

MEDICAL ETHICAL GUIDE- LINES

Advance directives



Schweizerische Akademie der Medizinischen Wissenschaften
Académie Suisse des Sciences Médicales
Accademia Svizzera delle Scienze Mediche
Swiss Academy of Medical Sciences

Issued by

Swiss Academy
of Medical Sciences (SAMS)
House of Academies
Laupenstrasse 7, 3001 Bern
Tel. +41 (0)31 306 92 70
mail@samw.ch
www.samw.ch

Design

Howald Fosco Biberstein, Basel

Translation

Jeff Acheson, Bottmingen

All the medical-ethical guidelines issued by the SAMS
are available in G/F/E/I online: www.sams.ch/guidelines

© SAMS 2017

Medical-ethical guidelines and recommendations

Advance directives

Approved by the Senate of the SAMS on 19 May 2009.
The German version is the binding version.

As of 1 January 2013, the guidelines were revised in the light of the new adult protection law.

These guidelines provide a basic overview of the instrument of advance care directives. A number of national organizations offer templates and consultations for writing advance care directives. Further information is available in German and French.

The SAMS is addressing this topic in depth as part of the national working group «Advance Care Planning»: sams.ch/advance-care-planning

Schweizer Berufsverband der Pflegefachfrauen
und Pflegefachmänner



The Swiss Professional Association for Nurses (SBK/ASI) recommends that its members and all other nurses should abide by these guidelines.

I. PREAMBLE	5
II. GUIDELINES	7
1. Addressees of the guidelines	7
2. Ethical significance of the advance directive	7
3. Legal conditions	7
3.1. Binding nature of the advance directive	7
3.2. Capacity	7
3.3. Voluntariness	8
3.4. Written form, dating and signing	8
4. Content of the advance directive	8
4.1. Description of personal values	9
4.2. Description of the aims of treatment	9
4.3. Appointment of a representative	10
4.4. Statements on specific situations	10
5. Information and advice on the drawing-up of an advance directive	12
5.1. Content of counselling	12
5.2. Counselling situations	13
6. Safekeeping and notification of existence of the advance directive	15
7. Revocation of the advance directive	15
8. Implementation of the advance directive	15
9. Change of wishes	16
10. Situations of conflict	17
III. RECOMMENDATIONS	18
IV. APPENDIX	19
Instructions regarding advance directives	19
Example Questions regarding the personal values	22
Information on the elaboration of these guidelines	24

I. PREAMBLE

All patients have the right to self-determination. Timely provision of comprehensive information about the medical situation, appropriate to the seriousness of the intervention and readily intelligible, is essential to enable patients or their representatives to formulate their wishes and make decisions. Respect for the patient's wishes is central to treatment and care. However, the right to self-determination is subject to certain limits: the wishes of a patient or representative to have a particular treatment performed have only to be complied with if the treatment is medically indicated. By contrast, refusal of treatment or care by a patient with capacity is binding.¹

Advance directives are an instrument of self-determination, allowing persons with capacity to specify the medical measures that they wish or do not wish to receive in the event of their incapacity. With the new adult protection law, advance directives have become more important; for patients who lack capacity, the authority to make decisions on medical interventions has been transferred to persons close to them. If an advance directive is available in this situation, it takes precedence.

Besides the advantages of an advance directive, its limitations however also have to be considered. The drawing-up of an advance directive requires personal engagement with disease, accident, the process of dying and death. In healthy phases of life it is only to a limited extent possible to transpose oneself into the situation of a serious illness or death, and basically it is difficult to imagine, in advance, which medical measures one would accept in borderline situations and which not. Special weight is therefore attached to the informed expression of a person's wishes and the careful drawing-up of an advance directive.

Advance directives are a means of communication between the patient, the physician, nursing staff, the person appointed in an advance directive (representative) and relatives. The treatment team² has important and varied tasks in regard to the drawing-up of the advance directive: for example, it can provide the patient with information on the formal requirements for an advance directive, indicate the possible course of an illness which the patient wishes to be mentioned in the directive, check that an existing advance directive has been updated or it can give concrete support in the drawing-up of an advance directive. Finally, in the implementation of the directive the treatment team has the responsible task, in the concrete situation, of acting in accordance with the patient's wishes.

1 An exception to this is protective placement under Art. 426 ff. of the Swiss Civil Code.

2 The interdisciplinary team providing medical care for the patient.

The aim of these SAMS guidelines is to provide guidance. The guidelines address the content of an advance directive and indicate which particular points should be taken into account when it is being drawn up, so that it can fulfil its function as an instrument of self-determination.

II. GUIDELINES

1. Addressees of the guidelines

The present guidelines are addressed primarily to physicians³, nurses and other professionals who advise patients in the drawing-up of an advance directive and who implement advance directives in a concrete decision-making situation. Furthermore, the guidelines can provide guidance for those persons who wish to formulate or update an advance directive.

2. Ethical significance of the advance directive

Ethically, the right of a person to express his wishes in an advance directive for situations where he may be incapacitated, is based on the principle of patient autonomy. This also includes the right of the individual to make decisions in his own interest on the basis of personal values and concepts.

3. Legal conditions

3.1. Binding nature of the advance directive

With the revised adult protection law, the binding nature of advance directives is established on a uniform basis throughout Switzerland. Accordingly, the physician must comply with an advance directive unless it contravenes legal requirements or there are reasonable doubts as to whether it was voluntary or still reflects the patient's presumed wishes.

3.2. Capacity

The possibility of drawing up an advance directive is open to all persons who have capacity;⁴ this includes minors who have capacity. A person drawing up an advance directive must be in the position to understand the implications of the advance directive and must be able to estimate, as far as this is possible, what consequences it would have in the case of a certain pathological condition.

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

4 Art. 16 of the Civil Code: "any person has capacity if he or she does not lack the capacity to act rationally by virtue of being under age or because of a mental disability, mental disorder, intoxication or similar circumstances."

Basically, it is assumed that a person who draws up an advance directive has capacity. In special situations, however, where capacity might afterwards be doubted, it is recommended to have one's capacity confirmed by a specialist at the time that the advance directive is being drawn up.

3.3. Voluntariness

An advance directive must be drawn up voluntarily, i.e. without external pressure or force. Also, the existence of an advance directive must not be made a condition for acceptance into a long-term care institution or for access to medical treatment and care.

3.4. Written form, dating and signing

An advance directive should be drawn up in writing, dated and signed by the person drawing it up. In principle, there is no limit on the time that the advance directive remains binding; on the other hand, the advance directive should be reviewed/revised, dated and signed at regular intervals. This is especially important if there have been any significant changes in the life situation or the health of the person drawing up the advance directive. While advance directives which fail to meet formal requirements are invalid, they may serve as an indication of presumed wishes.

4. Content of the advance directive

With an advance directive, a person anticipates possible incapacity. The person drawing up the directive can simply include a description of personal values and/or also specify which measures he agrees to and which he rejects.⁵ He can also appoint a representative who can decide, in his place, on the appropriate medical treatment. An advance directive can include statements on other subjects, such as organ transplantation, autopsy or organizational instructions, e.g. regarding the care of children, informing the employer etc.

Various organizations offer advance directives in different forms. Some of these only have to be signed, while others can include the person's own texts, or various options can be chosen. Such advance directives are as a rule less complicated. However, individual advance directives can be more precisely adapted to the life situation of the person(s) who draws them up and they therefore then allow less scope for interpretation.

⁵ The general exclusion of measures, i.e. irrespective of the situation for their application, is however not to be recommended (see Section 4.4.).

In an advance directive, acts that are not in accordance with the law cannot be requested.⁶ The advance directive may also not be used to request medical treatments that are not medically indicated. On the other hand, treatments that would be medically indicated may be refused. In this case it is recommended that the reason for the refusal be given, so that in the event of implementation of the directive there can be no doubt with regard to the formulation of the patient's wishes.

4.1. Description of personal values

For the decision-making process on the part of the treatment team, the description of the personal values of the person concerned is useful. From this it emerges what views of life, values and wishes, fears, expectations and hopes with regard to health and illness are decisive for the patient's wishes. Information on personal values can indicate what the person drawing up the advance directive understands by "quality of life" or living or dying "with dignity". In many cases these terms are used in a general way in connection with serious illness or incapacity, but they are too unspecific to provide concrete information in the case of a particular disease or illness. Information on personal values provides guidance in situations where it is not foreseeable whether a medical treatment will be successful or where the patient has not explicitly expressed wishes concerning particular measures.

4.2. Description of the aims of treatment

Pathological situations can require decisions regarding treatment, which are difficult to predict in advance. With the description of the aims of the treatment it can be explained whether and in what situations therapeutic measures are primarily intended to sustain life or to treat pain and symptoms of disease such as fear, restlessness, dyspnoea etc. Such a description of the aims of treatment provides the treatment team with important information on the patient's wishes in a concrete situation; however, the means and the ways of achieving this remain open.

6 According to Art. 114 of the Criminal Code, termination of life on request is a criminal offence. Assisted suicide cannot be covered by an advance directive, as the patient is required to have capacity at the time it is undertaken.

4.3. Appointment of a representative⁷

The person drawing up the advance directive may appoint another person who can make decisions regarding medical treatment when he is not in a position to do so himself. The patient's relatives or GP, or other natural persons, may be appointed as a representative. The person drawing up the advance directive can appoint a substitute in case the person appointed is not available for some reason. The content of the advance directive and any changes made to it at a later date should be discussed with the representative.

In the advance directive the person drawing it up may give the representative concrete instructions (e.g. regarding consent to or refusal of specific measures), but he may also limit himself to the appointment of a representative, leaving the decision, in concrete situations, to him.

If elderly persons are appointed as representatives, it should be pointed out in counselling that there is a risk that they may be unable to meet their commitments because of their age.

4.4. Statements on specific situations

The decision as to what specific points should be contained in the advance directive largely depends on the life situation and the wishes of the person who draws it up. The decision with regard to what degree of detail is appropriate is, however, not always easy. Often it is possible to assess individual measures only if a disease is already present and its course is predictable. The general exclusion of certain measures, i.e. irrespective of the circumstances of their implementation, is not to be recommended. Helpful, on the other hand, is information on the personal values of the person concerned (see Section 4.1.) and on the aims of treatment (see Section 4.2.).

Emergency medicine and intensive-care medicine⁸

In an acutely life-threatening situation medical measures may be taken, the success of which is not predictable in advance. In the advice that is given it should be pointed out that in emergency situations urgent measures must be taken without delay and that it is not always possible to consider the content of the advance directive. However, it should be mentioned that measures that are taken can be discontinued later, when the advance directive is available.

7 Previously known as a "person of trust" in earlier SAMS guidelines.

8 Cf. "Decisions on cardiopulmonary resuscitation" and "Borderline questions in intensive-care medicine" (medical-ethical guidelines and recommendations of the SAMS).

Fluids and food

The natural intake of food and fluids is part of basic medical care. Food and fluids must be made available to the patient in every situation, and he must be supported in his food intake. In contrast, artificial nutrition/hydration (enteral, e.g. by PEG⁹ tube, or parenteral) is in fact an intervention that can be stressful for the patient and one that he must first consent to. In this connection one has to differentiate between two possible situations, namely, whether artificial nutrition/hydration is a temporary therapeutic intervention (e.g. following a cerebral stroke with uncertain prognosis) or a long-term intervention (e.g. in patients with chronic severe brain damage¹⁰). It is useful to address these different situations in counselling.

End-of-life¹¹ and palliative care¹²

In the advance directive it can be established whether, in the case of a disease leading to death, medical measures (e.g. maintenance of vital functions) should not be taken or should be discontinued. The decision to discontinue or not to start treatment can influence the time of death. The advance directive can also contain further statements on the nature of palliative care and on other health-care measures. For example, medical or nursing measures indicated for prevention may not be carried out or may be reduced to a minimum if this corresponds to the aim of the treatment, as formulated in the advance directive. Patients may also include the wish for spiritual care in the advance directive.

Organ donation¹³

An advance directive may also contain a statement of consent or refusal to donate organs, tissues or cells for the purpose of transplantation. According to Art. 8 of the Transplantation Act¹⁴, the consent of the donor is necessary for the removal of organs, tissues or cells. If there is no documented consent or refusal on the part of the deceased person and if he has also not mentioned this to his relatives, the consent of his closest relatives is necessary. Statements on organ donation in the advance directive can relieve the relatives of the need to make a decision regarding the removal of organs under pressure of time. A person who is prepared to donate organs etc. should state this clearly by means of a Swiss transplant donor card.¹⁵

9 Percutaneous endoscopic gastrostomy.

10 Cf. "Treatment and care of patients with chronic severe brain damage" (medical-ethical guidelines of the SAMS).

11 Cf. "End-of-life care" (medical-ethical guidelines of the SAMS).

12 Cf. "Palliative care" (medical-ethical guidelines of the SAMS).

13 Cf. "The determination of death in the context of organ transplantation" (medical-ethical guidelines of the SAMS).

14 Federal Act of 8 October 2004 on the Transplantation of Organs, Tissues and Cells. Persons aged 16 years and over may declare their intention to donate (Art. 8, para. 7).

15 www.swisstransplant.org

Autopsy¹⁶, teaching and research¹⁷

The conditions under which an autopsy is permissible are determined on a cantonal basis. In some cantons consent to autopsy is assumed in principle if there are no known wishes to the contrary; in other cantons express consent on the part of the deceased person must exist or the consent of relatives must be obtained. It is recommended that consent to (or refusal of) autopsy be laid down explicitly in the advance directive.

The use of the cadaver or body parts for the purpose of medical training and/or research is only permissible with express consent. Persons who wish to give their consent should also include this in the advance directive.¹⁸

5. Information and advice on the drawing-up of an advance directive

There is no obligation to seek advice when drawing-up or updating an advance directive. However, counselling can provide helpful support and is therefore to be recommended. The advice can be provided by the patient's GP, the treating specialist or the nursing professional, or also by other competent, experienced professionals. With patients in whom a disease is diagnosed it is ideal if the treating specialist or the GP undertakes or is included in the counselling.

5.1. Content of counselling

The content of counselling on the advance directive is based on the patient's life situation. The motivation for the writing of the directive also plays an important role. Often several discussions are necessary, and these do not always result in a written advance directive.

16 No stipulations can be made concerning medicolegal autopsies carried out on behalf of the criminal investigation authorities in the case of an unusual death, in order to provide more precise information on the nature and the cause of death.

17 Cf. "Use of cadavers and body parts in medical research and in medical education and training" (recommendations of the SAMS).

18 A person who wishes to make his body available to an anatomical institute after his death should also lay this down in a special form which may be obtained from the various anatomical institutes.

Important points of the discussion include reflection on, and documentation of, personal values, information on possible situations of incapacity and clarification of the medical measures usually envisaged in these situations. The person responsible for drawing up the advance directive must also be aware especially of the consequences of starting, withholding or discontinuing medical measures. In the discussion he must be motivated to inform any representatives and relatives of the existence of an advance directive and to discuss its contents with them. If the patient so wishes, his representatives or relatives may be included in the counselling. If there is doubt with regard to the patient's capacity, clarification of this must be suggested.

The advice on the drawing-up of an advance directive must be understandable and in a form that is adapted to the patient in question. In particular, any fears, negative experiences, misconceptions (e.g. concerning diseases, but also with regard to autopsy or organ donation) and unrealistic expectations must be identified and discussed. There must be sufficient time for discussion, without pressure, of questions that are important for the patient.

The persons providing advice should be aware of the ethical, legal, medical and psychological requirements that are involved in connection with the drawing-up of advance directives. They should also be especially aware of their attitudes and personal values with regard to illness, dying and death. Because decisions of life and death are highly personal matters, the evaluations on the part of the counsellor remain in the background, and the primary aim of the discussion is to enable the person drawing up the directive to express his own wishes. The counsellor detects any uncertainties, draws attention to any existing contradictions, points out tensions with medical practice or conflicts of interest on the part of relatives, and through information and empathetic-critical direction of the discussion he contributes to clarification of the situation, so that an advance directive is created which is informative, practical and as free from contradictions as is possible.

5.2. Counselling situations

Advance directives are drawn up in different life situations and at all ages. Individual points requiring special consideration, depending on the baseline situation, are as follows:

Persons who are not ill

Even in persons who have so far been healthy, accidents or illness can lead to their suddenly being incapacitated. Advance directives of “healthy” individuals are necessarily kept rather more general, so that information on their personal values is therefore all the more important. It must be pointed out that should there be any change in the patient’s state of health the advance directive should be adapted accordingly.

Adolescents

Minors with capacity can decide to draw up an advance directive on the basis of their own experiences. The parents may also be involved, if the young person agrees.

Elderly persons¹⁹

The probability of developing dementia increases with advancing age. The expectations for this situation must therefore also be addressed in counselling and the patients supported in determining their wishes. As the possibility of developing dementia can trigger anxiety, it must be carefully clarified whether and to what extent the person concerned wishes to mention this. Information on the possibilities of treatment, nursing and health care can also contribute to the elimination of such anxiety.

Patients with somatic disease

In patients who are already suffering from a somatic disease at the time that an advance directive is drawn up, this should be adapted to the present disease situation. The possible course of the disease and the measures to be taken should be the subject of discussion and the patient’s wishes regarding treatment can be defined in detail.²⁰ Nevertheless, it should also be established what weight should be given, in the decision-making process, to criteria such as prognosis, expected outcome of treatment and the effect of possible therapy on the patient, and what curative and palliative measures may be taken.

Patients with a mental disorder²¹

Patients with a mental disorder can include in the advance directive their wishes regarding general therapeutic measures, but also specifically regarding the treatment of their mental disorder. They may also state their wishes concerning the

19 Cf. “Treatment and care of elderly persons dependent on care” (medical-ethical guidelines of the SAMS).

20 Such agreements regarding treatment between a patient and the care team are often referred to in the literature as “advance care planning”.

21 In some cases the drawing-up of an advance directive is integrated into the treatment itself, because this supports understanding of the illness and adherence to treatment.

treatment of an acute phase (e.g. isolation, neuroleptics etc.). For this situation the advance directive should contain as accurate a description as possible of the disease; this covers both the symptoms occurring in an acute phase and also the symptoms indicating that an acute phase is imminent. The advance directive may also contain information on the place where the therapeutic measures are carried out. The person drawing up the advance directive must be informed that situations of incapacity may exist in which coercive measures must be taken.

6. Safekeeping and notification of existence of the advance directive

It is the task of the patient to ensure that in case of need the existence of an advance directive is known and that the document is available.

The advance directive may be kept in different places:

- An advance directive may be carried by the patient or may be kept at his home.
- The advance directive may be kept by the GP or the patient's representative, and the patient carries a note with details of the place where the advance directive is kept.
- The patient may keep the advance directive in a place of safekeeping,²² entering details of the place of safekeeping on an ID card.

7. Revocation of the advance directive

The advance directive may be revoked by a patient with capacity at any time, either in writing or verbally. In cases of verbal revocation, however, problems of proof may arise. To avoid any misunderstanding, the person drawing up the advance directive should therefore destroy any directives that are no longer valid.

8. Implementation of the advance directive

So that an advance directive can be implemented, its existence must be known to the treatment and care team.

Advance directives must be integrated into clinical decision-making processes. This means that on entering a medical institution patients with capacity will be asked about an advance directive, the existence of which will be documented in the patient's dossier. Ideally, the advance directive will be discussed with the patient and it will be checked that it is up to date. In the event of the patient's transfer to another institution, the advance directive will be handed over to him.

²² Various organizations offer facilities for storing and transmitting advance directives at any time.

If a patient lacks capacity, it must be clarified whether he has drawn up an advance directive. In this connection, a document indicating the existence of an advance directive will be sought (see Section 6). If no reference to an advance directive appears on the insurance card, persons close to the patient (relatives, GP, etc.) should be asked.

If decisions regarding treatment are necessary, these will be made on the basis of the wishes expressed in the advance directive. If the patient has not expressed any wishes in the advance directive regarding the medical intervention in question, then the attending physician is to prepare a treatment plan in consultation with the person entitled to act as a representative.²³ The physician is to provide the representative with comprehensive information regarding the proposed medical measures. As far as possible, the patient lacking capacity should also 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.

If, in an emergency situation, it is not possible to clarify whether an advance directive has been drawn up, the appropriate urgent life-saving measures or measures to prevent serious consequences must be initiated immediately. As soon as the advance directive is available, however, it must be taken into account in further treatment.

9. Change of wishes

If there is evidence that the advance directive no longer corresponds to the patient’s presumed wishes, these must be carefully assessed with the aid of persons close to the patient (relatives, GP, etc.). If the assessment raises reasonable doubts as to whether the advance directive still reflects the patient’s presumed wishes, the directive is not to be taken into account by the attending physician.

The following can be evidence of a change of wishes:

- After the drawing-up of the advance directive the patient in a state of capacity has expressed wishes and preferences other than those contained in the advance directive, without, however, formally revoking or revising it.

23 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.

- The drawing-up or the updating of the advance directive took place a long time ago, and there has been a fundamental change in the circumstances of the patient's life.
- Since the advance directive was drawn up, new or less stressful therapeutic options have become established, which could give the patient new chances for a cure or for stabilization of his state of health, and it can be assumed that he would consent to these new options.
- The behaviour of a patient who lacks capacity is found to run contrary to his wishes as expressed in the advance directive. Especially in the case of patients with dementia there can be serious doubts as to whether the wishes contained in the advance directive correspond to the patient's presumed wishes.

In such a situation, decisions are to be made by the persons legally entitled to act as a representative, or, in an emergency, by the attending physician. Here, the aim should be to determine and to act in accordance with the patient's presumed wishes and interests, taking into account the diagnosis, prognosis and treatment options, and weighing up the burdens and opportunities. Any deviation from the wording of the advance directive must be recorded in the patient's dossier and must be justified.

10. Situations of conflict

Sometimes persons close to the patient (representatives, relatives, GP etc.) and members of the treatment and care team take different views concerning the interpretation of an advance directive with regard to a specific decision. In this case any available resources, such as the possibility of ethics support²⁴, should be used. If no such support is available or if it does not help in reaching an agreement, the adult protection authority may be involved. If for urgent reasons there is no time left for these steps, treatment must be guided by the best interests²⁵ of the patient.

²⁴ Cf. "Ethics support in medicine" (recommendations of the SAMS).

²⁵ This is understood to mean medical treatment dictated by the objective criteria of cure and alleviation (medical indication for a treatment).

III. RECOMMENDATIONS

The following recommendations support the implementation of these guidelines:

1. To health-care institutions

Health-care institutions should give instructions, internally, on the handling of advance directives, with which it should be established in particular when and how one should ask about the existence of an advance directive. They should take steps to ensure that physicians, nursing professionals and other specialists are familiar with the content of the guidelines.

2. To institutions involved in education, specialist training and continuing education in the health-care sector

Institutions that are involved in education and training should take up the subject “Advance directive” as part of their training programme and they should provide physicians, nurses and other professionals with the necessary knowledge and skills in this respect.

3. To organizations that offer advance directives

Organizations that offer advance directives should, if possible, also offer advice on the drawing-up of these directives and they should provide the possibility for their safekeeping, so that the transfer of the advance directive to the hospital where the patient is being treated is guaranteed at all times. The establishment of a central place of safekeeping should be investigated.

4. To patient organizations

Patient organizations should actively point out the possibility of drawing up advance directives. In this connection, special attention must be paid to persons who for reasons of language or for social reasons have up till now had little or no access to advance directives.

Instructions regarding advance directives

The following text is a short version of the medical-ethical guidelines “Advance Directives”. The short version does not replace reading of the complete guidelines, but is intended to provide instructions for general practice. The chapters refer to the chapters of the complete guidelines.

An advance directive determines the wishes of a patient in advance in case he is not capable of discernment; it can refer to different areas of application. In this connection the doctors, health-care professionals and other specialists have various tasks: they provide basic information on the advance directive, they address the subject in appropriate situations, they provide information on the requirements regarding the content and the nature of the advance directive, and they assist in the drawing up of an advance directive or they check with the patient that an already existing advance directive is up to date. It is important that the advance directive is discussed with the patient in a way appropriate to the respective patient. Anxiety regarding certain diseases or measures, negative experience with certain forms of treatment or fears must be discussed.

If a patient is no longer capable of discernment, it is the task of the treatment- and care-team to implement an existing advance directive in a concrete therapeutic situation, provided that the advance directive stipulates such a measure.

Not all doctors and health-care professionals have to be “specialists” as far as the advance directive is concerned. In large institutions it is helpful if there are individuals who have the necessary knowledge and are thus able to answer questions from specialists or patients and if necessary to give appropriate advice. Also, there are organisations that support medical doctors, health-care professionals and other persons concerned in the drawing-up of advance directives.

Is the advance directive binding? → Chapters 2 and 3

Legal regulations on advance directives have up until now existed only at the cantonal level, but not in all cantons. With the coming into force of the new Law on the Protection of Adults (earliest in 2012) the advance directive will be explicitly stated in Swiss Federal Law. According to this, an advance directive must be complied with, unless it violates legal regulations or there are indications that the patient has changed his mind. It is already true today that the clearer the advance directive is the more important is its role in the decision-making process.

Who can draw up an advance directive and what has to be considered? → Chapters 3.2 to 3.4 and 5.2.2

Any person who is capable of discernment may draw up an advance directive. This also applies in the case of adolescents who are capable of discernment. The decision to draw up an advance directive must be in accordance with the person's wishes, i.e. no one may be forced to draw up an advance directive. An advance directive must be drawn up in writing, dated and signed by hand. It can be altered or rescinded, in writing or orally, at any time. The patient should be informed of the importance of updating of the advance directive (see above). It is therefore recommended to check the advance directive on a regular basis. If the individual's personal values with regard to life, disease and death ("personal values") or his health situation changes, the advance directive should be adapted accordingly.

Contents of the advance directive → Chapter 4

- **Data on the identity** of the person drawing up an advance directive (surname, first name, date of birth)
- **Confirmation of capability of discernment** («In possession of my mental powers and after careful consideration, I hereby state for situations in which I am not capable, due to illness or accident, of expressing my present wishes the following»). Note: In situations in which there could later be doubt regarding an individual's capability of discernment (e.g. the early stages of dementia, psychiatric conditions), in order to avoid uncertainties the capability of discernment can also be confirmed by a medical doctor/third party.
- **Description of the scale of personal values:** What, precisely, do quality of life and "dying with dignity" mean for the individual concerned? What personal convictions, anxieties, expectations etc. have to be considered when making medical decisions in borderline situations? See "Questions regarding maintenance of personal values" in the Appendix.
- **Nomination of at least one personal representative** and information regarding contact with this person. Ideally, a substitute will also be nominated.
- **Information on the situations for which the advance directive is drawn up** and on the situations in which it must be implemented.
- **Information on the objectives** of a treatment in certain situations.
- **Acceptance or refusal of specific medical measures:** In the case of a disease that is already known to be present at the time that the advance directive is being drawn up, this should be mentioned and the advance directive should be adapted to the disease in question and its probable course, possible complications and possible measures.
- **Readiness to donate organs**
- **Handling of the corpse after death** (autopsy)
- **Date and signature**

Is every advance directive valid? → Chapters 3,4 and 9

In principle, the formal requirements must be met: writing, capability of discernment, voluntary nature, dating, personal signature.

There is no time limit on the validity of an advance directive. It is important that an advance directive corresponds to the patient's present wishes. Provided that there is no indication that the patient has changed his mind in the meantime (pointed out by the patient's personal representative or relatives, or by doctors, healthcare professionals and careers), it can be assumed that the advance directive corresponds to the patient's present wishes. If the patient's non-verbal expression (e.g. in the case of patients with dementia) leads to the assumption that the advance directive does not correspond to his present wishes, this must be carefully clarified in consultation with the patient's personal representative and his relatives. The decision should be made in consensual agreement of the treatment- and care-team, together with any personal representatives and relatives. Any deviation from the wording of the advance directive must be included in the patient's dossier and justified (see Chapter 9. "Change of wishes").

When is an advance directive implemented and what is the procedure? → Chapter 8

An advance directive is implemented only if a patient is incapable of discernment, i.e. is no longer able to express himself. If the patient is capable of discernment, on the other hand, his currently expressed wishes are valid.

If a patient is incapable of discernment, the following points must be clarified:

- Does an advance directive exist? (search for a corresponding document; questioning of the family doctor or the relatives)
- Has the patient nominated a personal representative? If so, this person must be informed and must be included in the planning of the treatment.

The advance directive provides the basis for the decision regarding treatment. If the patient has not expressed any wishes in the advance directive concerning the treatment in question, then the attending physician is to prepare a treatment plan in consultation with the person entitled to act as a representative. Ultimately, the decision on the proposed treatment is to be made by the representative in accordance with the patient's presumed wishes and interests.

Must the advance directive also be implemented in an emergency situation? → Chapter 8

The urgency with which measures must be initiated in an emergency situation, e.g. in the case of a road accident, usually does not allow to check the existence of an advance directive. The necessary life-saving measures therefore have to be initiated. Afterwards, it has to be checked whether an advance directive has been drawn

up, and if so it must be included in the planning of the treatment, and measures that have already been initiated perhaps have to be discontinued.

How does one know that an advance directive has been drawn up? → Chapter 6

It is up to the person drawing up an advance directive to provide information on the existence of an advance directive. This can be done verbally, for example on a person's admission to hospital. The information can also be provided in the form of an identity card or, in future, by means of an entry on the person's insurance card. The treating physician should, however, always ask whether an advance directive has been drawn up.

Advance directives are carried by the person concerned, handed over to the family doctor or the patient's representative, or kept in a safe place.

If the doctor knows that an advance directive exists and also knows where it is kept, he may ask for it to be given to him.

What is to be done if the doctor and the patient's representative or his relatives do not agree? → Chapter 10

An advance directive must be transposed into a concrete situation. It can happen that the patient's representative, the treatment team and the relatives are not of the same opinion. In this case ethical advice should be sought. If this also does not lead to any agreement, the legally prescribed authority (court of guardianship; after the new Law on the Protection of Adults comes into force: the adult-protection authority) shall be consulted.

Example Questions regarding the personal values

The following questions regarding the various subjects have been compiled as an aid in order to document the patient's personal values ("case history of values"). They can be put forward in the consultancy discussion or they may be answered directly by the person concerned. It is important that the questions are answered in the framework of the patient's present life situation. Consequently, the case history of values is always a "snapshot" representing a single moment, which can change in the course of time and therefore has to be adapted if necessary.

The description of the patient's scale of personal values is of major importance in the advance directive. It provides information on the concepts of life, fears, values and expectations that are of decisive importance for the patient. The information on the scale of personal values also serves as orientation in those situations where an advance directive does not provide accurate data on individual medical measures (chapter 4.1.).

Motivation: What motivates you to draw up an advance directive? Is there a concrete occasion for this? What do you wish to achieve with an advance directive and what do you wish to prevent? Have you discussed this with your relatives? Have you discussed it with your family doctor?

Life between birth and death: Where do you see yourself in your life? How important is it to you, to live a long life? In order to gain a few years of life, would you be prepared to live with certain limitations (e.g. need for care)? Or do you not wish to strive for extra years of life, but rather to live as independently as possible? What does “dying with dignity” concretely mean to you personally? What is the role of your close relatives/family, what tasks are they prepared to undertake and what can be expected of them?

Quality of life: What makes your life worth living? What activities, what thoughts and what personal values determine your life at the present time? Considering a possible disease or the advancing years, is it possible that you may change your ideas concerning your quality of life (e.g. with regard to ability to communicate, mobility, state of mind)? How important is it to you to be free from pain? To achieve this, would you be prepared to accept a clouded consciousness or, in the extreme case, even loss of consciousness?

Experience with disease, dying and death: Have you already had personal experience with disease? Or have you had experience with disease through the illness of third parties (e.g. your parents, partner or friends)? How have these experiences affected your attitude towards medicine and health care in general, and recourse to medical measures? Are you living with limitations or diseases at the present time? Would you see any sense in living, if your life were to be greatly restricted or if your personality were to be changed (e.g. coma, severe dementia)? In order to be able to survive in such a situation, would you be prepared to be subjected to stressful medical measures? What harmful conditions and impairments would be so serious for you that you would no longer wish to continue living?

Personal and religious convictions: Do you have religious, spiritual or ideological convictions; do you belong to a church or a similar group? Do these convictions influence your life in “borderline situations”, i.e. if your life is in danger (whether to continue living or to die). Are there any particular points or rituals which, on the basis of your ideological or religious convictions should be considered after your death (what is to be done with your body etc.?) Would you agree to the removal of organs and/or tissues after your death (organ donation)?

Information on the elaboration of these guidelines

Mandate

On 7 April 2006 the Central Ethical Committee (CEC) of the SAMS appointed a sub-committee to be responsible for the elaboration of guidelines and recommendations for advance directives.

Responsible sub-committee

lic. theol. Peter Lack, Basel, Chairman
Susanne Brauer, PhD, Zurich
Dr. med. Martin Conzelmann, Basel
Dr. med. Andreas Gerber, Berne
Prof. Dr. med. Bruno Gravier, Lausanne
Prof. Dr. med. Christian Kind, St. Gallen, President of the CEC from 27.11.08
Dr. iur. Jürg Müller, Basel
Prof. Dr. med. Claude Regamey, Fribourg, President of the CEC until 27.11.08
Prof. Dr. med. Bara Ricou, Geneva
Monique Sailer, Nursing Professional, cand. MNS, Brünisried
lic. iur. , Basel, MAE (Vice Secretary SAMS)
Dr. med. Urban Wirz, Subingen

Experts consulted

Dr. Arnd T. May, Aachen, Germany
lic. theol. Settimio Monteverde, MAE, Basel
Bruno Quement, Lausanne
Dr. Michaël Saraga, Lausanne

Consultation

On 27 November 2008 the Senate of the SAMS approved a first version of these guidelines to be submitted for official approval.

Approval

The definitive version of these guidelines was approved by the Senate of the SAMS on 19 May 2009.

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).

