Advance directives

Medical-ethical guidelines and recommendations

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

SBK
ASI

The Swiss Association of Nursing Professionals (Schweizer Berufsverband der Pflegefachfrauen und Pflegefachmänner – SBK) recommends that its members and all other nursing personnel read and apply these guidelines.

Advance directives

Medical-ethical guidelines and recommendations

I. Preamble

Over the past few years, in different guidelines, the SAMS has confirmed the importance of the advance directive as an instrument of self-determination on the part of patients.[1] Although it is possible for a patient to express his wishes in an advance directive, even today little use is made of this possibility; however, the advance directive is increasingly a subject of discussion in the public domain. With the coming into force of the new Law on the Protection of Adults[2], the advance directive will become more important; in the case of patients who are incapable of discernment, the power of decision on medical measures is transferred to persons close to them. If an advance directive exists in this situation, it takes first place.

Besides the advantages of an advance directive, its limitations however also have to be considered. The drawing-up of an advance directive requires personal involvement 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 take in borderline situations and which not. Special weighting is therefore attached to the informed declaration of a person's wishes and the careful drawing-up of an advance directive.

Advance directives are a means of communication between patient[3], doctor, nursing staff, persons representing the patient and his relatives. The treatment-team[4] 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.

The aim of the SAMS, with the present guidelines, is to provide orientation for the health-care sector. The guidelines explain 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.

---

1 See, in particular, "The patients' right to self-determination", medical-ethical guidelines of the SAMS.

2 The proposal for the new Law on the Protection of Adults was accepted by the National Council and the Second Chamber of the Swiss Parliament on 19 December 2008; the period allowed for submission of a referendum expired on 16 April 2009.

3 The corresponding texts concern both genders in the respective patient-groups.

4 From this, the interdisciplinary team will know who is treating the patient.

II. Guidelines

1. Addressees of the guidelines

The present guidelines are addressed primarily to medical doctors[5], nursing professionals and other specialist persons 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 orientation for those persons who wish to formulate or update an advance directive.

2. Ethical weighting of the advance directive

Ethically, the right of a person to express his wishes in the context of an advance directive, for situations where he may be incapable of discernment, 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 judgements and concepts.

3. Legal conditions

3.1. Binding nature of the advance directive

With the revised Law on the Protection of Adults, the binding nature of advance directives will be established on a uniform basis throughout Switzerland. According to this, the doctor must comply with an advance directive, unless this infringes legal regulations or if there is justified doubt as to whether it is based on the patient's free will or that it corresponds to his presumed wishes. Until the new law comes into force[6], the advance directive remains subject to any existing regulations at the cantonal level. These may differ: in certain Cantons the advance directive is apportioned independent validity, while in others it is an expression of a person's presumed wishes. Basically, today the following is already true: the clearer an advance directive is and the more concretely it applies to the present medical situation, the more important is its role in the decision-making process. In this connection, whether it is an individual or a standardised, preformulated advance directive, which the person concerned still has to sign, is of no importance.

3.2. Capability of discernment

The possibility of drawing up an advance directive is open to all persons who are capable of discernment[7], as well as minors who are incapable of discernment. A person drawing up an advance directive must be in the position to understand the implications of the advance

---

5 If they are taken up in the Standing Orders of the Swiss Medical Association (FMH), the guidelines will be binding for its members.

6 Because of the adjustments that are necessary in the Cantons, the new Law on the Protection of Adults will only come into force in 2012,at the earliest.

7 Art. 16 of the Swiss Civil Code: "Capable of discernment according to this law is any person who because of his childhood or as a result of mental illness, mental deficiency, alcoholism or similar conditions does not lack the ability to act and behave reasonably".

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.

Basically, it is assumed that a person who draws up an advance directive is capable of discernment. In special situations, where the capability of discernment might afterwards be placed in doubt, it is however recommended to have the capability of discernment confirmed by a specialist at the time that the advance directive is being drawn up.

3.3. Free will

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 the access of a patient to medical treatment and care.

3.4. Writing, dating and signing

An advance directive should be drawn up in writing, dated and signed by the person drawing it up[8]. In principle, there is no limit on the time that the advance directive remains binding; on the other hand, it is recommended to check the dating and the signing 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.

4. Contents of the advance directive

With an advance directive, a person anticipates his possible incapability of discernment. The person drawing up the directive can limit himself to the rewriting of the principle of the directive and/or also to specifically establishing which measures he agrees to and which he rejects[9]. He can also nominate a representative who can decide, in his/her place, on the appropriate medical treatment to be prescribed. An advance directive can included statements on other subjects, such as organ transplantation, autopsy or organisational instructions, e.g. regarding the care of children, informing the employer etc.

Various organisations 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.

In an advance directive negotiations that are not in accordance with the law are not permitted.[10] The advance directive may also not serve for the promotion of medical

---

[8] Until the new Law on the Protection of Adults comes into force, adherence to the formal instructions (writing, individual signature, dating) is not a precondition for the validity of an advance directive. However, cantonal regulations have to be observed.

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

[10] According to Art 114 of the Penal Code, termination of life on request is a punishable offence. Assisted suicide is not covered by the advance directive, as it requires that the patient is capable of discernment at the time of the assisted suicide.

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 patient's wishes.

4.1. Description of the 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. Data on the personal values can provide information on 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 incapability of discernment, but they are too unspecific to provide concrete information in the case of a particular disease or illness. Data on the personal values serve as orientation in situations where it is not foreseeable whether a medical treatment will be successful or in what situations the patient has not explicitly referred to certain measures.

4.2. Description of the aims of the 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 which situations therapeutic measures are primarily intended to maintain life or to treat pain and symptoms of disease such as fear, restlessness, dyspnoea etc. Such a description of the aims of a 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.

4.3. Nomination of a representative[11]

The person drawing up the advance directive may nominate another person who can make decisions regarding the medical treatment when he is not in the position to do so himself. The patient's relatives or other persons who are close to him, or even the patient's family doctor, may be nominated as a representative. However, if the person nominated is for any reason not available, the person drawing up the advance directive can name a substitute, who should discuss with the nominated representative the contents of the advance directive and any changes made to it at a later date.

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

If elderly persons are nominated as representatives, the risk that because of their age they may perhaps be unable to meet their commitments must be mentioned.

---

[11] Described as "person of trust" in the SAMS guidelines published up till now.

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 an illness or 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 Chapter 4.1.) and on the aim of the treatment (see Chapter 4.2.).

4.4.1. Emergency medicine and intensive-care medicine[12]

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 should be taken without delay and that it is not always possible to consider the contents of the advance directive. However, it should be mentioned that measures that are taken can be discontinued later, if an advance directive is found to exist.

4.4.2. Fluids and food

The natural intake of food and fluids is part of the 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, the artificial uptake of fluids and food (enteral, e.g. by tube, inserted by CEG[13], or parenteral) is in fact an intervention that can be stressful for the patient and one that he must first agree to. In this connection one has to differentiate between two possible situations, namely, whether the artificial uptake of fluids and food is a temporary therapeutic intervention (e.g. following a cerebral stroke with uncertain prognosis) or a long-term intervention (e.g. in patients with severe chronic brain damage[14]). It is useful to address these different situations in the advisory discussion.

4.4.3. End of life[15] *and palliative care*[16]

In the advance directive it can be established whether, in the case of a disease leading to death, medical measures (e.g. maintenance of the 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 the palliative care and on other health-care measures. For example, therapeutic or prophylactic measures 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.

---

[12] See also “Decisions on Resuscitation“ and “Borderline questions in intensive-care medicine“, medical-ethical guidelines of the SAMS.

[13] This means a tube inserted by means of a cutaneous endoscopic gastrotomy (CEG).

[14] See “Treatment and care of patients with severe chronic brain damage“, medical-ethical guidelines of the SAMS.

[15] See “Care of patients at the end of life“, medical-ethical guidelines of the SAMS.

[16] See “Palliative Care“, medical-ethical guidelines of the SAMS.

4.4.4. Organ donation[17]

An advance directive may also contain a statement of agreement or refusal to donate organs, tissues or cells for the purpose of transplantation. According to Art. 8 of the Law on Transplantations[18], the agreement of the donor is necessary for the removal of organs, tissues or cells. If there is no documented agreement or refusal on the part of the deceased person and if he has also not mentioned this to his relatives, the agreement 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 Swisstransplant donor's identity card[19].

4.4.5. Autopsy[20], teaching and research[21]

The conditions under which an autopsy is permissible are determined on a cantonal basis. In some Cantons agreement to an autopsy is assumed in principle if there are no known wishes to the contrary; in other Cantons express agreement on the part of the deceased person must exist or the agreement of the relatives must be obtained. It is recommended that agreement to (or refusal of) an autopsy be laid down explicitly in the advance directive.[22]

The use of the cadaver or body parts for the purpose of medical training and/or research is only permissible with express agreement. Persons who wish to give their agreement should also include this in the advance incentive.[23]

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, an advisory discussion can provide helpful support and is therefore to be recommended. The advice can be provided by the patient's family doctor, the treating specialist of the nursing professional, or also by other competent, experienced specialists. With patients in whom a disease is diagnosed it is ideal if the treating specialist or the family doctor undertakes or is included in the advisory function.

5.1. Contents of the advisory discussion

The contents of the advisory discussion on the advance directive are based on the patient's life situation. The motivation for the writing of the directive also plays an important role. Often

---

17 See "Determination of death with regard to organ transplantations", medical-ethical guidelines of the SAMS.

18 Federal Law on the Transplantation of Organs, Tissues and Cells, of 8 October 2004. Persons aged 16 years and over can make a declaration regarding such donation (Art. 8, Para. 7).

19 www.swisstransplant.ch

20 Excluded from the regulations are autopsies in legal medicine 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.

21 See "Use of cadavers and body parts in medical research and in medical training and further training". Recommendations of the SAMS.

22 Autopsies ordered by the authorities or by the law are excluded.

23 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.

several discussions are necessary, and these do not always result in a written advance directive.

Important points of the discussion include reflection on, and documentation of, the personal values, information on possible situations of incapability of discernment 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, not starting or discontinuing medical measures. In the discussion he must be motivated to inform any representatives and relatives present of the existence of an advance directive and to discuss its contents with them. If the patient wishes this, his representatives or relatives may be included in the advisory process. If there is doubt with regard to the patient's capability of discernment, 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, wrong ideas (e.g. concerning diseases and illness, 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 advisor 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 advisor detects any uncertainties, draws attention to any existing contradictions, points out fields of tension affecting medical practice or conflicts of interest on the part of the relatives, and through information and empathic-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. Advice situations

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

5.2.1. Persons who are not ill

Even in persons who have so far been healthy, accidents or illness can lead to their suddenly being incapable of discernment. Advance directives of "healthy" individuals are necessarily kept rather more general, so that data on their personal values are 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.

5.2.2. Adolescents

Minors who are capable of discernment 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.

5.2.3. Older persons[24]

The probability of developing dementia increases with advancing age. The expectations for this situation must therefore also be addressed in the advisory discussion 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.

5.2.4. 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.[25] Nevertheless, it should also be established what weighting should be given, in the decision-making process, to criteria such as prognosis, expected success of the treatment and the effect of possible therapy on the patient, and what curative and palliative measures may be taken.

5.2.5. Patients with mental illness[26]

Patients with a mental illness can include in the advance directive their wishes regarding general therapeutic measures, but also specifically regarding the treatment of their mental illness. They may also state their wishes concerning the 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 incapability of discernment may exist, and that in such cases emergency 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 corresponding 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 family doctor 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[27], entering details of the place of safekeeping on an insurance card[28].

---

[24] See also "Treatment and care of elderly persons who are in need of care", medical-ethical guidelines of the SAMS.

[25] Such agreements regarding treatment between a patient and the care-team are described in the literature as so-called "advanced care planning".

[26] In some cases the drawing-up of an advance directive is directly associated with the treatment itself, because this supports understanding of the illness and adherence to treatment.

7. Revocation of the advance directive

The advance directive may be revoked by the patient, who is capable of discernment, at any time, either in writing of verbally. To avoid any misunderstanding, the person drawing up the advance directive should 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-team and the care-team.

Advance directives must be integrated into the clinical decision-making processes. This means that on entering a medical institution patients who are capable of discernment 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.

If a patient is not capable of discernment, it must be clarified whether he has drawn up an advance directive or has nominated a representative. In this connection, a possible document on the existence of an advance directive will be sought (see Chapter 6) or the relatives and the family doctor will be asked. If decisions regarding treatment are necessary, these will be made on the basis of the patient's wishes, as expressed in the advance directive. If the patient has nominated a representative, this person must be consulted. The decision should be made with the mutual agreement of the treatment-team and the care-team, jointly with the patient's representative or his relatives.

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 considered and its requirements taken into account in the further treatment.

9. Change of wishes

If there are important indications that the advance directive no longer corresponds to the patient's wishes, this situation must be carefully clarified together with the patient's representative and his relatives. The decision should be made with the mutual agreement of the treatment-team and the care-team, jointly with any representatives or relatives.[29]

---

[27] Various different organisations provide safekeeping and pass on details of advance directives at any time.

[28] It is envisaged that in future the existence of an advance directive can be entered on the patient's insurance card; see "Regulations on the insurance card for obligatory health insurance", of 14 February 2007 (VVK).

[29] On the subject of decisions, see "The right of patients to self-determination", medical-ethical guidelines of the SAMS.

The following can be indications of a change of wishes:

- After the drawing-up of the advance directive the patient, being capable of discernment, has expressed wishes and preferences other than those contained in the advance directive, however without formally revoking or changing this.
- The drawing-up or the updating of the advance directive took place a long time ago, and the living conditions of the patient have not fundamentally changed.
- Since the advance directive was drawn up, new or less stressful therapeutic possibilities have become established, which could give the patient new chances for a cure or for stabilisation of his state of health, and it can be assumed that he would agree to these new possibilities.
- The attitude of a patient who is incapable of discernment 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 in fact correspond to the patient's presumed wishes.

In such a situation and taking into account the diagnosis, the prognosis and the possible treatments, and considering the effects of these on the patient and the benefits they offer, it is essential to determine and to consider the patient's presumed wishes. Any change to the wording of the advance directive must be included in the patient's dossier and must be justified.

10. Situations of conflict

Sometimes legal representatives, other representatives of the patient, his relatives or members of the treatment-team and the care-team are of a different opinion with regard to the interpretation of an advance directive with a view to a concrete decision. In this case any existing resources, such as the possibility of consulting an ethical advisor, should be used in the decision-making. If no such resources are available or if these do not help in reaching an agreement, the legally responsible authority must become involved. If for urgent chronological reasons there is no time left for these various steps, the treatment must be oriented towards the best interests[30] of the patient.

[30] This is understood to mean a medical treatment that is associated with 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 medical doctors, nursing professionals and other specialists are familiar with the various contents described in the guidelines.

2. To institutions involved in the training and further training of specialists in the health-care sector

Institutions that are involved in training and further training should take up the subject “Advance directive“ as part of their training programme and they should provide medical doctors, nursing professionals and other specialists with the necessary knowledge and competences in this respect.

3. To organisations that offer advance directives

Organisations 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 a central place of safekeeping must be investigated.

4. To patients’ organisations

Patients’ organisations 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.

Information on the elaboration of these guidelines

Responsibility

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. Michelle Salathé, Basel, MAE (Vice Secretary SAMS)
Dr. med. Urban Wirz, Subingen

Expert consultants

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

Submission for approval

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.