Palliative Care
Medical-ethical guidelines and recommendations

Palliative Care

Approved by the Senate of the SAMS on 23 May 2006
The German version is the original, binding version.

As of 1 January 2013, the guidelines were revised in the light of the new adult protection law.
The Swiss Professional Association for Nurses (SBK/ASI) recommends that its members and all other nurses should abide by these guidelines.

These guidelines are an integral part of the Code of the Swiss Medical Association (FMH).
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I. PREAMBLE

Palliative care has been discussed in various medical-ethical 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 specialization 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 support the use of palliative care in everyday medical practice, in all fields of medicine, but also in situations where curative therapeutic options are still practicable. Their objective is to encourage an attitude which recognizes the limits of medicine and confronts the process of dying as well as the feelings of helplessness often associated with this.

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

1. Definition
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 his illness. This includes the provision of support for relatives. Suffering is to be alleviated as effectively as possible, and social, psychological and spiritual aspects are also to be considered, 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 death are seen as imminent, 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.
– supports relatives in coming to terms with the patient’s illness and in grieving.

2. Area of application
Palliative care should be integrated into the overall treatment of all incurable diseases and, complementary to the therapeutic measures, in situations where the ultimate outcome is uncertain:
– irrespective of the patient’s age (from premature infants 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;
– integrated into the collaboration between physicians, nurses, social workers, therapists, the patient’s relatives and volunteers.

2 For the sake of simplicity, the masculine pronouns are used when both sexes are intended.
3 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 other close persons.
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 (biopsychosocial concept of 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 recede 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 opioids;
– 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 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 wishes 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 guided, in the case of patients who lack capacity, by any values and wishes that may have been previously expressed verbally or documented in writing (e.g. in an advance directive).4)

5. Decision-making processes
If he has capacity5, 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 to all concerned. Important decisions must be put down in writing, regularly reviewed and altered if this proves necessary.

4 Cf. “Advance directives” (medical-ethical guidelines and recommendations of the SAMS).
5 Capacity is assessed in respect of a particular action and according to the degree of complexity of that action. The patient must have capacity at the time the decision is made. Minors or legally incapacitated persons may also have capacity to consent to or refuse treatment.
The patient is to 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 difficult are situations where the patient no longer has capacity with regard to a particular medical measure. The attending physician must ascertain whether an advance directive is available. 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 act as a representative. As far as possible, the patient concerned is also to be involved in the decision-making process. 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. 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 limits 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.

6 With regard to medical interventions, the following persons, in the following order, are entitled to act as representatives for the person lacking capacity: (1) persons appointed in an advance directive or power of attorney; (2) a duly authorised deputy; (3) a spouse or registered partner who shares the same household or regularly provides personal support for the person lacking capacity; (4) the person who shares the same household as and regularly provides personal support for the person lacking capacity; (5) the offspring, (6) the parents or (7) the siblings, if they regularly provide personal support for the person lacking capacity (Art. 378 Civil Code). For patients receiving medical treatment in connection with an involuntary committal, Art. 434 Civil Code is applicable.

7 Cf. “Ethics support in medicine” (recommendations of the SAMS).
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 collaboration**

In palliative care, other specialists and volunteers often also play a significant role in the care of, and in the relationship with the patient besides the physicians 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 but also between the GP, outpatient services, hospital units and the institutions collaborate. By nominating a reference person, responsible for the patient, the organizational condition for this can be set up. Here, the GP can play a key role.

The need for interdisciplinary collaboration does not release the treating physicians, 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 illness, 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 disability 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 (advance care planning).

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

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

10 This includes, for example, addressing questions regarding the indication for further drug treatments, hospitalizations, transfers, surgical measures, intensive care, artificial respiration or resuscitation.
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 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 infants and newborns, children and adolescents and severely disabled children.\(^{11}\)

Premature infants and newborns \(^{12}\)

Half of the deaths in childhood occur in newborns, mainly as a result of prematurity, 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 familiarize themselves either with their child or with the medical situation. Therefore, special care has to be taken to include them 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-sustaining measures can be helpful.
- 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 patient group.
- 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 for leave-taking. 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 grieving process. Families must be supported and counselled in this endeavour.

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\(^{11}\) When the terms “child” or “children” are used in the text from now on, it is meant to include adolescents as well.

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.\(^\text{13}\)
- 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.
- Leave-taking rituals are very important for the family. The family, including the child’s siblings, must be supported in this.

Severely disabled children\(^\text{14}\)

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

For these children the following points have to be considered:
- Besides the special-needs educational 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.

\(^{13}\) Minors may have capacity to consent to treatment. Capacity is assessed for the specific situation and treatment.

\(^{14}\) Cf. "Treatment and care of patients with chronic severe brain damage" (medical-ethical guidelines of the SAMS).
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 treatment and the patient’s expectations with regard to end-of-life treatment 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 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 anti-cancer 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 limits 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 and if the course of disease is appropriately anticipated.
– 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 patient’s affairs in order.

8.4. Palliative care in geriatric medicine

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 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 care 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.

Elderly (generally multimorbid) patients often express a wish to die. In this situation, the task of the treatment team is to determine what underlies this wish, to alleviate distressing symptoms, and to detect and treat any depression. A wish for death is to be viewed not primarily as a wish for suicide, but as an expression of existential anguish.

When a patient’s ability to communicate is impaired, non-verbal signals, like the refusal to take food or drugs, must be respected, after treatable causes have been excluded. Documented previous expressions of the patient’s wishes (advance directives) are essentially binding.

15 Cf. “Treatment and care of elderly persons dependent on care” (medical-ethical guidelines and recommendations of the SAMS).
16 See the SAMS guidelines: “Treatment and care of patients with chronic severe brain damage,” Section 4.4, and especially the comments under 4.4.
8.5. Palliative care in psychiatry

Many psychiatric conditions can be chronic or are characterized 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 disability, 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 depression with repeated suicide attempts;
– severe schizophrenia, with poor quality of life in the opinion of the patient;
– severest anorexia;
– drug addiction.

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 for patients at the end of life

Patients who are approaching the end of their life are particularly dependent on palliative care. What is understood to be a good death cannot be defined according to objective criteria, but depends on very varied individual perceptions. 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. Wishes previously expressed by the patient are to take precedence. 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 duration of life. The effect on the duration of life, especially its shortening, is generally overestimated.

17 Cf. “End-of-life care” (medical-ethical guidelines of the SAMS), especially the definition of patients at the end of life in Section 1: “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.”
Withholding or withdrawing treatment

In view of the process of dying, the decision to withhold or to withdraw life-sustaining measures may be justified or even called for. Also, in the last few days of life there is often no subjective 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.

Sedation

Palliative care aims at maintaining the patient’s ability to communicate. Sometimes however, sedation may be indicated, in order to make symptoms that are difficult to treat temporarily more tolerable, until appropriate therapeutic measures have the desired effect.

Sedation refers to deliberate administration of sedatives in the lowest effective dosage, in close cooperation with a skilled interdisciplinary team, for the purpose of sustained alleviation of one or more treatment-resistant symptoms in a patient with advanced disease and limited life expectancy (days, weeks) by means of permanent or temporary reduction of consciousness.

Continuous sedation is a major decision. Whenever possible, it is to be discussed in advance with the patient or his representative (advance care planning).

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 accordace 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.

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18 Cf. “End-of-life care” (medical-ethical guidelines of the SAMS), comments on Section 3.1.
9.2. Leave-taking and grieving

The way of dealing 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 handling 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 grieving 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 organizational and financial support of palliative-care networks.

2. 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 (specialist training provided by professional associations and advanced nursing schools) and in the continuing medical education sector (professional associations, FMH, SBK etc.).

3. 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 for the public about the components and the possibilities of palliative care by professional associations and interested organizations (e.g. Cancer League, Lung League, Heart Foundation etc.).
IV. APPENDIX

**Literature**

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Education and postgraduate training in “Palliative Care”. National recommendations. 2002.

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Information on the elaboration of these guidelines

Mandate
On 13 June 2003 the Central Ethical Committee of the SAMS appointed a sub-committee to draw up guidelines on palliative care.

Responsible sub-committee
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Consultation
On 24 November 2005 the first version of these guidelines was passed by the Senate of the SAMS, for submission to the consultation procedure.

Approval
The definitive version of these guidelines was approved by the Senate of the SAMS on 23 May 2006.

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).