



## **Care of patients in the end of life**

Medical-ethical Guidelines of the SAMS

The German version is the original, binding version

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## I. Preamble

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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<sup>1</sup>, but also on family members, the doctors 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 emphasise 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 in need of care*.

For the particular problems that arise in the case of very underdeveloped premature babies, we refer to the *Recommendations of the Swiss Association for Neonatology on the care of premature infants at the limits of viability*.

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<sup>1</sup> 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.

## **II. Guidelines**

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### **1. Scope of application**

These Guidelines concern the care of patients at the end of life. These are patients whose doctor 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 doctor to explain the possibilities and limitations of both the curative and the palliative therapies that are available.

#### **2.1. Patients capable of making decisions**

Respect for the wishes of a patient who is capable of making decisions is central as far as medical intervention is concerned. Therefore, any medical treatment that is against the express wishes of the 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 who are legally incapacitated can also be capable of making decisions regarding medical interventions.

#### **2.2. Patients incapable of making decisions**

##### **2.2.1 Procedure in accordance with the assumed wishes of the patient**

If the patient is no longer able to express his wishes, his presumed wishes must be ascertained. The doctor or the nursing staff must therefore find out whether the patient has drawn up an advance directive, has given authorisation to a health care proxy, or has clearly expressed his wishes to his family members. Whether or not a legal representative has been appointed must also be clarified. If this is the case, the consent of this legal representative must be obtained.

##### *Advance directives*

All persons may stipulate, in advance, conditions covering the type of treatment they wish to receive should they become incapable (advance directives). These instructions must be followed, as long as they apply to the actual situation and there is no indication that they no longer reflect the patient's current wishes.

*Representative authorised for medical matters*

All persons may nominate, in advance and in writing, a “representative authorised for medical matters” (hereafter called “health care proxy”), who can agree to a particular treatment on the patient’s behalf, if he is no longer capable of making decisions. While taking into account any existing instructions by the patient, decisions must be made in agreement with the nominated health care proxy.

*Further instructions regarding the patient’s assumed wishes*

It is often the case that neither an advance directive on the part of the patient is available nor a health care proxy has been nominated, and that there is also no legal representative. In this situation, information should be obtained as to what the patient thought and how he acted up until the present moment. Here, discussion with family members and possibly with others (e.g. the family doctor) is as a rule of particular importance

**2.2.2. How to proceed in the best interests of the patient**

Sometimes there is no possibility of obtaining an indication of the patient’s assumed wishes, for example if there are no family members available for consultation or if for reasons of urgency, such as in the case of an accident, it is not possible to question third parties. In these cases, the decision of the treating physician must be made bearing in mind the best interests of the patient.

For children and adolescents who are incapable of making their own decisions it is, in principle, the wishes of the legal representatives that apply; as a rule, these are the parents. However, life and death decisions are an enormous and sometimes almost intolerable burden for parents. They should therefore be included in the decision-making process only to the extent that they wish to be. Decisions on treatment and care must be made in the best interests of the child or adolescent, in agreement with the parents or the legal representatives.

**2.2.3. Situations of conflict**

If the patient’s representatives (legal representatives or the health care proxy) refuse to accept a measure which from the medical point of view is absolutely in the interests of a patient who is incapable of making decisions, all the possibilities for mediation, for example through ethical consultations, must first be exhausted. If agreement cannot be reached, the guardianship authority must be called in. If in the case of an emergency situation there is no time for these steps, appropriate measures must be taken, even if these are against the wishes of the patient’s representatives.

**3. Treatment and care****3.1. Palliative care**

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 utilised 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 doctor's duty to alleviate pain and suffering, even if in individual cases this is intended to have an influence (shortening or prolongation) on the duration of life itself. With symptoms that are refractory to treatment, palliative 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.

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 recognised as far as this is possible..

### **3.2. Withholding and withdrawing treatment**

Faced with the process of dying, it may be justified or indicated to withhold or withdraw life-preserving 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, malaise and physical limitation, must be weighed against the possible benefits in terms of well-being, possibilities for personal relationships and the ability to participate in activities.

#### **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 to no purpose, or that are not compatible with the personal moral conscience of the doctor, the rules of medical practice or the applicable laws.

##### **4.1. Assisted suicide**

According to Article 115 of the Penal 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 doctor 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 doctor. On the one hand assisted suicide is not part of a doctor's task, because this contradicts the aims of medicine. On the other hand, consideration of the patient's wishes is fundamental for the doctor-patient relationship. This dilemma requires a personal decision of conscience on the part of the doctor. The decision to provide assistance in suicide must be respected as such. In any case, the doctor 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 doctor.

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 doctor. According to Article 114 of the Penal Code, killing on request is a criminal offence.

### III. Comments

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#### **ad 1. (Scope of application)**

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 characterise the onset of the process of dying. It must be emphasised, 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 capable of making decisions)**

The following criteria help to establish the *ability to make decisions* in accordance with Art. 16 of the Penal 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.

The ability to make decisions is estimated with a view to certain measures (also taking into account the degree of complexity of these measures); this ability to make decisions must exist at the moment the decision is taken.

#### **ad 2.2. (Patients incapable of making decisions)**

The *procedure regarding the consent* of a patient who is incapable of making decisions, who does not have a legal representative and who has also not nominated a health care proxy is not expressly regulated at the Federal level. On the other hand, corresponding legal regulations do exist at the Cantonal level; these are, however, not uniform in the different Cantons. In this respect, see: Treatment and care of elderly persons in need of care: Medical-ethical Guidelines and Recommendations, Footnote 6.

#### **ad 2.2.1. (Procedure in accordance with the assumed wishes of the patient)**

The assumed wishes are the wishes that the patient would probably express if he were still capable of making decisions. 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.

#### **ad 2.2.2 (How to proceed in the best interests of the patient)**

We understand "proceed 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 hypothetically reasonable person in a similar situation would presumably agree.

**ad 2.2.3. (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 the 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.

*Effect on 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. (Rejection or discontinuation of 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 who are in need of care 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 doctor who was responsible for the assisted suicide may not himself fill out the corresponding death certificate.

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#### **IV. Recommendations to the responsible health authorities**

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##### *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.

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**Approval**

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**Guidelines cited**

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