the collaboration between doctors, nurses, social workers, therapists, the patient's relatives³ and volunteers.

3. General aspects of palliative care

Questions of palliative care arise in all fields of medicine. Therapeutic measures and palliative care often complement one another and together form a whole. There is therefore often no clear-cut line of separation between therapeutic care and palliative care. The decisive element is primarily the change in the attitude of the patient and of those responsible for his care, when defining the aim of the therapy. In the palliative approach the efforts are centred on the progressive disease, the fate of the patient, his environment, his past history, his beliefs and personal convictions, and especially his thoughts and feelings regarding suffering, dying and death (bio-psycho-social concept of the disease).

Palliative care however, is also subject to misunderstandings, unreasonable expectations and risks.

Misunderstandings include:

- all major symptoms can always be alleviated;
- any alleviating treatment already constitutes palliative care;
- palliative care is seen as simply accompanying the dying process;
- palliative care is the equivalent to the withdrawal of all curative and other treatment.

Unreasonable expectations include:

- requests for assisted suicide or active euthanasia receed in all situations;
- the dying process can be influenced in such a way that death is always quiet and peaceful.

Risks include: Palliative Care

- is reduced to the prescription of opiates;
- is delegated exclusively to specialists;
- is applied as a replacement for valid therapeutic options;
- is initiated in place of medically indicated measures out of economic considerations.

4. Basic values and attitudes

The fundamental values and attitudes described below are particularly significant for palliative care.

4.1. Dignity of the patient

Dignity is an inherent human right, irrespective of a person's state of consciousness or the particular context. In this sense, dignity is lasting and must be respected unconditionally.

However, in situations of weakness – for example as in the case of far advanced disease and during the dying process – dignity is very vulnerable.

Carers and relatives show their respect for the patient's dignity particularly in the sense that they

- see the incurably ill or dying patient as a unique individual and meet him as such;
- take his special vulnerability into account, by their behaviour towards him as well as in any form of communication with him:
- are open for questions of meaning of life, futility and mortality and give the patient the possibility of bringing up existential questions.

The respect for a person's dignity includes the respect for his autonomy.

4.2. Autonomy

The term autonomy is understood to mean a person's ability to express his will and to live according to his own values and convictions. A person's autonomy is dependent on the level of information that he is given, the current situation and his readiness and ability to take responsibility for his own life and his own dying. Autonomy also includes responsibility towards others.

For the treatment team, respect for a person's autonomy means that they

- take into account the patient's biographical background;
- do not lose sight of the family dynamics;
- keep the patient and his relatives informed, as clearly and as frankly as possible;
- make sure that given information has been understood;
- always make sure that the patient's wishes have been understood correctly and that they are met, as far as this is possible;
- are aware, in the case of patients who are unable to communicate or incapable of expression, of any values and wishes that they may have expressed earlier, verbally or in writing.

5. Decision-making processes⁴

If he is capable of discernment⁵, the decision to carry out, to discontinue or not to start a particular therapeutic measure that has been suggested rests with the patient, after he has been fully informed of the circumstances in a clearly understandable manner (informed consent). The information that is necessary to enable the patient to make his decision is, as a rule, gathered by the team of carers. In this respect, the aim must be to arrive at a decision that is acceptable o all concerned. Important decisions must be put down in writing, regularly reflected and altered if this proves necessary.

⁴ In this respect, see also the medical-ethical guidelines of SAMS: The right of patients to self-determination (2005), which regulate the decision-making process, in detail, especially the decision-making process in the case of patients who are incapable of discernment.

⁵ *Discernment* is assessed in respect of a particular action and in fact according to the degree of complexity of that action. The patient must be capable of discernment at the time the decision is made. Minors or legally incapacitated persons may also be capable of discernment with regard to the approval or refusal of a treatment.

The patient will be allowed sufficient time – as far as this is possible – to make his decision. Factors that could influence his decision, such as the expectations of third parties or the feeling that he is being a burden to others, must be discussed.

Especially important are situations where the patient concerned cannot, or is no longer able to express himself with regard to a particular medical measure. If the patient was previously capable of discernment, everything necessary must be done to meet his presumed wishes. However, if there is no indication of the patient's wishes, the decision process must involve the relatives and the decision must be taken in the patient's presumed best interest.

In the case of difficult decisions, a structured ethical discussion or consultation can be helpful.

6. Communication

Open, adequate and sympathetic communication with the patient and, if he wishes it, also with his relatives, is an important aspect of palliative treatment and care. A comprehensible, repeated and stepwise explanation enables the patient to develop realistic expectations, to express his own wishes and to make decisions. Fundamental conditions for this are empathy and sincerity towards the patient and readiness to explain the possibilities and the limitations of both therapeutic and palliative treatment.

Sometimes, a patient may not wish to face up to his illness realistically. This attitude must be respected. It allows the patient to entertain hopes that can help him to better face difficult situations. Hope in itself can engender palliative effects.

If the relatives express the wish to protect the patient from bad news or, on the contrary, cannot accept the patient's denial of his disease, the background for such wishes must be investigated. However, the patient's right to be informed or to remain in ignorance takes priority over the wishes of the relatives. The relatives should however be supported in the handling of this difficult situation.

The care of severely ill and dying patients involves the risk of tension and conflicts between the patient, his relatives and his carers. The same level of information for all concerned, regular discussions and the nomination of a person to turn to, can be helpful in reducing tensions and overcoming conflicts.

7. Continuity and interdisciplinary collaboration⁶

In palliative care, other specialists⁷ and volunteers often also play a significant role in the care of, and in the relationship with the patient besides the doctors and the nursing staff. Mutual acceptance and esteem are therefore indispensable for an efficient collaboration. This requires the perception and recognition of one's personal limitations and possibilities.

To guarantee continuity in the treatment and care of the patient represents a very particular challenge. However, it is possible when all the specialists involved, not only within the institution

Interdisciplinary collaboration is understood to mean collaboration between different disciplines and collaboration between different professional groups.

⁷ Other *specialists*, for example are: physiotherapists, occupational therapists, art therapists, music therapists, dietetists, priests and spiritual counsellors the patient may want, psychotherapists or social workers.

but also between the family doctor, ambulant services, hospital units and the institutions collaborate. By nominating a reference person, responsible for the patient, the organisational condition for this can be set up. Here, the family doctor can play a key role.

The need for interdisciplinary collaboration does not release the treating physicians, the nursing staff and other specialists from their responsibility for the decisions and measures within their areas of competence.

8. Palliative care in different fields of medicine

Palliative care in the sense of the alleviation of symptoms, but also of support in coping with the disease, can be necessary in all chronic diseases. Optimal treatment of the underlying disease is in most cases also the best means of alleviating the symptoms; therapeutic and palliative measures complement one another. Besides increasing incapacity and dependence, many diseases, such as chronic heart, lung and kidney diseases, but also neurological conditions, can lead to life-threatening situations. In these cases palliative care means that, besides maintaining the patient's quality of life through supportive and alleviating measures, the handling of a possible deterioration of the patient's condition and of acute, threatening situations have to be discussed with all those involved, in good time and with foresight.⁸

8.1. Palliative care in paediatrics

The causes of death during childhood and adolescence are very different from those in old age. They have different implications for the palliative care of the child or the adolescent and of his family. With regard to age, causes for the illness and causes of death, these patients can be divided into three categories: premature babies and newborns, children and adolescents and severely handicapped children.⁹

8.1.1. Premature babies and newborns¹⁰

Half of the deaths in childhood occur in newborns, mainly as a result of premature birth, congenital diseases and malformations. Far-reaching decisions often have to be taken with great urgency. This situation is very difficult for the parents, because at this stage they have still not been able to familiarise themselves either with their child or with the medical situation. Therefore, special consideration has to be taken when they are included in the decision-making process.

Consequently, in the field of neonatology the following aspects have to be considered:

- As much time as possible must be allowed for the decision-making process. With this in mind, provisional life-maintaining measures can be helpful.

This includes, for example, addressing questions regarding the indication for further treatments with drugs, hospitalisations, transfers, surgical measures, intensive care, artificial respiration or resuscitation.

⁹ When the terms "child" or "children" are used in the text from now on, it is meant to include adolescents as well.

¹⁰See also "Recommendations on the Care of infants born at the limit of viability (22 to 26 weeks of gestation)" and "Recommendations for the palliative care of dying newborns" and the SAMS guidelines "Borderline questions in intensive-care medicine" and "Treatment and care of patients with chronic severe brain damage".

- Considerations of the possible consequences of the survival of a child must also be taken into account in the decision, as it is particularly difficult to make a prognosis in this patientgroup.
- Complications that are to be expected must be discussed at an early stage.
- Special attention must be paid to adequate pain and symptom control, because in these patients the detection of pain is particularly difficult.
- When their child dies, the parents must be given time and space to grieve. The care team supports them in this process.
- The interment of babies who die prematurely or who were stillborn is an important part of the mourning process. Families must be supported and counselled in this endeavour.

8.1.2. Children and adolescents

Besides accidents and suicide, cancer and heart disease and the consequences of diseases in the neonatal period are the most common causes of death in children and adolescents.

The following points play an important role in palliative care:

- The child is at the centre of attention and taking into account his age, his stage of development, his state of health and his own needs is included in the decision-making process.¹¹
- The child is seen in the context of his family.
- The sick child continues to develop and, in many ways, remains healthy. Therefore, he continues to need children's activities. This explains why it is important to maintain an everyday life appropriate to the child's age (e.g. attendance at kindergarten or school).
- The terminally ill child must be given the opportunity to arrange last things.
- Grieving rituals are very important for the family. The family, including the child's siblings, must be supported in this.

8.1.3. Severely handicapped children¹²

The care of children with severe congenital or acquired physical and mental handicap is particularly demanding and time-consuming. These children are often cared for in long-term socio-pedagogic institutions.

For these children the following points have to be considered:

- Besides the socio-pedagogic approach, it is important to identify treatable but frequently underestimated symptoms, such as pain. Access to adequate medical and nursing care has to be guaranteed.
- The treatment of these children requires specific knowledge. Specially developed instruments, for example for the assessment of pain, have to be used.

Minors can be considered as capable of discernment when it is a question of giving their consent to a treatment. The capacity for discernment is assessed according to the concrete situation (consent) and the concrete treatment. See "Right of patients to self-determination", medical-ethical guidelines of the SAMS.

 $^{^{12}\}mathrm{See}$ also the SAMS guidelines: "Treatment and care of patients with chronic severe brain damage".

8.2. Palliative care in intensive-care medicine

The treatment team in an intensive-care unit fights for the patient's survival, often however in the knowledge that in all probability he may die, despite all the efforts. In many cases the period of uncertainty is prolonged because of the increasing number of therapeutic possibilities that are available. In these situations, in view of the uncertain prognosis the team also has to consider palliative measures, parallel to the therapeutic measures that are already being taken.

Palliative care in intensive-care medicine means, in particular,

- that all the other medical measures are complemented by adequate pain and symptom control:
- that the question of possible complications is addressed in good time;
- that the intensity and the limitations of the treatment and the patient's expectations with regard to the treatment at the end of his life are discussed;
- that decision-making processes can take place and adaptations to the therapeutic objectives can be made in spite of time pressure;
- that as far as possible patients and their relatives are openly informed of the severity of the situation and the probability of a fatal outcome.

8.3. Palliative care in oncology

In contrast to chronic degenerative conditions, "cancer", in our perception, is still often associated with incurability and death. This metaphorical dimension affects the patient, his relatives and his carers. Even though in certain situations palliative measures should to be the primary concern of all those involved, the difficulty of dealing with the inevitability of the dying process and death may nevertheless lead the treating physician and the patient to undertake an anticancer therapy which under the circumstances may not be very promising. There is then the risk that excessive therapeutic zeal may lead to not taking palliative care into consideration. The most important aspect of such therapeutic endeavour may be to alleviate feelings of helplessness. Appropriate explanation of the advantages and disadvantages of an anti-cancer therapy and the possibilities and limitations of palliative care is extremely important in order that cancer patients will not undertake a hopeless form of therapy, accompanied by serious side effects out of an unrealistic sense of hope.

For palliative care in oncology, the following points have to be considered:

- Incurable cancer is a disease with a limited survival time, which has effects of a physical, mental and social nature.
- The patient must be properly informed regarding prognosis, with or without treatment, and the possible impairment of his quality of life due to the side effects of the treatment. Chemotherapy and radiotherapy may be suggested to the patient, not only as therapeutic, but also as palliative measures. The benefits of such therapies and the disadvantages, due to side effects, must be weighed up very carefully and discussed with the patient.
- The sequential introduction of therapeutic and palliative measures can be avoided, if symptoms are already competently and adequately controlled when there is still a chance of a cure.

- Tension and conflicts frequently occur between patients, carers and relatives. As a rule they are an expression of different or unrealistic expectations. Only through repeated, authentic information can those concerned develop realistic expectations.
- The decision not to continue an unrealistic fight against cancer to the bitter end can give the patient and his relatives space and time to take leave and to put the patent's affairs in order.

8.4. Palliative care in geriatric medicine¹³

Old age is often associated with chronic disease and multimorbidity. Thanks to the advances that have been made in medicine, there are today many possibilities for complex surgical and therapeutic interventions. There is a danger of seeing elderly patients as a conglomerate of various organic disorders where each of these will be treated separately. This can lead to an increasing number of prescriptions of various drugs. Palliative care applies the approach with geriatric patients of regularly re-assessing the suitability of the treatment, the patient's compliance and possible drug interactions. The indication for intervention is above all based on its effect on the quality of life and on the gain in independence for the patient, and not solely on medical feasibility. On the other hand, no therapeutic options should be left out solely because of a patient's age.

Chronic pain is common in elderly patients but it is often not treated adequately, because the patients and the caring team look upon it as an unalterable fact. In order to allow for adequate analgesic therapy, pain assessment with suitable instruments is important in all patients, especially for those with dementia.

When a patient's ability to communicate is impaired, non-verbal signals, like the refusal to eat or to take drugs, must be respected, after treatable causes have been excluded. ¹⁴ Documented previous expressions of the patient's wishes may be helpful in the decision-making process.

8.5. Palliative care in psychiatry¹⁵

Many psychiatric conditions can be chronic or are characterised by frequent relapses. In such cases palliative care, which is not aimed primarily at fighting the disease but aims at the best possible way of dealing with the symptoms or the handicap, is all the more important. Often, this approach can enhance the quality of life and diminish the risk of suicide.

Difficult situations may arise, especially in the case of:

- refractory depressions with repeated suicide attempts;
- severe schizophrenia, with poor quality of life in the opinion of the patient;
- severest anorexia;
- drug addiction.

¹³See also the SAMS guidelines and recommendations: "Treatment and care of elderly patients who are in need of care".

¹⁴ See the SAMS guidelines: "Treatment and care of patients with chronic severe brain damage", Chapter 4.4, and especially the comments under 4.4.

¹⁵See also the SAMS guidelines: "Coercive measures in medicine".

Mentally ill patients may also be suffering from somatic diseases. There is then a risk that their symptoms may be overlooked or not correctly diagnosed. In these situations, close collaboration between psychiatrists, psychotherapists and specialists in other medical disciplines is necessary.

9. The dying process and death

9.1. Palliative care of patients approaching the end of life¹⁶

Patients who are approaching the end of their life are particularly dependent on palliative care. Palliative care should provide the best possible support for the patient right up to the end. What is understood to be a *good death* cannot be defined according to objective criteria, but depends on very varied individual perceptions. Previously expressed wishes by the patient should be taken into account. The views of the patient's relatives and the members of the care team have to be considered in the evaluation process; however, they should not be decisive. Even with optimal palliative care, a *good death* cannot be guaranteed since it is closely associated with the patient's life history. Drug therapy and general nursing care should be used with the aim of alleviating the symptoms, but measures involving severe side effects should be avoided. Pain and suffering should be alleviated, even though in isolated cases, this could affect the time of survival. The effect on the time of survival, especially its shortening, is generally overestimated.

9.1.1. No treatment or discontinuation of treatment

In the course of the process of dying, the decision to prescribe or to discontinue life-prolonging measures may be justified or even called for. Also, in the last few days of life there is often no need for liquids and food. Artificial hydration should therefore only be used after careful assessment of the expected effect and possible unwanted side effects. In the decision whether or not to use artificial hydration, criteria such as prognosis, possible success of the treatment in terms of quality of life and the discomfort associated with this particular procedure must be considered

9.1.2. Sedation

Palliative care aims at maintaining the patient's ability to communicate. Sometimes however, sedation may be indicated for a limited period, in order to make symptoms that are difficult to treat temporarily more tolerable, until appropriate therapeutic measures have the desired effect. In this case the patient should be sedated only for as long as is necessary for alleviation of the symptoms.

In the presence of severe side effects, which are refractory to treatment, continuous sedation may be necessary. In this case the comatose state induced by medication will continue until

¹⁶See also the SAMS guidelines: "Care of patients in the end of life", especially the definition of patients at the end of life in Item 1: "These are patients for whom the doctor is convinced, on the basis of clinical signs, that a process has started which, he knows from experience, will lead to death within a few days or weeks".

When one speaks of sedation, various and varying terms are used (palliative sedation, terminal sedation etc.).

This partly explains the great fluctuations in the prevalence.

death. Such sedation should be instituted only with the consent of the patient. The possibility of temporarily arousing the patient from the sedation must be discussed with him. In patients who are no longer capable of discernment, the possibility of sedation should have been discussed earlier or be content of the patient's living will. The patient's suffering may sometimes be almost unbearable for the relatives or the carers, but this must not be a reason for sedating the patient if it is not in accordance with his wishes. It is recommended to draw up and to follow a decision-making protocol in the hospital, which also includes a follow-up discussion with the relatives and the carers after the patient's death.

In the special situation of withdrawal of treatment (extubation in the intensive-care unit), where the patient's death is imminent, sedation may be indicated.

Sedation at the end of a patient's life must not be used with the deliberate intention of shortening life, although it may possibly have this effect. This differentiates end of life sedation from direct, active euthanasia.

9.2. Leave-taking and mourning

The manner of care with the deceased must be as respectful as it is with any living person, irrespective of where the death may have occurred.

This means, in particular, that

- the care of the body should respect and honour the familial, socio-cultural and spiritual needs of the affected persons as far as this is possible;
- the institution and the members of its staff make it possible for the relatives to have the space and the time they need in order to take leave of the deceased person in an appropriate manner. The relatives are supported in their grief and informed of the possibilities for obtaining such support;
- special attention and support will also be given to the care team.

10. Research

Research must be encouraged in all areas of palliative care, in order to be able to evaluate new methods and measures as objectively as possible before their general application in practice. In view of the subjectivity of the various factors recorded (e.g. pain, quality of life etc.), the qualitative and quantitative methods of investigation must first be evaluated for their relevance, practicability and suitability. Persons whose condition requires palliative care are often particularly vulnerable.

III. Recommendations

The recommendations listed below are addressed especially to the institutions of the health-care sector and the education, graduate and postgraduate sectors, to political authorities and those responsible for financing.

The following basic conditions are considered to be essential for the implementation of palliative care in the outpatient and hospital sectors:

- 1. The promotion and support of palliative care by federal and cantonal health authorities and the organisational and financial support of palliative-care-networks.
- That palliative care be an intrinsic part of training programmes: at the undergraduate level (in medical faculties, nursing schools and schools for therapists), at the postgraduate level (continued education curricula of the professional associations and advanced nursing schools) and in the continuous postgraduate training sector (professional associations, FMH, SBK etc.).
- A fundamental reflection about the financing of palliative care in the hospital and outpatient sectors. The decision not to proceed with therapeutic measures in hopeless situations, but to replace these with palliative care must not lead to an additional financial burden for the patient.
- 4. Integration of palliative care in existing therapeutic and nursing concepts and ongoing quality control of the palliative care provided.
- 5. Promotion of research in all areas of palliative care.
- 6. Information of the general public about the components and the possibilities of palliative care by professional associations and interested organisations (e.g. Cancer League, Lung League, Heart Foundation etc.).

IV. Appendix

Switzerland

- The Fribourg Manifesto: A national strategy for the development of palliative care in Switzerland, Fribourg 2001.www.palliative.ch
- Standards: Principles and guidelines for palliative medicine, care and accompaniment in Switzerland. Published by: Swiss Association for Palliative Medicine, Care and Accompaniment (SGPMP). 2001. www.palliative.ch
- Education and postgraduate training in "Palliative Care". National recommendations formulated by the working-group, "Education and postgraduate training" of the SGPMP. 2002. www.palliative.ch
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<u>International</u>

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- WHO Definition of Palliative Care. www.who.int/cancer/palliative/definition/en
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- A Guide to the Development of Palliative Nurse Education in Europe. Report of the EAPC Task Force.
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Mandate On 13 June 2003 the Central Ethical Committee of the SAMS appointed

a sub-committee to draw up guidelines on palliative care.

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