



Treatment and care of elderly persons who are in need of care

Medical-ethical guidelines and recommendations

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The German version is the binding version.

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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.

Treatment and care of elderly persons who are in need of care

Medical-ethical guidelines and recommendations

(The German version is the original, binding version.)

I. Preamble

The demographic development in Switzerland means that over the next few years the number of elderly, mainly very old persons will rise, so that there will also be a marked increase in the number of persons in need of care. This is happening at a time of change in traditional family structures, at a time when values and attitudes are undergoing great changes and more and more importance is being attached to the autonomy of the individual, and at a time of rising health-care costs.

All these factors mean that the treatment and care of elderly persons who are in need of care is associated with various different areas of conflict. There may be a conflict between the necessary care and attention on the one hand and respect for the autonomy of an elderly person on the other. A dilemma often exists between the necessary encouragement and activation of an elderly person and his wish to be left in peace. When should a disease be treated and when should there be no therapeutic intervention? Especially in institutions providing long-term care, conflict also exists between privacy and the public nature of a person's existence, because while an institution represents the private living environment of the elderly person, the care that it provides is at the same time of a collective nature. The discussion regarding costs in the health-care sector has further accentuated the challenges in the treatment and care of elderly persons who are in need of care.

In the light of these considerations the following text pursues three objectives: Firstly, it makes it clear that age and the need for care must not lead to the withholding of measures that are deemed necessary; secondly, thanks to the *Guidelines*¹ it offers medical doctors, nursing staff and therapists² help in making decisions in difficult situations; thirdly, in the *Recommendations*³ it points out the important requirements and conditions for the effective treatment and care of elderly persons who are in need of care.

Also addressed here, however, are institutions that are involved in pregraduate and postgraduate education and further training, as well as political authorities, who are invited to take these present Guidelines and Recommendations into account when making their decisions in the area of the treatment and care of elderly persons who are in need of care, they are called upon to.

The treatment and care of younger persons who are in need of care is expressly not the subject of these Guidelines. In their case, specific additional aspects have to be considered.

¹ The Guidelines of the SAMS are addressed to medical professionals (medical doctors, nursing staff and therapists) and are, in principle, binding; this applies especially in the case of doctors, because as a rule the Guidelines are taken up in the statutes of the FMH (Swiss Medical Association).

² Physiotherapists, ergotherapists, activation therapists, speech therapists, psychologists.

³ As the SAMS has no regulatory authority as far as institutions providing long-term care are concerned, instead of guidelines only "recommendations" are formulated.

II. Guidelines (for medical doctors, nursing staff and therapists)

1. Scope of application

The present Guidelines are addressed to medical doctors, nursing staff and therapists, who are responsible for the care of elderly persons who are in need of care, either at home, in hospitals or in institutions providing long-term care. One speaks of an “elderly person“ when a person is over the age of 65 years; “in need of care“ means that a person is permanently dependent on assistance or support in his everyday activities (i.e. dressing, body care, eating, use of the toilet, mobility, planning the day, social contacts). As a rule, a person’s dependence on care increases markedly after the age of 75 years.

2. Principles

2.1. Appropriate care

Elderly persons who are in need of care have the right to appropriate treatment and care up to the end of their life. A patient’s age and his need for care must not lead to the withholding of measures that are deemed necessary. The treating physician, the nursing staff and the therapists base their decisions on a joint evaluation of medical, psychological, social and functional aspects and the person’s environment. In the care they provide, they respect the dignity, the private sphere and the intimate sphere of the elderly person, even if he⁴ is no longer capable of discernment or is suffering from mental disorder.

2.2. Continuous personal care

For adequate care to be assured, personal contact between the doctor and the elderly person in need of care is essential. In these elderly persons a change in the place where they live (at home, in hospital or in an institution providing long-term care) can also mean a change in the medical responsibility. Doctors who are responsible for the care of elderly patients in a hospital or an institution have to organise themselves in such a way that it is at all times clear with whom the medical responsibility lies; they have to keep the elderly person (or, if he is incapable of discernment, the relevant person of trust [see 3.3.] or the legal representative) informed accordingly. In the case of a change of medical responsibility, the doctors concerned must ensure that the responsible doctor is provided with all the information necessary for the continued care of the patient.

Often, various different professionals are involved in the care of an elderly person, which makes it difficult for him to know which of these professionals is in fact responsible for the coordination of the care being provided. In the field of the Spitex home-care service, in hospitals and in the long-term care institutions, the care and therapy team names one qualified contact person for each elderly patient and informs him, and if appropriate also his family, of this accordingly.

⁴ For the sake of simplicity, although both male and females are meant, only the masculine personal pronouns (he, him, his) are used throughout this text.

2.3. *Collaboration with the patient's social environment*

Whenever possible, the treating physician and the appointed contact person maintain good relations with the elderly person's social environment (relatives, friends, acquaintances), in regard to the various aspects concerning his treatment and care. Such contacts are of course subject to the agreement of the elderly person, who is capable of discernment, and to the rules of professional secrecy and confidentiality.

In the care of elderly persons who are living at home, a large part of the necessary tasks are undertaken by family members; this can be very demanding. It is the duty of the doctors, nursing staff and therapists to advise and support these relatives or others who are looking after the elderly person.

2.4. *Interdisciplinary collaboration*

Doctors, nursing staff, therapists and many other individuals and professional groups are involved in the care and treatment of elderly persons who are in need of care. For this reason it is necessary that the doctors, the nursing staff and the therapists collaborate with one another systematically and in the framework of appropriate structures, and with the other professional groups involved. In institutions providing long-term care, attention also has to be given to collaboration with the house and kitchen staff and with the administrative personnel, observing the rules of professional secrecy and confidentiality.

2.5. *Appropriate pregraduate and postgraduate education and further training*

Elderly persons who are in need of care are often also at the same time suffering from several different chronic diseases (multimorbidity). In addition, psychological, social, spiritual and environmental factors play an important role in the care of these patients. This requires that the doctors, the nursing staff and the therapists involved should have specific experience and competence in geriatrics, gerontology and geriatric psychiatry. This competence also includes, in particular, collection of data on the patient's state of health through a multidimensional assessment and the implementation, carrying out and evaluation of appropriate measures.

Doctors, nursing staff and therapists who look after elderly persons who are in need of care are under the obligation to increase this competence through further education and training.

3. Decision-making processes

3.1. *Principle*

The right to respect of human dignity, personal freedom and autonomy applies, without restriction, to every individual. The law recognises the basic rights, which are respect of personal dignity, protection of physical integrity and self determination.

The limitations on personal autonomy, which increase with advancing age and which disturb the balance between an individual's dependence and independence, should in no way affect his *right* to respect of dignity and autonomy. Therefore it is necessary to have binding decision-making procedures and structures, which make possible a decision-making process that takes into account the self-determination and the dignity of the elderly individual. In this connection special care must be taken to ensure that the elderly person is able to express his

wishes, that he has sufficient time for important decisions and that he can make decisions without being under pressure.

3.2. Instructions drawn up by the patient in advance

Each person may draw up instructions in advance in regard to the medical treatment and care that he may wish to receive or that he would reject if he should become no longer capable of discernment. Provided a patient is capable of discernment, he may alter or cancel at any time the conditions that he made in advance at any time.

The doctors, the nursing staff and the therapists point out to the elderly persons that they can draw up such conditions in advance and regularly update them; they discuss together who should undertake this task.

3.3. Authorised representatives in medical matters

Every person can name, in advance, an authorised representative in medical affairs (hereinafter called "person of trust") who, if that person becomes incapable of discernment, can give his agreement, on that person's behalf, to medical, nursing and/or therapeutic measures. The doctors, the nursing staff and the therapists make elderly persons aware, in good time, of the possibility of their nominating a person of trust and of the need to regularly update this authorisation; they discuss together who should undertake this task.

3.4. Drawing up of basic principles for decision-making within the team

Various measures such as the treatment of a behavioural disorder, the treatment of decubitus ulcer or the placement of a feeding tube often call for an interdisciplinary decision-making process. Before the treating physician suggests such a measure to the elderly person and then prescribes it, with the person's agreement, he discusses the patient's care and treatment with the responsible contact person and takes his opinion into account.

The solution of complex situations (e.g. questions of future planning, advice to the patient's relatives, problems of living with other people in a home) often calls for an interdisciplinary decision-making process that is oriented towards the wishes of the elderly person and takes into account his ideas, his objectives, his wishes and his needs. Such situations have to be discussed and possible solutions and corrective measures agreed on by all those involved before they are suggested to the elderly person by the responsible professional.

The need for interdisciplinary collaboration does not relieve the treating physicians, the nursing staff and the therapists from their obligations and responsibilities in regard to relevant decisions within their particular area of professional responsibility.

3.5. Information of the patient

The elderly person in need of care has the right to be informed by the doctor, by the person responsible for his care or by the therapist, of any diagnostic, nursing or therapeutic measures that are to be taken, so that he can agree to them freely. The information must be provided in a suitable manner, i.e. it must be understandable and clearly defined – with details of possible alternatives – and adapted to the situation. The benefits and risks of each alternative must be explained. If possible, and if the elderly person is in agreement, his person of trust or another person who is close to him must also be informed, so that he can support the patient in making his decision.

If the elderly person is incapable of discernment, his person of trust or his legal representative will receive this information; this person must of course also receive the information in an appropriate form.

3.6. *Permission of the elderly person who is capable of discernment*⁵

Doctors, nursing staff and therapists may carry out a particular measure only with the freely given permission of the elderly person, who has been fully informed and is capable of discernment.

If an elderly person who is capable of discernment refuses the measures suggested to him, after he has been informed of these and of the possible consequences of refusal, then the doctor and the nursing staff must respect his decision. If in the opinion of the responsible professionals this decision to refuse the measures suggested is not in the best interests of the elderly person concerned, they will then seek another possible treatment that would be likely to be acceptable to him.

3.7. *Procedure for obtaining permission in the case of an elderly person who is incapable of discernment*

If an elderly person is incapable of discernment as far as making a decision is concerned, the doctor or the nursing staff will clarify whether he has drawn up instructions regarding his wishes, whether he has nominated a person of trust and/or whether a legal representative has been named.

The patient's instructions, made by him advance, must be followed, provided there is no concrete indication that these no longer correspond to the wishes of the person concerned at that time.

If there are no instructions available or if there is well-founded doubt as to whether the wishes expressed at the time are still valid, the doctor must in any case obtain the agreement of the person of trust nominated by the elderly person or of the legal representative (who may yet have to be appointed). Each decision must be oriented towards the presumed wishes of the elderly person who is incapable of discernment, and must be taken in his best interests. If the decision of the person of trust or the legal representative seems to be contrary to the presumed wishes of the elderly person, the doctor must contact the guardianship authority.

If, in the absence of the patient's instructions, there is neither a person of trust (or if this person refuses the task or is not in the position to undertake it) nor a legal representative, or if it is not possible to consult these persons in an emergency situation, then the doctor, the nursing staff and the therapists have to make their decisions in an interdisciplinary exchange of views, according to the objective interests and the presumed wishes of the person concerned

⁵ From the legal point of view, the capability for discernment is defined as the capacity of a person who is not devoid of the faculty to act reasonably because of his young age or as a result of mental illness, feeble mindedness or other similar causes (Art. 16 of the Civil Code).

The following criteria help to determine whether the person is capable of discernment (Source: H.B. Staehelin, Ther. Umschau 1997; 54: 356-358)

- the ability to understand information in regard to the decision that is to be made;
- the ability to correctly weigh up the situation and the consequences arising from possible alternatives;
- the ability to rationally assess the information received in the context of a coherent evaluation system;
- the ability to make and express his own choice.

It is the task of the responsible health-care professional to assess, in each individual case, whether the person is capable of discernment. In the case of difficult decisions, a specialist (e.g. a psychiatrist or a geriatrician) must be consulted. The person's capability of discernment is assessed in relation to a particular treatment (and in fact in relation to the nature and the degree of complexity of this treatment); he must be capable of discernment at the time the decision is made. Either the person is capable of discernment in regard to a certain treatment – or he is not.

– on condition that no contrary cantonal regulations exist in this respect.⁶ Whenever possible, the patient's social environment (spouse or partner, persons who are close to him and/or relatives) should be included in this decision-making process.

4. Treatment and care

4.1. Promotion of health and prevention

It is the task of the doctors, the nursing staff and the therapists to suggest to the elderly person in need of care, and to make possible, measures that will allow him to retain or to promote his physical, mental and social faculties and resources. Elderly persons who are in need of care are particularly frequently exposed to certain risks (e.g. falls, immobility, depression, eating disorders, bedsores, violence and abuse). It is the task of the doctors, the nursing staff and the therapists to recognise these risks in good time and, after informing the elderly person and obtaining his agreement, to take the necessary preventive measures.

4.2. Acute treatment

It is the task of the doctors, the nursing staff and the therapists to ensure that in the event of acute illness elderly people who are in need of care receive adequate explanation and treatment. In this case the specific care required in view of the patient's dependence (e.g. in dementia, decubitus ulcer or incontinence), also in the acute hospital, must be guaranteed.

4.3. Rehabilitation

It is the task of the doctors, the nursing staff and the therapists to suggest to the elderly person in need of care, and to make possible, those treatments and other measures (e.g. social contacts, physiotherapy, psychotherapy, ergotherapy, speech training, dental treatment, provision of hearing aids) and care (including social contacts, diet, mobilisation, physical activity, organisation of everyday activities) that will allow him, as far as possible, to retain or to regain his physical, mental and social faculties and resources.

4.4. Palliative treatment

All elderly persons in need of care must be guaranteed access to palliative medicine, nursing and care in good time, irrespective of where they are living. Both in institutions providing long-term care and in ambulant therapy or in hospital, the doctors, nursing staff and therapists know and apply the concepts of palliative care. The doctor, the nurse and the therapist recog-

⁶ The treatment of the person who is incapable of discernment, who does not have a legal representative nor a person of trust is not expressly regulated at the Federal level. On the other hand, corresponding legal regulations do exist at the cantonal level; however, these differ from canton to canton. In some cantons the right of decision rests, under certain circumstances, with the doctor (e.g. Aargau, Appenzell A. Rh., Berne, Lucerne, Thurgau, Zurich [Status 2003]). Other cantons envisage the granting of powers of representation to the family or to close persons of trust (e.g. Neuchâtel, Jura, Ticino). Still others require that the doctor consults the guardianship authority in regard to the nomination of a legal representative (e.g. Geneva). Today, elderly persons in need of care who are in institutions providing long-term care often do not have a representative in medical matters. With a view to the implementation, in the medium term, of the principle of the nomination of a representative if a person is incapable of discernment (as is envisaged according to the Convention on Biomedicine, which is about to be ratified), these Guidelines specifically include the requirement that doctors, nursing staff and therapists should encourage their patients, in good time, to nominate a duly empowered "person of trust". Also, all doctors are advised, in case of doubt, to seek legal advice from the responsible guardianship authority.

nise particularly troublesome symptoms such as pain, anxiety, depression and hopelessness and, with the cooperation of the patient's family, treat them thoroughly. Palliative care is an interdisciplinary process; if needed, and if wished by the elderly person concerned, spiritual help may be provided.

5. Dying and death

5.1. *Accompaniment and care of the dying*

The accompaniment and care of the dying is defined and regulated in the medical-ethical guidelines of the Swiss Academy of Medical Sciences, "Care of patients in the terminal phase of life".

5.2. *Dealing with a person's wish for assisted suicide*

If an elderly person in need of care expresses the wish to commit suicide, the team responsible for his care tries to discuss this with him. In any case, the doctor and the nursing staff take steps to provide the person concerned with the best possible protection and support. In particular, they explain to him possible improvements in his treatment and care. In this connection, account has to be taken of the elderly person's many different dependences, which can increase the risk of suicide. The team responsible for his care ensures that the necessary palliative, therapeutic and/or psychiatric measures are suggested and carried out, and also that spiritual help is suggested and, if desired, provided.

6. Documentation and data protection

6.1. *Case history and documentation of the care provided*

The doctor keeps a case history for each elderly person in need of care for whom he is responsible. In this case history, the doctor records data on the patient's personal history, investigations carried out, the results of these investigations and their assessment, other measures taken and the course of the patient's condition, and attaches medically relevant documents. The nursing staff also keep a case record⁷. The relevant aspects of the medical documentation are made available to the responsible nursing staff and the therapists.

The therapists document the therapeutic procedures (observations on the drawing up and planning, and on the setting of the objectives, the planning and the evaluation of the measures

⁷ The purpose of the nursing dossier is as follows:

- it presents the patient's situation from the nursing point of view (assessments);
- it defines the aims of the nursing measures, the principal interventions carried out and the results of these;
- it makes it possible to check the way in which the nursing measures have been carried out (procedure sheet).

The dossier contains at least

- the treatment records (assessments containing the needs and wishes of the elderly person or of his therapeutic representative, and information to give better understanding of the individual situation) and the necessary care arising from these (aims and measures);
- a transcript of the interdisciplinary discussion (e.g. "curves", drug therapies etc);
- a transcript of the therapeutic measures and observations carried out;
- an evaluation of the therapeutic measures (interventions), that is to say, of the effects of these measures and of the adaptations that were necessary (nursing procedure)

taken). A compilation of the most important observations, objectives and results is made available to the responsible doctor and the responsible nursing staff.

The elderly person and/or his person of trust have the right to see the case history and the nursing documentation and to have these explained to them; they can request copies of these documents.

The case history and the nursing documentation include the latest valid version of any instructions made by the patient in advance, data on the person of trust or on a possible legal representative, and any protocols on measures that restrict the patient's freedom of movement etc.

6.2. *Duty of confidentiality*

The doctor, the nursing staff and the therapists are bound to professional secrecy.

Data may be collected, filed, evaluated and passed on to third parties only under strict observation of the legal requirements covering data protection.

The geriatric assessment instruments to be used must have first been checked for their comparability and informative value, and the elderly persons concerned must be informed of the purpose of the study and that data will be collected.

Data that require particular data protection are the nursing documentation and the case history, which are handled and stored in such a way that only authorised persons can have access to them. For the electronic data-processing, the strict requirements regarding data-access protection and the security of data transfer and data filing must be observed.

The data may be used for scientific purposes, only after they have been rendered completely anonymous. Non-anonymous data may be passed on to third parties only with the express consent of the person concerned or of his representative if he is incapable of discernment.

7. **Use of measures restricting personal freedom**

7.1. *Principle*

Behavioural disorders, restlessness and confusion in elderly patients in need of care can lead to a risk to themselves and/or to others, or to serious molestation of others. The use of measures that restrict personal freedom⁸ in order to avoid such risks represents an encroachment on the elderly person's basic rights. Also, such measures do not always lead to a reduction of the risks, but can increase them even further. Therefore the use of measures that restrict movement must, in principle, remain the exception.

7.2. *Conditions*

Unless the legal regulations require otherwise, a measure that restricts personal freedom may be used only under the following conditions:

- a) The person's behaviour represents a considerable danger to his own safety or health, or to those of others, or it impairs to a large extent the peace and well-being of third persons.
- b) The abnormal behaviour observed cannot be attributed to obvious causes such as pain, the side effects of drugs or interpersonal tensions and conflicts.
- c) Other measures that restrict personal freedom to a lesser extent have failed or are not possible.

⁸ e.g. immobilisation with drugs, restriction of freedom of movement with belts or other measures restricting freedom, such as forbidding smoking, for example. In certain cantons, immobilisation with drugs is considered as a forced medical measure and is therefore subject to special regulations.

A measure that restricts personal freedom is discussed jointly by the doctor, the nursing team and the therapist before it is suggested to the elderly person concerned (or, if the person is incapable of discernment, to his person of trust or his legal representative).

The elderly person, or his person of trust or his legal representative, must be informed of the purpose, the nature and the duration of the proposed measure in an understandable and appropriate manner; at the same time he must be told the name of the person responsible for carrying out the measure in question (see under Para. 7.3).

In principle, a measure restricting personal freedom may be taken only with the agreement of the elderly person or, if he is incapable of discernment, with the agreement of his therapeutic representative of his legal representative.

If a person is incapable of discernment and has neither a person of trust nor a legal representative, or if a request for further instructions in an emergency situation is not possible, the doctor, the nursing staff and the necessary responsible therapist have to decide on such a measure in the best interests of the person concerned, in the framework of an interdisciplinary decision-making process including the person's relatives in accordance with the above mentioned criteria⁹. Short-term decisions taken by an individual professional must be discussed and decided a second time in accordance with this procedure.

7.3. Written protocol

A protocol that contains at least the purpose, the duration and the nature of each measure taken, with the name(s) of the responsible person(s) and the results of the regular re-assessments, is kept in the case history and/or in the nursing documentation.

7.4. Complementary measures

One must always be aware that with measures that restrict personal freedom there is always a risk of harm to the patient. Therefore one has to ensure the best possible monitoring of the person concerned while the measure is being carried out. It must be evaluated at regular intervals, the frequency of which depends on the nature of the particular measure in question. The measure is terminated as soon as the conditions detailed in Para. 7.2 no longer apply.

8. Abuse and neglect

Elderly persons who are in need of care are particularly vulnerable and must be protected against the use of violence in any form, whether physical or psychological, abuse or neglect. All signs of the use of violence, abuse or neglect which the nursing team observes in an elderly person must be carefully documented in the case history and in the nursing records, and all the objectifiable findings (size, localisation, appearance etc.) must be recorded. The nursing staff and the therapists must report any signs of violence that they observe to the treating physician.

The doctor, the nursing staff and the therapists must take the necessary steps to prevent further mistreatment. If necessary, and with the agreement of the elderly person concerned (or, if he is incapable of discernment, with the agreement of the person of trust or the legal representative), this information is passed on to the responsible authority. If for any reason this

⁹ Other legal instructions which, for example, generally require the nomination and the agreement of a person of trust or of a legal representative, are reserved.

agreement is not obtained, if it is in the best interests of the patient, the responsible authorities must anyway be informed.

9. Admission to an institution providing long-term care

The elderly person should leave the place where is at present being treated and be admitted to an institution providing long-term care only if, because of the lack of facilities for his proper care or the limited possibility for rehabilitation, remaining at home or returning home is no longer in his best interests. In certain situations, early admission to such an institution can be very useful, for example if in this way the person's social integration can be promoted.

Before a patient's planned admission to an institution providing long-term care, the responsible physician carries out a multidimensional geriatric assessment. This assessment must be carried in the hospital with the participation of the nursing staff and the therapists and, if possible, in collaboration with the treating physician, the Spitex personnel responsible for the ambulant therapy and persons from the elderly person's social environment. The doctor informs the person concerned and, if appropriate, also the persons from his social environment of the result of this assessment and discusses with him the need for him to be admitted to an institution providing long-term care, and the possible alternatives that exist.

III. Recommendations (to long-term residential care institutions)

1. Scope of application

The following recommendations are addressed primarily to the managements of institutions providing long-term care and to the responsible authority; however, they can similarly be addressed to other institutions (hospitals, Spitex services), that also treat and care for elderly persons in need of care. These recommendations are thus also addressed to doctors, nursing staff and therapists who operate in these institutions.

The following recommendations constitute the basic conditions that are essential in these institutions for the satisfactory treatment and care of elderly persons. Such recommendations are formulated for each area of activity defined in the foregoing Guidelines.

2. Principles

The institution protects and respects the rights of the elderly person.

Protection of personal freedom and dignity

The elderly person has the right to have his personal freedom respected. He has the right to be treated with politeness and respect, and also the right that account be taken of his dignity, his well-being and his individuality.

Respect for the person's private and intimate spheres

The institution respects the elderly person's private sphere and his intimate sphere, including his sexual freedom.

The room (or the part of the room) in which the elderly person lives is part of his private sphere and must be respected as such by the staff of the institution. In discussion with the institution, the elderly person may arrange the room (or part of it) according to his own wishes and tastes, particularly by bringing his own furniture and pictures etc. He is provided with a lockable cupboard in which he can keep his personal belongings. If a room is occupied by several persons, the institution takes the necessary steps to protect the private sphere and the intimate sphere of each individual.

The staff of the institution treats any observations from the elderly person's private or intimate spheres, or events that he wishes to share only with a limited circle (friends, relatives) ,with discretion, and passes these observations on to third parties only if this is necessary in order to ensure the proper treatment and care of the person concerned.

Maintenance of social contacts

The institution supports the maintenance and development of the elderly person's relationships with his relatives and his social environment. It informs the relatives about the cultural activities within the institution and endeavours to integrate them. The institution makes it possible for private, confidential discussions and encounters to take place in undisturbed surroundings.

The elderly person has the right to maintain external contacts (letters, visits, newspapers, telephone, television, Internet etc.).

Freedom of opinion and religious freedom

The elderly person is free to express his opinions, so long as they do not give offence to third parties or infringe the law (e.g. racist attitudes). The institution sees to it that the opinions expressed are respected.

The institution respects the elderly person's religious freedom and allows the practice of religious rites or forms of expression; however, these must not encroach upon other persons or the social environment.

Right of assembly

The institution respects the elderly person's right of assembly. The institution encourages its residents to get together as much as they can and provides rooms where they can meet each other socially.

Political rights

The institution sees to it that the elderly person can freely exercise his political rights. It ensures that another person does not exercise these rights on his behalf and does not take advantage of his dependence on others in order to influence him.

Participation in everyday organisation

The residents of the institution who are able to express their opinions are invited to take part in decisions on questions concerning organisation of the everyday life of the institute, living together and arranging events. The institution regulates the nature and form of this participation in the making of decisions.

Right of appeal

The institution establishes an internal procedure for the handling of complaints (on medical, nursing and/or administrative matters). The elderly person himself, his representative and/or his relatives may appear as complainants.

The institution ensures that complaints are dealt with rapidly, carefully, in confidence and without any disadvantage for the complainant. If the complaint is justified, the institution takes the necessary measures. If the institution rejects the complaint, it informs the complainant of the possibilities of recourse or, if necessary, refers him to the ombudsman or to other independent appeal authorities.

3. Decision-making processes

Within the framework of the procedure for admission, the institution ascertains whether the elderly person has nominated an "authorised proxy" to act for him should he become incapable of discernment, who can look after his interests in administrative (incl. financial) matters, and an "authorised representative in medical matters" ("person of trust"), who has to make decisions on his behalf in regard to his treatment and care.

If this is not the case, the institution advises the elderly person to delegate such powers of representation to persons of his choice; if necessary, the institution assists the elderly person in his search for suitable persons. The functions of the "authorised proxy in administrative matters" and of the "person of trust in therapeutic matters" can be carried out by one and the same person or by two different persons.

The institution records the names of the "authorised proxy" and the "person of trust" in the administrative dossier; it ensures that the doctor, the nursing staff and the therapists are informed of the existence of a "person of trust".

4. Treatment and care

Guarantee of adequate treatment and care

Before the institution takes a person into its care, it checks whether his state of health and his level of dependence on others make it possible to care for him in the institution, and whether it has the staff and the facilities necessary for his adequate treatment and care.

Quality assurance

All institutions that treat and care for elderly persons who are in need of care ensure that they have a comprehensive quality management for the adequate treatment and care of their patients.

Qualified personnel

The institution ensures that its professionals have the appropriate education and training which qualify them for the functions that they perform. The institution also supports and promotes the regular postgraduate and further training of its personnel, with particular attention to problem-oriented training in interdisciplinary teams.

The institution appoints a home-doctor who is responsible for the organisation of the medical care provided in the institution and who has the necessary knowledge for this. If there are several doctors working in the institution, after discussion with them all, one of them should be appointed as the responsible home-doctor.

5. Dying and death

Care and accompaniment of the dying

The care and accompaniment of an elderly person in the terminal phase of life must take into account his needs and his convictions. The institution take steps to ensure that the elderly person is supported as much as possible (and as much as he himself wishes) by his social environment. The dying person must be able take leave of those closest to him, undisturbed and in a suitable place, and has the right to the spiritual support of his choice.

The institution creates the right environment for the funeral rituals and rites for all those involved. The institution respects the special religious and cultural funeral rituals of the surviving dependants.

Attitude when faced with the wish for assisted suicide

A special situation arises when, in an institution providing long-term care, an elderly person in need of care plans to commit suicide with the assistance of others (e.g. a euthanasia organisation). This situation can arise because according to Swiss Law the right to assisted suicide is not a criminal offence, except when selfish motives are involved (Article 115 StGB). There are certain institutions which for these reasons allow assisted suicide. In such situations account has to be taken of the fact that an institution providing long-term care has a special duty of protection and must therefore take into account the following:

- a. It must ensure that the person concerned is capable of discernment.
- b. Care must be taken to ensure that the decision for suicide is not due to outside pressure or to inadequate explanation, treatment or care.
- c. Care must be taken to ensure that the feelings of the other residents and the staff of the institution are respected.

Elderly persons who are in need of care have a special relationship of dependence on the staff of the institution; for the staff, this relationship can lead to a conflict of interests. For this

reason and out of consideration for the other residents, the staff of an institution providing long-term care must at no time be actively involved in the suicide of a resident.

6. Documentation and data protection

The elderly person (or, if he is incapable of discernment, his person of trust or his legal representative) may consult the relevant administrative dossier and have it explained to him.

The institution respects the legal dispositions on data protection. In the case of electronic data-processing it pays special attention to these dispositions (namely for the purpose of fixing tariffs, quality assurance or research).

7. Use of measures restricting personal freedom

The institution ensures that with the use of any measure that restricts personal freedom the conditions laid down in Para. 7 of these Guidelines are met.

8. Abuse and neglect

The institution takes steps to ensure that there is no abuse or neglect of elderly persons; it sees to it that Para. 8 of these Guidelines is known to, and is applied by all those concerned.

9. Admission to a long-term residential care institution

Information

Before an elderly person agrees to enter an institution providing long-term care, he (and, if appropriate, his therapeutic representative, his administrative representative or his legal representative) must be given the opportunity to get to know the institution personally, to have a discussion with a responsible person in the institution and to receive all the relevant information (incl. the Regulations).

The institution must provide him (or, if he is incapable of discernment, his person of trust or his legal representative) with written documentation containing easily understandable information on the general conditions for admission and residence, the rights and obligations, the modalities and costs of the care provided and the internal and external appeal authorities. The elderly person's financial situation must also be discussed.

Consent

After he has received the necessary information, the elderly person who is capable of discernment himself decides whether he will enter the institution. If he is incapable of discernment, the decision may be made only by his person of trust or by his legal representative.

If it seems necessary to admit an elderly person to an institution providing long-term care against his specifically expressed wishes, this must happen only after discussion with the responsible guardianship authorities (by means of the procedure for detention in the interests of the individual's welfare).

Regulation of financial affairs

In order to avoid conflicts of interests, the capital and the income of the elderly person are administered by himself (or by his proxies) and not by the institution. The institution sees to it that members of the staff do not accept any donations (or financial gifts or legacies), except for occasional small presents.

Cancellation of contract

Unless there are important reasons for doing so, the institution may not at a later stage cancel the contract with an elderly person in need of care whom it has admitted. If necessary, the institution may help the elderly person to find another institution that can care for him in a manner appropriate to his state of health and his need for care.

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IV. Appendix

The Appendix lists those documents which

- a) *are of a legal nature and have to be strictly observed according to their area of application (Europe, Switzerland, Swiss cantons;*
- b) *as Guidelines of the SAMS, cover certain aspects of the treatment and care of elderly persons in need of care;*
- c) *contain further literature on the subject "Treatment and care of elderly persons in need of care" and which were useful to the sub-committee in the drawing up of the Guidelines and Recommendations.*

a) Legal bases

- Convention on the protection of human rights and human dignity in regard to the application of biology and medicine, of 4 April 1997 (not yet ratified by Switzerland)
<http://www.ofj.admin.ch/themen/bioeth/konvention-biomedizin-d.pdf>
- Swiss Federal Constitution: Art. 7-36 (Fundamental Rights)
<http://www.admin.ch/ch/d/sr/c101.html>
- Federal Law on Data Protection, of 19 June 1992
http://www.admin.ch/ch/d/sr/235_1/index.html
- Code of Civil Law Art. 27 ff. (Protection of legal personality), Art. 360 ff. (Guardianship Rights; in course of revision) <http://www.admin.ch/ch/d/sr/c210.html>
- Code of Civil Law Art. 115 (Inducement and assistance in committing suicide), Art. 181 (Duress), Art. 320 (Violation of official secrecy), Art. 321 (Violation of professional secrecy) http://www.admin.ch/ch/d/sr/311_0/index2.html
- Cantonale Laws on Health
- <http://www.federalism.ch/documentation/claws/gesundheit/>
- Cantonale Laws on Residential care institutions
<http://www.federalism.ch/documentation/claws/gesundheit/>
- Cantonale Laws on Data Protection
<http://www.federalism.ch/documentation/claws/>

b) Medical-ethical Guidelines of the Swiss Academy of Medical Sciences (www.samw.ch)

- "Care of patients in the terminal phase of life" (2004)
- "Treatment and care of long-term patients with severe brain damage" (2003)
- "Research studies in humans" (1997)
- "Emergency measures in medicine" (in preparation)

c) Further literature

- Agence Nationale d'Accréditation et d'Evaluation en Santé: Evaluation des pratiques professionnelles dans des établissements de santé; Limiter les risques de la contention physique de la personne âgée. 2000. www.anaes.fr/publication/geriatrie
- Arbeitsgruppe «Ethische Richtlinien» des Heimverbandes Schweiz, Fachverband Betagte: Grundlagen für verantwortliches Handeln in Alters- und Pflegeheimen. 1997.

- Arbeitsgruppe Gesundheit (AGX) der Schweizerischen Datenschutzbeauftragten: Bericht 2003 betreffend Pflegebedarfsabklärungssysteme (Bewohnerbeurteilungssysteme) in Alters- und Pflegeheimen.
- Association Alzheimer Europe: Directives relatives aux différentes mesures destinées à restreindre la liberté de mouvements. Position paper 2001.
www.alzheimer-europe.org
- Association Alzheimer Europe: Les droits des personnes atteintes de démence. 2001.
www.alzheimer-europe.org
- Association vaudoise d'établissements médico-sociaux: Charte éthique. 2001.
- Baumann-Hölzle R.: Moderne Medizin – Chance und Bedrohung. Kap. 20: Ethische Probleme in der Geriatrie. Kap. 21: Gelungenes Altwerden und Sterben im Spannungsfeld von Macht und Menschenwürde. Peter-Lang-Verlag, Bern/Berlin. 2001.
- Comité européen pour la cohésion sociale (CDCS)/Conseil de l'Europe: Améliorer la qualité de vie des personnes âgées en situations de dépendance. 2002.
(<http://book.coe.int>)
- European Association for Directors of Residential Care Homes for the Elderly: Charte européenne des droits et libertés des personnes âgées en institution. 1993. www.ede-association.org
- Forum stationäre Altersarbeit/ Santésuisse: Konzept zur Einführung eines institutionalisierten Qualitätsmanagements in Schweizer Pflegeheimen gemäss KVG. 1998.
- Gebert A., Kneubühler H.-U.: Qualitätsbeurteilung und Evaluation der Qualitätssicherung in Pflegeheimen. Huber-Verlag, Bern. 2001.
- International Association of Gerontology: The Older Person's Charter of Standards. 1997. www.sfu.ca/iag
- Kesselring A.: Beurteilung der Verhältnismässigkeit von RAI-Items aus pflegewissenschaftlicher Sicht. Institut für Pflegewissenschaft der Universität Basel, 2003.
- Mettner M., Schmitt-Mannhart R.: Wie ich sterben will. Patientenautonomie, Selbstverantwortung und Abhängigkeit am Lebensende. NZN Buchverlag, Zürich. 2003.
- Schönenberg H.R.: Qualitätssicherung und Qualitätsförderung im Langzeitpflegebereich. Managed Care 2000; Nr. 2: 21-23.
- Schweizerischer Berufsverband für Krankenpflege: Qualitätsnormen für die Pflege und Begleitung von alten Menschen. Bern. 1994.
- Schweizerischer Berufsverband für Krankenpflege et al.: Rund um den Heimeintritt: Broschüre für ältere Menschen und ihre Angehörigen. Ott-Verlag, Thun.
- Schweizerische Gesellschaft für Gerontologie: Richtlinien zur Anwendung freiheitsbeschränkender Massnahmen bei der Behandlung und Pflege betagter Personen. 1999. (www.sgg-ssg.ch).
- Schweizerische Sanitätsdirektorenkonferenz: Empfehlungen zum Vollzug des KVG im Bereich der Pflegeheime und der Spitexdienste. 1998.
- Schweizerischer Senioren und Rentner-Verband: Vorschlag zu einem Kantonalen Gesetz betreffend Heime für alte Menschen und Menschen mit Behinderung. 2001.
- Stuck A.E.: State of the Art: Multidimensionales geriatrisches Assessment im Akutspital und in der ambulanten Praxis. Schweiz Med Wschr 1997; 127: 1781-1788.
- United Nations: United Nations Principles for Older Persons. 1999.
<http://www.un.org/esa/socdev/iyop/iyoppop.htm>
- Weltärztebund: Deklaration von Hong Kong über die Misshandlung älterer Personen. 1989. www.bundesaerztekammer.de/30/Auslandsdienst/99.Handbuch2000.pdf
- WHO Division of Mental Health: Psychiatry of the elderly – a consensus statement. 1996. http://www5.who.int/mental_health/download.cfm?id=000000017