

## Medical-ethical guidelines: Management of dying and death

Swiss Academy of Medical Sciences

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### I. Preamble

Provision of treatment, care and support for patients who are facing death is a key medical duty, requiring a high degree of respect for the patient's dignity and autonomous wishes, and considerable ethical responsibility. The fulfilment of this duty must be guided by the principles of palliative care<sup>1</sup>. Palliative care is especially important in the terminal phase, but it should be introduced at a much earlier stage in the course of a chronic condition and provided in parallel with curative efforts. If necessary, access to appropriate specialised services should be ensured.

Since the publication of the SAMS guidelines on "End-of-life care" in 2004, the topics of dying and death have been increasingly subject to professional and public debate. The focus has generally been on the desire for self-determination at the end of life, but also deserving of reflection is the question how this demand for self-determination affects individuals themselves, their relatives<sup>2</sup>, medical professionals and society.

In May 2015, the Central Ethics Committee of the SAMS appointed a subcommittee to revise the guidelines on end-of-life care. In its work, the subcommittee drew, inter alia, on a study commissioned by the SAMS concerning Swiss physicians' attitudes to assisted suicide<sup>3</sup> and also considered the results of the National Research Programme "End of life" (NRP 67)<sup>4</sup>. In the revised guidelines, the scope (Section 1) has been expanded. The guidelines now cover not only end-of-life care but also discussions with patients who have been diagnosed with a terminal disease (Section 3) and management of the desire for death (Section 4). Assisted suicide in patients not facing imminent death – an area not previously covered by SAMS guidelines – is thus also addressed. This expansion raises fundamental questions (cf. Section 6.2).

The guidelines divide possible actions by medical professionals involved in the management of dying and death into three categories:

- Actions which are in accordance with the generally acknowledged goals of medicine and thus essentially form part of the responsibilities of all medical professionals (Section 6.1).

- Actions which are controversial, the performance of which is a matter for physicians who are personally convinced, in a particular case, that they serve the patient's best interests. Here, physicians act on their own responsibility and on no account can they be obliged to perform such actions. If these actions are carried out, certain rules must be complied with to ensure that they are in accordance with the wishes of a patient who has capacity (Section 6.2).
- Actions which contravene Swiss law and are thus prohibited (Section 6.3).

The guidelines first set out ethical principles (Section 2). They then offer guidance for discussions with patients on dying and death (Section 3) and the desire for death (Section 4). Section 5 deals with decision-making processes, and Section 6 with actions which possibly or certainly hasten the onset of death. Finally, a glossary of key terms is provided. The definitions underlying the guidelines, as well as some reflections on the goals of medicine, can be found in the Annex, Section 2.

The guidelines are essentially based on three principles:

- Firstly, for each medical action in the management of dying and death, it must be clearly defined, together with the patient or authorised representative, what goal is being pursued with regard to the time of death: is it to be delayed if possible; is it not to be influenced, with death being accepted if it occurs as the disease takes its course; or is the intention to hasten death?
- Secondly, the self-determination of a patient with capacity must be respected. The extent to which autonomously expressed wishes can be put into effect may, however, be restricted by the rights of other people concerned – be they relatives or medical professionals.
- Thirdly, vulnerable patients confronting dying and death must be protected against the uncritical fulfilment of desires which they have expressed, if there is evidence that these do not reflect their informed, voluntary and considered wishes.

In the application of these principles, discussions with the patient are of the utmost importance. Providing information tailored to the individual situation, listening carefully and openly addressing the patient's wishes will facilitate shared end-of-life decision-making. Also important are

discussions with and support for relatives. The continuous communication process which this necessitates can be demanding and stressful.

The guidelines seek to mediate between different viewpoints and values, and to ensure that the self-determination of all parties – patients, relatives and medical professionals – is respected and protected. The prime concern – patient welfare- oriented management of death and dying – must not either place excessive demands on relatives or undermine medical professionals' conception of their role. If this is to be achieved, a more extensive social debate will be required on what goals should be pursued by and what responsibilities assigned to medicine in the future. Before medicine assumes new responsibilities which do not accord with its traditionally recognised goals, it should be considered whether it is not being asked to resolve problems which are in fact the responsibility of other actors within society.

## II. Guidelines

### 1. Scope

The guidelines are addressed to physicians, nurses and other professionals who provide treatment, care and support for patients<sup>5</sup> facing dying and death<sup>6</sup> – in particular, the following three groups:

- Patients who, according to a clinical assessment, have entered the dying process<sup>7</sup>, in cases where this process cannot be arrested or the person concerned no longer wishes to receive life-sustaining treatment.
- Patients suffering from a disease that will in all likelihood prove to be fatal since no curative treatment options are available.
- Patients who seek medical assistance in ending their lives, irrespective of whether or not death is already foreseeable. This request differs markedly from what is generally expected of a physician in the face of dying and death, in that what is desired is self-determination regarding the time of one's own death. Patients whose desire to die is not primarily attributable to a medical condition may also consult a physician for this purpose, especially since the desired form of assisted suicide requires a medical prescription.

Patients can belong to these various groups simultaneously or successively.

The guidelines are also applicable for children and adolescents of any age, and for patients with mental, psychosocial and multiple disabilities. At certain points in the text, reference is made to particular considerations for these groups of patients. In addition, specific guidelines issued by professional societies<sup>8</sup> and the SAMS<sup>9</sup> are to be observed.

In emergencies and in other acute situations where death is unexpectedly imminent, the guidelines are applicable *mutatis mutandis*. The relevant SAMS guidelines<sup>10</sup> are also applicable.

## 2. Principles

### 2.1. Right to self-determination

All patients have a right to self-determination over the entire course of their disease until death. Prerequisites for autonomous decisions are timely and comprehensive information on the medical situation and open, empathetic communication as to the possibilities and limits of curative treatments and palliative care.

Patients who lack capacity have a right to be involved in the decision-making process. For children and adolescents, it should be assessed in particular cases whether they have capacity in relation to the decision in question. If they do have capacity, the right to make a decision passes from the parents to the child. The decision will, however, be influenced by the complex interactions existing between the child and the two parents.<sup>11</sup>

Impairments of capacity are common in fatal diseases and especially during the dying process. In view of the patient's resultant vulnerability, the treatment team must be aware of the risk of paternalism: as well as paying attention to the wishes and preferences expressed by the patient, it must also seek evidence of earlier written or verbal statements concerning preferred treatment options. If an advance directive is available, this must be complied with if the patient lacks capacity.

The right to self-determination provides protection against paternalism, but it also allows for the possibility of foregoing active participation in the decision-making process. If patients are unable or unwilling to make the effort to decide for themselves, they may adopt and tacitly accept treatment recommendations made by others. However, this by no means implies that they lose the right to change their mind at any time. The treatment team and the patient's representative have a duty to attend carefully to any signs of a reawakened desire for self-determination.

### 2.2. Self-determination in a social context

Patients are embedded in a social environment and generally interact with persons close to them and with the treatment team. Such relationships may strengthen their capacity for self-determination, if the people around them help them to cope with the disease situation and to formulate their wishes concerning treatment and care in accordance with their own individual values. At the same time, there is a risk that patients may be unduly influenced by the expectations and judgments of relatives and the treatment team, regardless of whether or not this is the intended result. Likewise, patients may feel overly responsible for those close to them and neglect their own interests.

Impairments of capacity, and hence autonomy, arising from the patient's condition can often be mitigated or even eliminated if appropriate measures are taken. The following points should be noted:

- Capacity involves a number of abilities, such as grasping the situation, recognising various possible options and the consequences thereof, evaluating options on the basis of individual preferences, and communicating one's decisions and wishes. These abilities should be supported without exerting pressure and in an empathetic manner.

- In patients with impaired capacity, it should be determined which of the above abilities are present and how these can be taken into account in the decision-making process. Patients who lack capacity also have a right to be involved in decision-making as far as possible.
- Persons close to the patient should be engaged to facilitate communication, provided that this is in accordance with the patient's wishes and interests.
- Sufficient time and the necessary aids should be available for discussions and communication.
- If the patient's preferences can only be apprehended empathetically, on the basis of familiarity with earlier statements and reactions, the treatment team and relatives must be aware that this involves the risk of projection of one's own wishes and ideas.

### 2.3. *Quality of life*

In the medical treatment and care of patients facing dying and death, appropriate consideration of quality of life is essential. For those providing care, this means:

- focusing on patients' subjective experience – in particular, how their symptoms are perceived, as well as their suffering or degree of satisfaction with their overall situation;
- bearing in mind that, in patients facing dying and death, quality of life can be improved not only by alleviating suffering but also by promoting hope and enjoyment;
- identifying the relevant dimensions of quality of life (physical, emotional, intellectual, spiritual, social and economic);
- respecting how the various aspects of quality of life are weighted from the patient's perspective;
- in patients whose ability to communicate is impaired, assessing their subjective experience as far as possible on the basis of objective observations;
- in so doing, remaining aware of the risk of projecting one's own ideas, preconceptions, wishes and fears;
- explicitly addressing (and considering separately) the quality of life of relatives and caregivers, which is often closely linked to the patient's quality of life.

### 2.4. *Suffering and its alleviation*

Suffering always affects the whole person. Those who suffer feel helpless in the face of an unremitting, highly unpleasant sensation. The causes of suffering can spring from all dimensions of human life and do not by any means fall exclusively within the province of medicine. Suffering can be caused, not only by symptoms of physical and mental disorders, but also by restrictions in everyday life and in social relations, losses and a sense of purpose- or hopelessness – either individually or in mutually reinforcing combinations.

The extent and nature of factors leading to suffering can be assessed – at least partly – from the outside, especially by close associates. The resultant suffering itself, however, can only be apprehended on the basis of what is communicated (verbally and non-verbally) by the person concerned. The degree of suffering subjectively experienced in response to factors of the same kind can vary considerably, depending on the personality and environment.

Suffering is alleviated by removal or avoidance of the causative factors. Sufferers can also mobilise resources which mitigate or compensate for these factors so that a new inner equilibrium is attained. If these efforts are at least partly successful, suffering can be more readily tolerated. But if severe suffering is perceived as chronic or progressive and any hope of alleviation or resolution has been lost, it is often described as intolerable. Intolerable suffering need not be persistent and can, thanks to palliative care or spontaneously, give way to improvement and new hope. However, it is also possible that patients' suffering will be felt to be intolerable permanently, until their death. No objective criteria exist for suffering in general or for intolerable suffering in particular. Intolerability can only be designated as such by sufferers themselves; it is not ascribable by others. It may, however, be more or less comprehensible to others.

Disease-related physical pain is a common cause of suffering. The expression "mental suffering" is also frequently used. In palliative care, to emphasise the significance of suffering not caused by physical symptoms, the concept of "total pain"<sup>12</sup> has been developed, encompassing all dimensions of a patient's suffering. However valuable this may be for holistic care, there is a risk that this use of language could promote an uncritical extension of medical practice to the management of psychosocial and existential suffering.<sup>13</sup> Analgesic drugs are not suitable for the treatment of psychosocial or existential suffering. The fact that sedation can be used to diminish or even completely eliminate the sensation and expression of suffering must not prevent patients from being offered non-medical measures – in particular, psychosocial and spiritual support and common human compassion.

### 2.5. *Establishment of the treatment goal*

The overarching goal of treatment must be established together with the patient or the authorised representative: is the aim to preserve the patient's life as far as possible? Is the focus to be placed on the alleviation of suffering, even if the onset of death may be hastened as a result of the treatment? Or is it desired that the onset of death should be as rapid as possible? As treatment is pursued, all the professionals involved must be guided by this treatment goal and consider, prior to each measure, whether the intention with which it is undertaken is consistent with this goal.

Certain measures, such as the administration of analgesic drugs or continuous deep sedation, can be employed both to treat symptoms and to deliberately bring about death. Likewise, the withdrawal of life-sustaining measures can not only represent a transition to symptom-directed treatment only, with death being accepted as a consequence, but also be employed as a means of deliberately ending life. For the purposes of ethical and legal evaluation, the intention of the physician and other professionals performing the action is decisive. To ensure that a planned action is permissible, the treatment team's intention must therefore be clearly defined. This is to be agreed with the patient and relatives, and the procedure is to be defined accordingly. The intention is evident, for example, in the choice of medication and dose control.

### 2.6. Care and support for relatives

Relatives are also affected by the patient's dying process, which may be highly stressful for them. At the same time, thanks to their intimate knowledge of the patient, they can offer the treatment team important information on the patient's situation and presumed preferences. In addition, they are often involved in the provision of care and support, as well as influencing the patient's views and expectations.

The complex role played by relatives – as affected family members, informants and co-caregivers – is highly demanding. As a result, relatives may sometimes overtax themselves and repress their own suffering in relation to their imminent loss, or they may withdraw. It is up to the members of the treatment team to bear these risks in mind and, if appropriate, to be proactive in minimising them. Successfully involving relatives in the patient's care can have positive effects on the processes of leave-taking and grieving. Empathy and expertise are called for in particular when caring for the relatives of dying children, or for children facing the death of a parent.

The complexity of the relatives' role becomes apparent in the debate on the place of death: over the past century, grave suffering and dying were increasingly "delegated" by society to institutions, and by relatives to professionals. With the development of palliative care, efforts have been made to bring dying back from "institutional virtuality" to everyday reality. This reflects the wishes of many people who would prefer to die at home, in their familiar surroundings. However, the great importance attached to this desire can also give rise to unreasonable expectations. Dying at home is sometimes even taken to be an indicator of good palliative care. But while the patient's wish is made the central concern, relatives are frequently pushed to their limits unless they receive sufficient support (e.g. information on home care services). If the patient's needs are wrongly conceived as taking precedence over those of the relatives, the demands placed on the latter can be excessive. Important though the patient's idea of the ideal place of death may be, the possibilities of their social environment must also be taken into account. The constraints imposed by society on the choice of setting for end-of-life care are also accentuated by the increasing number of people who do not have any relatives that would be willing and able to act as caregivers.

### 3. Talking about dying and death

Discussions of dying and death are an important element in the treatment and care of patients. This is the case not only when the terminal phase is imminent or has already begun, but also in the early stages of confronting a disease with a grave prognosis (e.g. malignancies and chronic heart, lung and kidney failure, as well as neurodegenerative disorders and dementia), and also whenever the topic is raised by a patient. The physician should endeavour not only to offer potentially curative or life-extending measures, but also to recognise the patient's need to discuss existential matters – and encourage the patient to do so. How and when this topic should be broached cannot be standardised. An approach which is suitable from the individual patient's perspective should be pursued, taking the cultural background into account.

Both the physician's role in discussions and the information to be communicated will change over the course of a serious illness. It is important that the patient should be informed in an appropriate manner, at an early stage, of the gravity of the prognosis and the fact that the disease is highly likely to be fatal. When, as the disease progresses, death becomes foreseeable, other subjects may become important. It is the physician's responsibility to find out what the patient wishes to discuss or is anxious about. Fears can often be effectively allayed by providing information on the expected course of death and the possibilities of palliative care. Even so, uncertainties may remain which have to be endured. In the terminal phase, information becomes less and less important, and the priority should be active, attentive and empathetic listening.

Many dying patients have a need to talk about dying and death with professionals. However, this is not the case for all patients. If a patient does not wish to discuss this subject, this should also be respected.

A sound knowledge of techniques for conducting discussions is essential for talking about dying and death. These can be learned. The discussions require an appropriate, peaceful environment and sufficient time. Often, it will be useful to have a number of discussions, with the patient determining who is to take part in each case. Just as important as discussion techniques is appropriate management of the emotions associated with dying and death. Engagement with one's own mortality provides a basis for talking with patients about dying and death. This makes it easier to understand the attitudes, needs and fears of the patient (and relatives). The physician's fundamental approach should involve a readiness to understand and accept the patient's wishes. Discussions are more easily conducted and more helpful for patients if the professionals responsible make it clear in advance what role they will play in the management of the dying process. They should also consider what positive treatment goals they wish to offer the patient (e.g. support during the dying process and alleviation of suffering).

Discussing dying and death with sick children and adolescents calls for particular sensitivity and experience. Often it is useful to have discussions both with the parents and child together and separately, and also to encourage discussions between the child and parents.

Continuity is also important: discussions should take place regularly and not include too much information. The content should be consistent, comprehensible and adapted to the course of disease and the dying process. It is important to make sure that the information has been assimilated by the patient (and relatives). "Any remaining questions" should also be addressed as long as this is permitted by the patient's cognitive functions.

These discussions can be adversely affected and misunderstandings can arise if dying patients are cared for by different physicians, organisations or hospitals. Inadequate coordination can lead to contradictory statements and uncertainty as to what has been communicated. In the worst case, the patient may consequently adopt a defensive posture towards further discussions. Responsibilities for (the content of) discussions should therefore be agreed within the interprofessional team, and the content should be recorded in writing.

The relatives should also – subject to the patient’s agreement – be engaged in continuing discussions. The patient may or may not be involved in these discussions, but should always be informed about them. Discussions should also be held with children (or adolescents) of seriously ill parents, adapted to their level of development.

Relatives often lack experience of the dying. As they have never witnessed a person’s death, they may have unrealistic ideas about the dying process. It is therefore helpful, particularly in the last phase of life as the grieving period approaches, if they are informed about the physical and mental reactions which may occur prior to the onset of death (e.g. loss of sensation of hunger/thirst, clouded consciousness and confusion, muscle jerking, interrupted breathing and the “death rattle”).

#### 4. Management of the desire for death

If a patient expresses a wish to die, the care team must take this seriously and seek an explanation. The underlying motives, both for a vaguely expressed wish to die and for a determined request for active termination of life, may vary widely. Often, patients are ambivalent, and a wish to carry on living co-exists with the wish to die. Desires for death should be discussed openly and without making value judgements. The primary aim should always be to seek to understand the patient’s suffering. If this suffering can be alleviated, appropriate options should be offered. These may take the form not only of medical/nursing measures, but also of assistance with activating individual and social resources from the patient’s personal environment. It must be discussed – with the patient, or in the event of incapacity with the authorised representative or relatives – what treatment goal is to be pursued and what medical treatments are desired or refused. The results can be recorded in a care plan (cf. Section 5.2).

In evaluating the patient’s suffering, the care team should adopt a comprehensive approach – also consulting experts, if necessary. In particular, it must be carefully assessed whether the desire for death is a symptom of a mental disorder.<sup>14</sup> With the patient’s consent, the relatives should be involved in this assessment.

In many cases, the desire for death subsides after detailed discussions. There are, however, situations in which the desire for hastened death persists. In this case, various avenues are open. If the patient so requests, life-sustaining treatments can be withdrawn. Some patients choose to refuse food and fluids (so-called terminal fasting). There are also situations in which the patient finds none of these options acceptable and explicitly requests assisted suicide. Physicians receiving such a request must then decide for themselves whether or not to accede to it; they must inform the patient of their decision and about possible alternatives.

Desires for death can also be expressed by children and adolescents. They should be discussed together with the family but – in the case of older children and adolescents – always with the patient alone as well, since the patient’s wishes may possibly otherwise be concealed out of consideration for the parents.

A special situation arises when the parents of minors who lack capacity, or authorised representatives of adults permanently lacking capacity, express a wish for the rapid death of the patient for whom they are responsible. While

they deserve respect and understanding, it must also be explained to them that, under the law, life-sustaining measures may only be withheld or withdrawn if this is in accordance with the patient’s best interests and presumed wishes, and that active measures to terminate life are prohibited.

## 5. Decision-making processes

### 5.1. Shared decision-making

The self-determination of the informed patient with capacity also plays a decisive role in the management of dying and death. However, informed consent to medical interventions should be seen only as the end point. The aim is, through a joint process, to promote patients’ active engagement with their situation.

Shared decision-making calls for a process in which the physician and other professionals, taking the patient’s ideas and current knowledge into account, listen to his or her needs, desires and fears, and seek to determine the patient’s preferences. This also applies for children and adolescents. Together with the patient, it should be discussed, based on the best possible evidence, what treatment goals are appropriate in this particular case, what therapeutic and nursing measures can be used to achieve these goals, and what kind of psychosocial support is desired. The patient (with capacity) must make the final decision on whether the treatment offered is to be carried out.

A patient who lacks capacity should be involved as far as possible in the decision-making process. If a clearly formulated advance directive or care plan is available, then this will determine the choice between alternative treatment options, or in favour of refusal of treatment. If the patient’s wishes cannot be ascertained, then a decision must be made by the authorised representative<sup>15</sup> in accordance with the patient’s presumed wishes and best interests. A detailed account of the role of the patient and the authorised representative in decision-making is included in the Glossary (Annex, Section 1).

### 5.2. Advance care planning<sup>16</sup>

Since patients’ capacity for self-determination is often increasingly restricted in the last phase of life, it is important to explore with them their conception of their illness, and their ideas, values and wishes concerning treatment and care, as well as their spiritual needs, before this becomes impossible as a result of deterioration in their health and state of consciousness. In the course of these discussions, a plan can be developed, defining the measures to be taken should certain symptoms or complications occur. In particular, the procedure in the event of an emergency should also be discussed. The discussions and the resultant agreements should be documented and made available to the professionals responsible for care and also, with the patient’s consent, to the authorised representative and the relatives. Care planning must be reviewed at regular intervals and adapted to the patient’s current health status. In outpatient and inpatient care, patients with a fatal disease should be encouraged, and offered support, to engage in an individual planning process of this kind. For children and adults who lack capacity, care planning should be undertaken with the authorised representative.

In this process, patients can essentially be supported by professionals of any kind (e.g. GPs and specialists, in- or outpatient specialists, nurses, psychologists, pastoral and social workers). Additional support can be provided by so-called facilitators<sup>17</sup> – specifically trained non-medical professionals. This may be particularly valuable in complex disease situations and in large institutions where numerous professionals are involved. It is, however, always essential that advisers have both the requisite medical knowledge and communication skills.

### 5.3. Involvement of relatives

Relatives are, first and foremost, persons also affected by a patient's condition, but they are also frequently involved in the provision of care and support. In addition, relatives play an important role as informants in determining the (presumed) wishes of patients who lack capacity, and they act as representatives for patients who can no longer decide for themselves.

Relatives are here defined as all persons close to the patient. Under the relevant legislation, patients can themselves appoint a person to act as their representative in the event of *incapacity*; this need not be a relative. If no representative has been appointed, the legally specified hierarchy is applicable.<sup>18</sup>

Relatives not authorised to act as representatives may, with the patient's consent, be informed about the patient's health status and treatment. It is therefore advisable to discuss with the patient, at an early stage, which relatives are to be informed and how they are to be involved over the course of the disease. It is often appropriate to encourage the patient to fully inform the main relatives, since open dialogue and the courage to address even difficult matters can make things easier in the last phase of life. On no account should relatives who are minors be overlooked.

### 5.4. Conflict situations

Relatives may be confronted with decisions made by a patient which they find incomprehensible, or which conflict with their own values. Problems may arise if relatives acting as representatives give priority – consciously or unconsciously – to their own values and ideas. As a result, they may misinterpret or fail to recognise the needs of the patient, which may change as the disease progresses. In such cases, the treatment team must raise this issue and seek to resolve it through dialogue.

The patient's wishes take precedence. However, respect for the right to self-determination can come under pressure. Conflicts may arise if patients demand treatments which are futile, request actions which physicians cannot reconcile with their conscience (e.g. assisted suicide), or express wishes which place excessive strain on relatives (e.g. the wish to die at home). In such situations, it is advisable to hold a number of discussions. Ethics support may promote acceptance of the final decision by all parties.

If a conflict arises because authorised representatives disagree among themselves, a solution should be sought in a series of discussions, with ethics support being provided. If no further dialogue is possible, the child and adult protection authority should be called in. This also applies to situations in which there is evidence that the patient's interests are endangered or no longer safeguarded – e.g. if a

professional ignores or misinterprets an advance directive, or if authorised representatives pursue their own interests and disregard the presumed wishes or the interests of the patient lacking capacity.

In the event of differences of opinion within the care team, the reasons need to be carefully explored. Different underlying values should be discussed. Here, recourse to ethics support may be helpful.

## 6. Actions possibly or certainly hastening the onset of death

Actions which – possibly or certainly – hasten the onset of death<sup>19</sup> comprise, firstly, accepted actions in accordance with the generally acknowledged goals of medicine<sup>20</sup>; secondly, controversial actions; and, thirdly, impermissible actions, prohibited under Swiss law.

### 6.1. Generally accepted actions

Typical actions – part of generally accepted medical practice – which may hasten the onset of death are the withholding or withdrawal of life-sustaining measures, pharmacological symptom relief and sedation for refractory symptoms. These are generally used in combination, within the context of symptom-directed treatment only<sup>21</sup>, with the intention being to ease the patient's dying process. Here, the fact that the time of death will possibly or certainly be influenced is accepted, but not intended.

#### 6.1.1. Withholding or withdrawal of life-sustaining measures

If a patient with capacity refuses the institution or continuation of life-sustaining measures, accepting death as a consequence, this decision must be respected. This is also the case if a patient with capacity requests that a device which is essential for the maintenance of vital functions be switched off or removed (e.g. a ventilator or pacemaker). The physician is not being asked to support the patient's intention to bring about death, but only to discontinue a medical intervention to which the patient with capacity no longer consents.

If the patient lacks capacity and no advance directive is available, the authorised representative decides whether the patient would have chosen to undergo a proposed treatment, and thus whether it should or should not be performed. The information and advice provided should include an assessment of expected survival time and quality of life with and without the treatment under consideration. The decision is based on the prognosis, taking into account the suffering which would be caused by any treatment, and the patient's values and preferences, if these are known. The more uncertain the effects of treatment on survival time and quality of life, the more difficult it is to determine the patient's best interests. If the best interests are not clear and the patient's presumed wishes are not known, the views and values of authorised representatives assume greater weight. They should be supported in making a decision – even in these situations – which as far as possible takes account of the patient's personality.<sup>22</sup>

Intensive-care interventions may only be initiated or continued if there is a reasonable prospect that the patient will thereby be enabled to survive with appropriate quality of life outside the acute medical setting.<sup>23</sup> Neither patients

nor relatives are entitled to demand treatments with no prospect of success<sup>24</sup>.

When life-sustaining measures are withdrawn, the symptoms occurring as a result require careful attention and appropriate treatment. It is advisable to administer preventive pharmacotherapy for symptoms expected to occur following the withdrawal of such measures. However, this may not be done with the intention of bringing about death as rapidly as possible.

### 6.1.2. Relief of pain and other symptoms

Optimal relief of pain and other symptoms is a core responsibility of those providing care for dying patients. The symptoms are often multidimensional and call for inter-professional and interdisciplinary care. This does not mean that direct contacts with all the professionals involved will necessarily be required. The various professional perspectives should, however, be taken into consideration in decision-making processes and integrated into the patient's treatment and care. In complex situations, specialised palliative care services should be used.

Symptoms commonly observed in the last days of life include pain, dyspnoea, anxiety, agitation and confusion. These should be actively sought (by questioning and examination) and treated. Various drugs indicated in these situations may extend or shorten survival time. Concerns that the use of such drugs (e.g. analgesics, benzodiazepines) could shorten the patient's life must not lead to underdosing. The primary aim must be effective relief of symptoms, with any shortening of survival being accepted as the price to be paid. Conversely, medication must not be administered at a level exceeding that required for optimal treatment of symptoms.

### 6.1.3. Sedation

With palliative measures, even complex symptoms can generally be controlled or reduced to a tolerable level. In situations where symptoms remain refractory<sup>25</sup> and so persistent as to be intolerable for the patient, there exists the treatment option of temporary or continuous palliative sedation, i.e. controlled use of medication intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of suffering. The selection and dosage of drugs are based on the treatment goal (e.g. comfort, relief of suffering). The duration of sedation depends on the situation triggering its use.

As well as somatic symptoms, refractory psychological and/or existential distress may be an indication for transient sedation to provide respite for the patient. The patient's fear of a specific refractory symptom (e.g. sensation of suffocation) or the risk of an emergency situation (e.g. severe dyspnoea, massive haemorrhage) can also be grounds for considering the option of anticipatory palliative sedation. This requires that the treatment team be familiar with the possibilities and limits of this therapy.<sup>26</sup>

Continuous deep sedation until death may only be performed in dying patients and requires specific preliminary assessments. Not infrequently, disagreements exist within the treatment team as to whether the dying process has already begun.<sup>27</sup> These should be discussed openly, and a consensus sought. Before sedation is initiated, the necessary time and space should be allowed for "last things" to

be said and done, and for leave-taking. With the patient's loss of the ability to interact, inner conflicts may also arise for relatives, involving, in particular, the fear or the wish that sedation could directly or indirectly hasten the onset of death. It must therefore be clear for all concerned that continuous deep sedation until death must not be used for the purpose of ending life, but that the aim is to ease the dying process which has already begun. For this reason, the depth of sedation applied is to be symptom-guided.

Both injudicious use of sedation (e.g. because relatives or the care team find the situation hard to bear) and injudicious withholding of sedation are to be avoided. The care team should give an honest answer to the question: for whom does sedation offer respite – for the patient, members of the care team, or the relatives. Depending on the answer given, the decision may need to be reviewed. Here, the following points should also be considered:

- that sedated patients lose their ability to interact and to participate in decision-making;
- that the prospect of palliative sedation can be distressing for patients, relatives and care team members;
- that the care team may reject sedation because it is associated with a sense of failure, or conversely may advocate sedation prematurely because they find the situation harder to bear than even the patient does;
- that in the evaluation of psychological, existential and spiritual distress it can be difficult for members of the care team to separate their own feelings and values from those of the patient.

Since (especially continuous) sedation involves a risk of abuse – in the sense of deliberately causing death – it may only be applied and performed under controlled conditions, on the basis of professional standards and with appropriate record-keeping.

When a decision on the use of sedation is to be made, answers to the following questions must be given and documented:

- Is the suffering intolerable for the patient?
- Is sedation in accordance with the patient's conceptions/wishes?
- Are the symptoms refractory? (Cf. the definition in the Glossary.)
- What methods have been applied to date? Have alternative treatment options been used? If not, why not?
- Would the involvement of a specialised palliative care team be helpful?
- Are treatment services appropriate for the patient's symptoms available? If not, would it be useful and reasonable to transfer the patient?
- How long is the patient expected to survive?
- Does the patient wish to have spiritual support?
- Has the patient/authorised representative been informed about the consequences of sedation and given consent?

In addition, in the case of continuous deep sedation until death:

- Is death foreseeable (within hours or days)?

If sedation is performed, the following points are to be included in the records:

- aim of sedation (symptoms to be influenced);
- expected duration of sedation (temporary or continuous until death);
- hydration (yes or no, indicating the amount and route of administration);
- medication (type, dosage, reasons for dose adjustments);
- monitoring (symptom scores, depth of sedation, adverse effects).

## 6.2. Controversial actions

Requests by patients with capacity to support their intention to bring about their own death pose challenges for medical professionals' understanding of their role in terms of professional ethics. At stake, on the one hand, is their autonomy in the exercise of their profession; on the other hand, they are being asked to display empathy and compassion, which are also required by their professional ethics.

Respect for professional ethical norms and the values deriving from them is one of the fundamental duties of medical professionals. Whether providing active support for patients who intend to end their own lives is compatible with this duty is a matter of controversy among professionals and the public. For this reason, professionals providing treatment must each decide for themselves whether or not they believe such actions to be compatible with the goals of medicine<sup>28</sup>. Before they decide to support a patient's request in a particular case, they must make sure that their action is for the benefit of the patient. This requires an interpersonal relationship with the patient in which compassion, judgement, trustworthiness and integrity are central elements. If, however, they withhold their support, they must on no account force their views on the patient; instead, they must inform the patient in good time what options they are prepared to consider. In this situation, as far as this is possible and desired by the patient, an existing relationship – adjusted in a respectful manner – should be continued.

Assisted suicide, in particular, arouses heated debate. Given the legal framework for assisted suicide in Switzerland and differing attitudes to the management of the desire for death among physicians, other medical professionals and the public, the tensions between the ethical requirements for promotion of self-determination and for protection of life cannot be resolved. Nonetheless, the clearest possible guidelines should be provided for medical professionals. The formulation of objective medical criteria for the acceptability of assisted suicide is problematic since, firstly, such criteria would give rise to difficult questions of demarcation and, secondly, in situations where the criteria were met, assisted suicide would be automatically defined as an option. Patients and medical professionals could thus find themselves under pressure to explain why they do not wish to consider this option. In addition, what leads to a patient's autonomous desire for suicide is not the objective medical condition but the subjective experience of intolerable suffering. While this cannot be expressed in objective terms, it can – through intersubjective comprehension – be convincingly stated by the treating physician. Howev-

er, in order to justify why assisted suicide should be considered a medical matter at all, medically definable symptoms of disease or functional impairments must be present. In view of the exceptionally far-reaching consequences of the decision, possible *incapacity* must be particularly carefully excluded, and it must be conscientiously verified that the patient's desire for suicide is well-considered, not due to external pressure and enduring.

The situation in the case of support for voluntary refusal of food and fluids – increasingly widely discussed in recent times – requires nuanced consideration. Depending on the situation and the wishes of the patient desiring to pursue this course, the actions involved may be generally accepted (in the context of end-of-life care), controversial, or impermissible.

### 6.2.1. Assisted suicide

Under Art. 115 of the Swiss Criminal Code, assisting suicide is not an offence, provided that one does not act from selfish motives. This applies to everyone.

If a patient makes a request for assisted suicide, this is a desire for death and, as such, requires careful assessment.<sup>29</sup> At the same time, the patient should be encouraged to discuss the desire for suicide with his or her relatives.

The role of physicians in the management of dying and death involves relieving symptoms and supporting the patient. Their responsibilities do not include offering assisted suicide, nor are they obliged to perform it. Assisted suicide is not a medical action to which patients could claim to be entitled; it is, however, a legally permissible activity. It can be performed by physicians if they are convinced that the requirements given below are met.

Assisted suicide involves actions which are intended to enable a person with capacity to carry out the suicide – in particular, prescribing or dispensing a drug for this purpose. The prescription of a drug for the purpose of suicide must be reported to the competent cantonal authorities within 30 days.<sup>30</sup>

Like other patients, those who wish to take their own life with an assisted suicide organisation are entitled to inspect and receive a copy of their records. If the patient so wishes, the attending physician can also conduct an assessment of cognitive functions and, if appropriate, issue a certificate of capacity in relation to general, everyday decisions. Such an assessment does not constitute participation in assisted suicide. The physician may also assess and, if appropriate, certify capacity specifically in relation to assisted suicide (which cannot be inferred from everyday decision-making capacity). The patient cannot, however, demand such an assessment.

If an autonomous desire for suicide persists in a patient who has been carefully informed and assessed, a physician may – on the basis of a decision for which he or she is personally responsible – perform assisted suicide, having verified that the following five requirements are met; it must be additionally confirmed by an independent third party (who need not be a physician) that the first two requirements are met:

- The patient has capacity in relation to assisted suicide.<sup>31</sup> It must be documented that *incapacity* has been carefully excluded by the physician. If a mental disorder, de-

mentia or another condition frequently associated with lack of capacity is present, capacity must have been assessed by an appropriate specialist.<sup>32</sup>

- The patient's desire is well-considered, not due to external pressure and enduring. If there is evidence of a problematic relationship of dependency<sup>33</sup>, careful consideration must have been given to its possible influence on the desire for suicide.
- The symptoms of disease and/or functional impairments are a source of intolerable suffering for the patient.
- Medically indicated treatment options and other types of assistance and support have been sought and have proved ineffective or are rejected as unacceptable by the patient, who has capacity in this regard. The patient's desire not to continue living in this situation of intolerable suffering is comprehensible for the physician on the basis of the previous history and repeated discussions, and the physician finds it justifiable to perform assisted suicide in this particular case.

The final action in the process leading to death must always be performed by the patient. Death as a result of assisted suicide must be reported to the competent authorities as an unnatural death. Before, during and after an assisted suicide, consideration is to be given to the needs of relatives, but also of the interprofessional care team and other persons concerned, and the necessary support is to be provided.

#### 6.2.2. Support and symptom management for voluntary refusal of food and fluids

Voluntary refusal of food and fluids (VRFF; terminal fasting) is adopted by some patients as a means of shortening the dying process. The refusal is voluntary if wishes to this effect have been clearly expressed by a person with capacity. An appropriate space and sufficient time are always required to discuss the ideas underlying VRFF.

The topic of VRFF may arise at various points in the course of a disease, raising different questions in each case. In the terminal phase, sensations of hunger and thirst are frequently diminished. This may encourage the decision to adopt VRFF and facilitate its implementation for all concerned, since only actions generally accepted in the care of dying patients are expected of the treatment team. Refusal of food in patients with progressive cognitive impairment (e.g. dementia) calls for careful assessment of whether this reflects their wishes or is due to other reasons.<sup>34</sup>

More difficult are those situations in which patients who are not dying opt for VRFF. The decision as to whether or not support can be offered depends crucially on the patient's motivation and health status, and the values of the health professionals concerned. If support is provided, advance planning with the patient and within the care team is indispensable, so that those concerned can also proceed with certainty after the onset of incapacity. It must be discussed at an early stage how symptoms of hunger and thirst are to be managed, as well as any concomitant symptoms, such as pain, nausea or anxiety. Sedation for the purpose of suppressing sensations of hunger and thirst is not permissible. Even if provisions to the contrary are specified in an

advance directive, food and drink may not be withheld if they are requested by the patient.<sup>35</sup>

### 6.3. Impermissible actions

In Switzerland, actively bringing about a person's death is always a criminal offence. As well as the administration of a lethal dose of one or more drugs on a single occasion, abruptly or gradually increasing doses of medication (for relief of symptoms or sedation) to the lethal range – without this being justifiable on the basis of symptoms that are documented or can be predicted with certainty – constitutes homicide. The same applies to continuous, non symptom-guided sedation until death with simultaneous withholding of nutrition and hydration before the beginning of the terminal phase.

#### 6.3.1. Voluntary euthanasia

A patient's request for euthanasia is to be refused, even if it is genuine and insistent. Homicide at the victim's request is an offence under Art. 114 of the Swiss Criminal Code.

Causing death by withdrawing life-sustaining measures at the explicit request of a patient with capacity is not active euthanasia.<sup>36</sup>

#### 6.3.2. Involuntary euthanasia

Involuntary (i.e. unrequested) euthanasia is an offence under Art. 111, 113, 117 of the Swiss Criminal Code. The withdrawal of life-sustaining measures in a situation where there is no prospect of a successful outcome is not deemed to be active euthanasia.<sup>37</sup>

## III. Annex

### 1. Glossary

#### (Physician-)assisted suicide

Actions undertaken by a physician or nurse with the intention of enabling another person to carry out a desired suicide. These actions include prescribing or dispensing a drug, or placing a line for the administration thereof, for the purpose of suicide.

#### Advance care planning (ACP)

A process in which strategies and treatment goals are discussed, defined and continually adapted to the actual course of disease by patients, and possibly their relatives, together with health professionals. ACP involves exploring patients' conception of their illness, their values, ideas and spiritual needs, as well as treatment goals and measures, before complications or acute deterioration in their health or state of consciousness make shared decision-making impossible. The procedure in the event of an emergency (e.g. development of complications) should also be discussed. The discussions and the resultant agreements should be documented and made available to the professionals responsible for care, and to relatives.

#### Decision-making: role of the patient and the authorised representative

Depending on the capacity for self-determination, the patient's role in decision-making on medical interventions varies considerably. If the patient loses capacity and no ad-

vance directive is available, an authorised representative assumes the role of the patient in the decision-making process. The representative must decide in accordance with the patient's presumed wishes and best interests. The patient lacking capacity must, as far as possible, be involved in the decision-making process.

The following possible decision situations exist:

#### *Autonomous decision by the patient with capacity*

The patient, who has capacity in relation to the proposed treatment, makes the final decision him/herself as to whether or not it is to be performed.

#### *Decision determined in advance (advance directive)*

The patient with capacity can determine in writing, in advance, which medically indicated interventions he or she would consent to or refuse in the event of future incapacity. If an adequately specified eventuality subsequently occurs, and there is no evidence to suggest that the patient's wishes have changed in the meantime, then the advance directive is taken to be an expression of the patient's autonomous wishes.

#### *Decision in accordance with the patient's presumed wishes*

In the event of incapacity and in the absence of a sufficiently clear advance directive, surrogate decision-making becomes indispensable. In the case of patients who formerly had capacity, it may be conjectured what their decision would be if they still had capacity. For this purpose, the following may be useful: earlier written statements not taking the form of an advance directive, as well as reported verbal statements on the question at issue, but also more general evidence of the patient's values and preferences.

#### *Decision in accordance with the patient's best interests*

In cases where a patient has never had capacity or no evidence of presumed wishes can be obtained, decisions – in the absence of a subjective judgement – can only be based on the patient's (objective) best interests. The treatment promoting these interests is that which is the preferred, medically indicated option for the patient's specific clinical situation ("treatment of choice") and appears appropriate for the individual situation. Here, the authorised representative must decide whether the patient can reasonably be expected to undergo this treatment, or which option is to be chosen if various treatments are equally indicated.

#### **Facilitators**

Professionals with specific knowledge in the areas of communication, ethics and law, who support the ACP process.

#### **Intention**

The intention with which a medical action is performed relates to the desired consequences thereof. Generally, there is a primary intention on the basis of which the action is indicated. Expected additional consequences may either be also intended or merely accepted, depending on whether they are desired or undesired. For the moral and legal evaluation of medical actions, the agent's intention is of decisive importance.

#### **Medical intervention**

Individual medical action (e.g. conducting a consultation, prescribing a drug, performing a surgical or nursing procedure, employing mechanical ventilation). It is based on an intention, within the framework of an overarching treatment goal, and is performed in the specific context of the patient's clinical condition and wishes, taking alternative treatment options into account. The indication for a medical intervention depends essentially on the intended and unintended consequences to be expected. The continuation of an existing treatment and the deliberate withholding of certain medical actions are also considered to be medical interventions. In these guidelines, medical actions serving the controversial treatment goal of ending life are not described as medical interventions.

#### **Palliative sedation**

Continuous or temporary reduction of consciousness deliberately induced by administration of sedative drugs in the lowest effective dosage to provide sustained relief of one or more refractory symptoms in a patient with advanced disease.

#### **Refractory symptom**

Symptom for which use of all available treatment options by a specialised palliative care team fails to produce satisfactory relief of suffering. Here, the treatment burden must be reasonable, given the individual life situation and disease stage, and relief must be achieved within an appropriate time frame, taking into account the expected survival time.

#### **Treatment goal**

The change in or stabilisation of a patient's condition aimed for at a given time. The treatment goal can comprise a number of individual goals, the pursuit of which may even have opposing effects. Measures aimed at sustaining life may impair quality of life and, conversely, measures to improve quality of life may shorten life. To formulate a consistent treatment goal, the individual goals must therefore be prioritised.

#### **Treatment with no prospect of success**

Ineffectiveness of treatment is to be distinguished from little or no likelihood of benefit. Ineffectiveness is marked by a deterioration in the condition of a patient receiving treatment. Treatment offers little or no likelihood of benefit in cases where there is no reasonable prospect of the patient being able to return to an appropriate living environment.<sup>38</sup>

## **2. Treatment goals in the management of dying and death**

Defined in this section – without any ethical evaluation – are the possible overarching treatment goals and approaches which may be agreed by the physician with the patient.

### **2.1. Definition of possible treatment goals**

#### **2.1.1. Comprehensive life-sustaining and restorative treatment**

All medical interventions considered suitable for sustaining life and, as far as possible, restoring the patient's vital

functions are employed. A treatment-related decrease in quality of life, if unavoidable, is accepted.

### **2.1.2. Restricted life-sustaining and restorative treatment**

Certain particularly burdensome treatment options (e.g. renal replacement therapy, certain surgical procedures, cancer treatments, etc.) are avoided in the interests of better quality of life, while other life-sustaining and restorative interventions are maintained. Treatment may be thus restricted on account of the patient's wishes, an unfavourable prognosis, multimorbidity, or other factors.

### **2.1.3. Symptom-directed treatment only**

All medical interventions aimed at sustaining life or restoring vital functions are withheld. Interprofessional treatment and support focus on the relief of distressing symptoms of a physical, psychological, social and spiritual nature and the best possible preservation of quality of life. The dying process is accepted, irrespective of how long it may last. There is no intention to hasten death.

### **2.1.4. Ending of life**

Death is to be deliberately brought about in the most painless and least distressing possible manner. This (controversial) action is undertaken primarily with this intention.

## **2.2. Definition of medical actions possibly or certainly hastening the onset of death**

### **2.2.1. Withholding or withdrawal of potentially life-sustaining measures**

Even with comprehensive life-sustaining treatment, medical interventions are withheld or withdrawn if they prove ineffective or superfluous with regard to the preservation of life. With more restricted treatment, individual life-sustaining interventions are avoided because, in the patient's view, the associated impairment of quality of life outweighs the expected benefit of a possible increase in survival, or because the patient wishes treatment to be withheld for other reasons. With symptom-directed treatment only, no medical interventions are employed with the primary aim of sustaining life.

When a potentially life-sustaining treatment is withheld or withdrawn, it is generally assumed that this will lead to a shortening of life. Very often, however, it turns out that, after the withdrawal of treatment, the opposite may be the case, if the discontinued treatment was actually doing more harm than good.

### **2.2.2. Treatment of pain, dyspnoea and other distressing symptoms**

Irrespective of the treatment goal with regard to survival time, adequate treatment of symptoms is of crucial importance for the patient's quality of life. In principle, the respiratory depressant effects of drugs used for this purpose may lead to a shortening of life. Experience shows, however, that this rarely occurs if the dosage is suitably adapted to the symptoms, and that life may sometimes also be extended to a certain degree by optimal pain treatment.

### **2.2.3. Sedation**

Sedatives designed to treat agitation and anxiety or to relieve otherwise intractable physical symptoms can be em-

ployed in connection with all treatment goals. Potentially life-shortening effects are to be expected only with prolonged, deep sedation, owing to a combination of respiratory depression, reflex suppression and dehydration. Factors determining the effects of sedation are the patient's condition at the outset, disease progression, depth of sedation, application with or without spontaneous awakening trials, and supportive therapy (management of secretions and hydration).

### **2.2.4. Support and symptom management for voluntary refusal of food and fluids**

Voluntary refusal of food and fluids (terminal fasting) is a way of ending life which can be pursued by patients themselves essentially without medical assistance. Support in the form of nursing and drug-based symptom management can, however, improve quality of life in the terminal phase.

### **2.2.5. Physician-assisted suicide<sup>39</sup>**

The decisive characteristic of physician-assisted suicide is that a drug prescribed in a lethal dose is self-administered by the patient. Medical actions involved in assisting suicide are the prescription or dispensing of a lethal drug, or the placement of an intravenous cannula for its administration by the patient. These medical actions have life-ending effects, provided that the drug is actually ingested by the patient and is not prevented from taking effect by intervening factors.

### **2.2.6. Administration of medication to end life (not permissible)**

The administration of an acutely lethal dose of one or more drugs with the aim of ending life.

## **2.3. Goals of medicine**

The professional status of people working in medicine places them under an obligation to employ legitimate medical means, on their own responsibility, to achieve goals which are compatible with the medical professions' own understanding of their role. Over the course of the history of medicine, a group of goals has emerged upon which a broad consensus exists both within the profession and among the public at large. Essentially, these involve promoting the welfare of patients by exerting a positive (quantitative or qualitative) influence on their lives, and not harming them. At the same time, the consistent pursuit of such goals also serves to guarantee the integrity and trustworthiness of the medical professions in the eyes of patients and society.

In patients ineluctably confronted with dying and death, the generally acknowledged goals of medicine – as formulated, for example, by the SAMS<sup>40</sup> – are differently weighted. The overarching goal is to provide good care and support for the dying and their relatives. The goals of palliative care are of central importance, while the preservation of life is no longer possible or no longer desired. While improvement of physical integrity and promotion of functioning, or prevention, no longer play a central role, they must by no means be disregarded for specific problems. While the body is subject to progressive decline, the significance of psychological, social and spiritual well-being may increase. This should be taken into consideration, with medical interventions being adapted accordingly.

The possible treatment goals in the management of dying and death defined in Section 2.1 of this Annex can thus be evaluated as follows: with the onset of the dying process, the goal of comprehensive life-sustaining and restorative treatment is no longer relevant. What is generally indicated is a progressive transition from restricted life-sustaining and restorative treatment to symptom-directed treatment only, with the pace of transition depending on the clinical course and the patient's wishes. The intention of the physician is to alleviate suffering and ease the dying process by withholding life-sustaining measures. Death is accepted, but not deliberately brought about. In contrast, the ending of life as the primary intention of treatment is not among the generally acknowledged goals of medicine.

What promotes welfare in a given situation can only be judged by patients themselves. On this basis, they can establish their personal treatment goals. It is then the responsibility of those providing treatment to determine whether these goals are compatible with the goals of medicine which are binding for them personally, and whether they can offer medically indicated measures which are suitable for achieving the patient's goals.

Increasingly, however, medicine is confronted with patients' requests which are only regarded as compatible with the goals of medicine by some members of the medical professions. The attitude to be adopted vis-à-vis such requests – in particular, for support in bringing about death – is a matter of dispute within the professions and among the public, as it concerns actions which are ethically controversial. Patients can by no means claim to be entitled to such actions. Practical guidance on the procedure to adopt in such situations is given in Section 6.2 of the guidelines.

#### IV. Footnotes

<sup>1</sup> Cf. "Palliative care". SAMS Medical-ethical guidelines (2006, updated 2013); Best Practice Recommendations: <http://www.palliative.ch/en/professionals/working-groups-standards/best-practice>

<sup>2</sup> The term "relatives" is used to refer to persons close to the patient.

<sup>3</sup> Brauer S., Bolliger C., Strub J.-D. Swiss physicians' attitudes to assisted suicide: a qualitative and quantitative empirical study. *Swiss Med Wkly* 2015; 145:w14142.

<sup>4</sup> <http://www.nfp67.ch/en>

<sup>5</sup> Here, patients are defined as persons receiving treatment, care or support from physicians, nurses and/or other medical professionals in connection with matters relating to their own death; this does not necessarily imply that these persons are ill.

<sup>6</sup> On being incorporated into the Code of the Swiss Medical Association (FMH), SAMS guidelines become binding for all members of the FMH.

<sup>7</sup> Cf. Section 6.1.3.

<sup>8</sup> Cf., for example «Perinatale Betreuung an der Grenze der Lebensfähigkeit zwischen 22 und 26 vollendeten Schwangerschaftswochen». *Schweiz. Ärztezeitung* 2012; 93(4): 97–100.

<sup>9</sup> Cf. "Medical treatment and care of people with disabilities". SAMS Medical-ethical guidelines (2008, updated 2013).

<sup>10</sup> Cf. "Intensive-care interventions". SAMS Medical-ethical guidelines (2013); "Decisions on cardiopulmonary resuscitation". SAMS Medical-ethical guidelines (2008, updated 2013).

<sup>11</sup> Cf. "Assessment of capacity". SAMS Medical-ethical guidelines (scheduled for publication in December 2018).

<sup>12</sup> "Total pain" is understood as suffering which has causal roots in various levels of experience (physical, mental, social, spiritual/existential, cultural) and which is expressed phenomenologically in individually varying degrees on these various levels. The important point is that this pain cannot be relieved by purely biological (e.g. pharmacological) measures. Here, a multidimensional and interprofessional approach is required. The longer total pain lasts, the more suffering will also be experienced by relatives and caregivers. Sometimes, relief can only be achieved, if at all, not so much by modification of therapeutic measures as by a change in expectations.

<sup>13</sup> Frequently also referred to as "spiritual suffering".

<sup>14</sup> Challenging situations – increasingly common in practice – arise when the desire for death in a person with a mental illness is closely linked to the psychopathological symptoms or is even itself to be understood as a symptom of the disorder. In this case, while capacity remains the central criterion, its assessment by a psychiatric professional is particularly complex.

<sup>15</sup> 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).

<sup>16</sup> Cf. National Framework for Advance Care Planning (2018), available in French/German.

<sup>17</sup> Cf. Glossary.

<sup>18</sup> Cf. Footnote 15.

<sup>19</sup> Cf. Annex, Section 2.2.

<sup>20</sup> Cf. Annex, Section 2.3.

<sup>21</sup> Cf. Annex, Section 2.1.

<sup>22</sup> This is only possible to a limited extent in patients whose ability to communicate is severely restricted (infants, patients with serious multiple disabilities). In the case of newborns, who have never been able to express preferences, the parents decide on the basis of their own values.

<sup>23</sup> Cf. "Intensive-care interventions". SAMS Medical-ethical guidelines (2013), Section 6.4.

<sup>24</sup> Cf. Glossary (Annex, Section 1).

<sup>25</sup> Cf. Glossary.

<sup>26</sup> Cf. Cherny NI, Radbruch L. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliat Med.* 2009; 23(7):581–593.

<sup>27</sup> Cf. «Betreuung sterbender Menschen und ihrer Angehörigen», Version Fachperson, Best Practice Recommendations, <http://www.palliative.ch>

<sup>28</sup> Cf. Annex, Section 2.3.

<sup>29</sup> Cf. Section 4. Management of the desire for death.

<sup>30</sup> Cf. Art. 11 para. 1bis Narcotics Act (NarcA). A list of the cantonal offices to which reports are to be submitted can be found on the SAMS website, <http://www.sams.ch/guidelines>.

<sup>31</sup> Cf. “Assessment of capacity”. SAMS Medical-ethical guidelines (scheduled for publication in December 2018).

<sup>32</sup> In 2006, the Federal Supreme Court ruled that, in the case of patients with mental illness, a detailed psychiatric opinion is required (BGE 133 I 58 E. 6.3.5.2).

<sup>33</sup> For example, in the form of a problematic care situation, financial straits, etc.

<sup>34</sup> Cf. “Care and treatment of people with dementia”. SAMS Medical-ethical guidelines (2017).

<sup>35</sup> Cf. “Advance directives”. SAMS Medical-ethical guidelines (2009, updated 2013); cf. “Care and treatment of people with dementia” SAMS Medical-ethical guidelines (2017).

<sup>36</sup> Cf. Section 6.1.1.1.

<sup>37</sup> Cf. Section 6.1.1.1.

<sup>38</sup> Cf. “Intensive-care interventions”. SAMS Medical-ethical guidelines and recommendations (2013), Section 5.4.

<sup>39</sup> The term “assisted suicide” is used synonymously.

<sup>40</sup> Cf. «Ziele und Aufgaben der Medizin zu Beginn des 21. Jahrhunderts». Report of an expert group of the SAMS, the FMH and the five Medical Faculties (2004).

## V. Information on the preparation of these guidelines

### Mandate

In May 2015, the Central Ethics Committee (CEC) of the SAMS appointed a subcommittee to revise the medical-ethical guidelines on “End-of-life care” (2004/2014).

### Subcommittee responsible

Professor Christian Kind, St. Gallen (Chair)

Dr Daphné Berner, Corcelles (former Cantonal Medical Officer)

Susanne Brauer, PhD, Ethics, Zürich (CEC Vice Chair)

Sonja Flotron, Nursing/Palliative Care, Reconvilier

Professor Heinz Gutscher, Social Psychology, Zürich

Professor Daniel Hürlimann, Law, St. Gallen

Professor Samia Hurst, Ethics, Genève

Dr Roland Kunz, Geriatrics/Palliative Care, Zürich

Dr Settimio Monteverde, MME, MAE, RN, Nursing/Ethics, Zürich and Bern

Dr Hans Neuenschwander, Oncology/Palliative Care, Lugano

Professor Hans Pargger, Intensive Care, Basel

Professor Walter Reinhart, Internal Medicine, Chur

Dr Florian Riese, Psychiatry/Palliative Care, Zürich

lic. iur. Michelle Salathé, MAE, Law, SAMS, Bern (ex officio)

Professor Markus Zimmermann, Ethics, Fribourg

### Experts consulted

PD Dr Klaus Bally, Basel

PD Dr Georg Bosshard, Zürich

Professor Steffen Eychmüller, Bern

Professor Bernhard Rüttsche, Luzern

Bianca Schaffert, MSN, Schlieren

Dr Marion Schafroth, Liestal

Professor Jan Schildmann, Bochum

Professor Friedrich Stiefel, Lausanne

Dr Henri Wijsbek, Amsterdam

### Consultation procedure

On 16 November 2017, the Senate of the SAMS approved a draft version of these guidelines to be submitted for consultation to professional associations, organisations and other interested parties. The comments received have been taken into account in the final version.

### Approval

The final version of these guidelines was approved by the Senate of the SAMS on 17 May 2018.

### Original versions

English version in the original layout available at <https://www.samw.ch/en/Publications/Medical-ethical-Guidelines.html>

German version available at <http://www.samw.ch/de/Ethik/Richtlinien/Aktuell-gueltige-Richtlinien.html>

French version available at <http://www.samw.ch/fr/Ethique/Directives/actualite.html>