

MEDICAL ETHICAL GUIDE- LINES

End-of-life care

Issued by

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Medical-ethical guidelines

End-of-life care

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The German version is the original, binding version

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I. PREAMBLE

People in the final phase of life are often in need of special protection and help. They bring home to us the finite nature of all human existence. The decisions to be made at the end of a person's life place great demands, predominantly on the patient himself,¹ but also on family members, the physicians and the team responsible for the patient's care. The purpose of these Guidelines is to indicate the tasks, possibilities and limitations associated with the care of patients who are approaching the end of their life. The principal aims are to alleviate suffering and to ensure the best possible quality of life for the patient and support for his family members.

In contrast to the most recent version of the Guidelines, of 1995, this new version addresses exclusively the situation of dying patients. The Guidelines for the treatment and care of patients with chronic severe brain damage have for the first time been drawn up separately. Nevertheless, since there are common questions and problems, we emphasize the importance of these Guidelines for the principal questions that are addressed here. The same applies for the Guidelines on ethical questions in intensive medicine and for the Guidelines on the treatment and care of elderly persons dependent on care.

For the particular problems that arise in the case of extremely premature infants, readers are referred to the recommendations of the Swiss Society of Neonatology.²

- 1 In the interests of easier readability of the text, the masculine designations of persons (he, him, his) are used throughout these Guidelines. However, the text is always understood to also include female persons.
- 2 See "Perinatal care at the limit of viability between 22 and 26 completed weeks of gestation in Switzerland," *Swiss Med Wkly* 2011;141:w13280.

II. GUIDELINES

1. Scope³

These Guidelines concern the care of patients at the end of life. These are patients whose physician has arrived at the conclusion, on the basis of clinical signs, that a process has started which, as experience indicates, will lead to death within a matter of days or a few weeks.

The same criteria apply to neonates, young children and adolescents in the terminal phase of life; where special considerations have to be taken into account for these paediatric patients, they are dealt with in the corresponding paragraphs.

2. Patients' right to self-determination

Every patient has the right to self-determination. The full and accessible explanation of the medical situation to the patient or his representative, in good time, is a precondition for them to be able to make their own choices and reach their own decisions. This requires sensitive, frank communication, and a readiness on the part of the physician to explain the possibilities and limitations of both curative treatment and palliative care.

2.1. Patients with capacity

Respect for the wishes of a patient with capacity is central as far as medical intervention is concerned. Therefore, any medical treatment that is against the express wishes of such a patient is not permitted. This is the case even if, in the opinion of third parties, the patient's wishes do not seem to be in his best interests. Minors or persons for whom a deputy has been appointed may also have the capacity to consent to medical interventions.

2.2. Patients lacking capacity

Procedure in accordance with the presumed wishes of the patient

If the patient is no longer able to express his wishes, the physician must ascertain whether an advance directive⁴ is available. If an advance directive is available, the instructions it contains are to be complied with. If the patient has not expressed any wishes regarding the medical intervention in question, then the care team is to prepare a treatment plan in consultation with the person entitled to

3 On being incorporated into the Code of the Swiss Medical Association (FMH), the guidelines become binding for all members of the FMH.

4 Cf. "Advance directives" (medical-ethical guidelines and recommendations of the SAMS).

act as a representative.⁵ The physician is to provide the representative with comprehensive information regarding the proposed medical measures. Ultimately, the decision on the proposed treatment is to be made – in accordance with the patient’s presumed wishes and interests – by the representative. This imposes a heavy responsibility on a person who is closely involved emotionally. The prime goal with regard to the proposed treatment should therefore be to reach a consensus supported by all parties.

For difficult decisions, it may be helpful to obtain ethics support.⁶

3. Treatment and care

3.1. Palliative care⁷

Patients in the final phase of life have a right to palliative care. This comprises all the medical treatments and nursing care, and psychological, social and spiritual support for both patients and members of their families, with the aim of alleviating suffering and ensuring the best possible quality of life for the patient.

The efforts of the team responsible for the care of the patient centre on effective symptomatic therapy. This also includes provision for the patient’s needs and the availability and support of the patient and his family members. All potentially helpful technical and human resources (e.g. specialists in psychological, social and spiritual support) should be utilized as and when necessary. Palliative care should be made available in good time and wherever the patient happens to be (in hospital, in another institution or at home).

It is the physician’s duty to alleviate pain and suffering, even if in individual cases this may influence (shorten or prolong) the duration of life itself. With symptoms that are refractory to treatment, sedation may sometimes be necessary. Here it is pointed out that the patient should be sedated only to the extent that this is necessary for alleviation of the symptoms.

5 Under the law, the following persons are entitled, in the following order, to act as representatives in relation to medical interventions: persons appointed in an advance directive or power of attorney; a duly authorized deputy; relatives and other close persons who regularly provide the patient with personal support (spouse or registered partner, person sharing the same household, offspring, parents, siblings). In the case of minors, the holders of parental authority are entitled to act as representatives.

6 Cf. “Ethics support in medicine” (recommendations of the SAMS).

7 Cf. “Palliative care” (medical-ethical guidelines and recommendations of the SAMS).

Whenever possible, decisions on treatment and care should be made jointly by the team responsible for care of the patient and the family members. The involvement of the family members is important, bearing in mind their dual role as carers and cared for.

Any wishes concerning the form that the terminal phase of the patient's life should take must be supported. The care provided should also include support of members of the patient's family, in many cases also after the patient's death.

The deceased person must of course always be treated with respect; the cultural and religious rituals of the family must be recognized as far as this is possible.

3.2. Withholding or withdrawing treatment

Faced with the process of dying, it may be justified or indicated to withhold or withdraw life-sustaining measures. In the decision-making process criteria such as the prognosis, the expected outcome of treatment in terms of quality of life, and the undesirable effects of the proposed treatment on the patient all play a role.

In principle, these same considerations also apply in the case of neonates, infants and young children. However, the fact that in these groups it is not possible to determine the presumed wishes or the personal characteristics of the patient is a complicating factor. Recourse to measures for maintaining vital functions that may place heavy demands on the patient must therefore depend mainly on the prognosis. Here, the burden placed on the patient by the treatment, in the form of pain, discomfort and physical limitation, must be weighed against the possible benefits in terms of well-being, possibilities for personal relationships and capacity for experience.

4. The limits of medical intervention

Respect for the patient's wishes reaches its limit if the patient asks for measures to be taken that are ineffective or inappropriate, or that are not compatible with the personal moral conscience of the physician, the rules of medical practice or the applicable laws.

4.1. Assisted suicide

According to Article 115 of the Swiss Criminal Code, helping someone to commit suicide is not a punishable offence when it is done for unselfish reasons. This applies to everyone.

With patients at the end of life, the task of the physician is to alleviate symptoms and to support the patient. It is not his task to directly offer assistance in suicide, he rather is obliged to alleviate any suffering underlying the patient's wish to commit suicide.

However, in the final phase of life, when the situation becomes intolerable for the patient he or she may ask for help in committing suicide and may persist in this wish.

In this borderline situation a very difficult conflict of interests can arise for the physician. On the one hand assisted suicide is not part of a physician's task, because this contradicts the aims of medicine. On the other hand, consideration of the patient's wishes is fundamental for the physician-patient relationship. This dilemma requires a personal decision of conscience on the part of the physician. The decision to provide assistance in suicide must be respected as such. In any case, the physician has the right to refuse help in committing suicide. If he decides to assist a person to commit suicide, it is his responsibility to check the following preconditions:

- The patient's disease justifies the assumption that he is approaching the end of life.
- Alternative possibilities for providing assistance have been discussed and, if desired, have been implemented.
- The patient is capable of making the decision, his wish has been well thought out, without external pressure, and he persists in this wish. This has been checked by a third person, who is not necessarily a physician.
- The final action in the process leading to death must always be taken by the patient himself.

4.2. Killing on request

Even if requested seriously and insistently, the killing of a patient must be refused by the physician. According to Article 114 of the Criminal Code, killing on request is a criminal offence.

III. COMMENTS

ad 1. Scope

According to this definition, a distinction has to be made between patients who are approaching the end of their life and patients with incurable, progressive diseases that may persist for several months, or even years. The clinical signs are understood to mean all the observations, for example deteriorating vital functions, objective findings with unfavourable prognosis and assessment of the patient's general condition, which characterize the onset of the process of dying. It must be emphasized, however, that the start of the terminal phase is often connected with medical decisions regarding the withdrawal or the refusal of treatment, so that its definition is always associated with a certain vagueness.

ad 2.1. Patients with capacity

The following criteria help to establish capacity in accordance with Art. 16 of the Civil Code:

- the ability to understand information regarding the decision that is to be made;
- the ability to correctly weigh up the situation and the consequences resulting from possible alternatives;
- the ability to weigh up, rationally, information obtained in the context of a coherent system of evaluation;
- the ability to express his own choice.

Capacity is assessed with regard to certain measures (also taking into account the degree of complexity of these measures); it must exist at the moment the decision is taken.

ad 2.2. Patients lacking capacity

Procedure in accordance with the presumed wishes of the patient

The presumed wishes are the wishes that the patient would probably express if he still had capacity. They are based on the evaluation of all the available information, such as an advance directive, nomination of a health care proxy, earlier expression of his wishes and other biographical information.

Family members, in the sense of these Guidelines, are understood to be persons who are close to the patient, especially spouses or partners, children, parents and siblings.

Acting in the best interests of the patient

We understand “acting in the best interests of the patient” to mean carrying out measures that seem to be indicated, medically and in connection with the care of the patient, and to which a hypothetical reasonable person in a similar situation would presumably agree.

Situations of conflict

Although family members do not have the right to make decisions, in the case of conflict a consensus must be sought.

ad 3.1. Palliative care

Limitations of palliative medicine

Not all suffering associated with dying and death is avoidable. The recognition and acknowledgement of medical limitations is therefore an integral part of the care of the patient and the family members. In especially difficult situations it is likely that considerable demands will be placed on the team responsible for the care of the patient, external professional support may be sought.

Influencing the duration of life

The “life-shortening effect” of centrally acting substances has long been overestimated. Generally analgesics and sedatives, if they are correctly used exclusively for the control of symptoms in the last few weeks of life, are not associated with a shortening of the survival time.

Analgesics and sedatives can also be misused in order to bring about death. As a general rule, however, a difference between the alleviation of pain and symptoms, in the palliative sense, and the intention to end life, is clearly already evident in the dosage or in the increase of the dosage of the drug.

Postgraduate training and further training

The care of patients approaching the end of their life calls for specialist knowledge and abilities in the field of palliative medicine, care and support.

ad 3.2. Withholding or withdrawing treatment

The life-sustaining measures that may be taken include artificial rehydration and feeding, artificial respiration and cardiopulmonary resuscitation. Depending on the situation, the possible administration of oxygen, medication, transfusions and dialysis or surgical interventions must also be decided on.

ad 4.1. Assisted suicide

When dealing with the wish for assisted suicide in old people's homes, the guidelines and recommendations on the treatment and care of elderly persons dependent on care⁸ also have to be taken into account.

Superiors can forbid their subordinates to assist a person in committing suicide, but they may not order them to do so.

The decision-making process leading to assisted suicide or to its rejection must be documented.

The death of a patient as a result of assisted suicide must be reported to the examining authorities as an unnatural death, for investigation. The physician who was responsible for the assisted suicide may not himself fill out the corresponding death certificate.

⁸ "Treatment and care of elderly persons dependent on care" (medical-ethical guidelines and recommendations of the SAMS).

IV. RECOMMENDATIONS FOR THE RESPONSIBLE HEALTH AUTHORITIES

Resources

In spite of the limited resources, the policy of the responsible health authorities should be to ensure that all patients receive palliative care at the end of their life, in the sense of these Guidelines.

The various institutions should be given the task and the opportunity of creating the conditions required to achieve this, such as appropriate premises, human resources, support for the team responsible for the care of the patients, etc.

Pregraduate and postgraduate training

Palliative medicine and care should be integrated into the pregraduate, postgraduate and further training of all professional groups involved in the care of patients.

V. APPENDIX

Information on the elaboration of these guidelines

Mandate

On 8 February 2002 the Central Ethics Committee of the SAMS appointed a sub-committee to draw up guidelines on end-of-life care.

Responsible sub-committee

Dr. Markus Zimmermann-Acklin, Lucerne, Chairman
Dr. Jürg Bernhard, Berne
Dr. Georg Bosshard, Zurich
Prof. Ulrike Büchs, Winterthur
Qualified Nurse Christine Champion, Moudon
Dr. med. Daniel Grob, Zurich
Prof. Dr. med. Christian Kind, St. Gallen
Dr. med. Hans Neuenschwander, Lugano
Prof. Dr. med. Rudolf Ritz, Basle
Lic.iur. Michelle Salathé, Basle (ex officio)
Qualified Nurse Elisabeth Spichiger, Berne
Dr. med. Philipp Weiss, Basle
Prof. Dr. med. Michel Vallotton, Geneva; President, Central Ethical Committee (ex officio)

Experts consulted

Dr. med. Klaus Bally, Basle
Prof. Dr. med. Verena Briner, Lucerne
Prof. Dr. theol. Johannes Fischer, Zurich
Attorney-at-law Hanspeter Kuhn, Berne
Lic. theol. Settimio Monteverde, Basle
Catherine Panchaud, M.Sc, Puidoux
PD Dr. phil. Klaus Peter Rippe, Zurich
Prof. Dr. iur. et Dr. h.c. Kurt Seelmann, Basle
Prof. Dr. med. Frédéric Stiefel, Lausanne
Prof. Dr. med. Andreas Stuck, Berne

Consultation

On 27 November 2003 the Senate of the SAMS approved a draft version of these guidelines, to be submitted for consultation.

Approval

Approved by the Senate of the SAMS on 25 November 2004.

Revision

In 2012, these Guidelines were revised to reflect the legal situation in Switzerland as of 1 January 2013 (Swiss Civil Code; Adult Protection Law, Law of Persons and Law of Children, Art. 360 ff.; Amendment dated 19 December 2008).



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