Medical treatment and care of people with disabilities



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

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

© SAMS 2017



Medical-ethical guidelines and recommendations

Medical treatment and care of people with disabilities

Approved by the Senate of the SAMS on 20 May 2008. 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.

l.	PREAMBLE	5
II.	GUIDELINES	7
1.	Scope	7
2.1. 2.2. 2.3. 2.4. 2.5. 2.6. 2.7. 2.8.	Basic principles Respect for dignity Respect for autonomy Equity and participation Consideration of quality of life Care and responsibility Appropriate treatment and care Continuous personal care and interdisciplinary cooperation Collaboration with the social environment	8 8 9 9 10 11 11 12
3. 3.1. 3.2.	Communication Information on medical treatment and care Information on diagnosis and prognosis	12 13 14
4. 4.1. 4.2. 4.3.	Decision-making processes Patients with capacity Patients lacking capacity Decision-making within the care team	15 15 16 17
5. 5.1. 5.2. 5.3. 5.4. 5.5. 5.6. 5.7.	Treatment and care Aetiological diagnosis Health promotion and prevention Acute therapy Treatment of mental disorders Rehabilitation Palliative care Dying and death	17 17 17 18 19 19 20 21
6. 6.1. 6.2.	Documentation and data protection Medical records and documentation on care Confidentiality and obligation to inform third parties	21 21 22
7. 7.1. 7.2. 7.3.	Maltreatment and neglect Definitions Recognition of risk situations and prevention Procedure in case of concrete suspicion	22 22 23 24

8.	Sexuality	24
8.1.	Consequences and risks of sexual activity	25
8.2.	Contraception and sterilization	25
8.3.	Parenthood	27
8.4.	Protection against sexual abuse	27
9.	Periods of life and transitions	28
9.1.	Transition from childhood to adulthood	28
9.2.	Transition to old age	29
9.3.	Transfer to a social or sociomedical institution	30
10.	Research	31
III.	RECOMMENDATIONS	32
1.	Recommendations to political authorities and those responsible for	
	payment of costs:	32
2.	Recommendations to health-sector and medical institutions	32
3.	Recommendations to social and sociomedical institutions with	
	responsibility for the care of persons with disabilities	33
IV.	APPENDIX	34
	Glossary	34
	Information on the elaboration of these guidelines	36

I. PREAMBLE

A considerable number¹ of people of all age-groups are themselves affected by disability² at some time in the course of their life. Over the last few decades increased attention has been paid to their place in society and their condition has been placed in the context of general human rights.³ Persons with disabilities are threatened in many ways: by patronizing restrictions on their self-determined way of life and by neglect, by social barriers or by active exclusion. The recognition and support of the right to self-determination and self-responsibility and the removal of obstacles to free participation in social life are essential preconditions for the individual's defence against such threats. There is also the need to take active steps to integrate people with disabilities into all areas of society.

In their nature, their severity and their duration and also in their social context, disabilities vary over an extremely broad, continuous spectrum. Their importance with regard to medical⁴ treatment and care can correspondingly also be very different:

A disability can be directly related to treatment: preventive, curative, rehabilitative and palliative measures are intended to eliminate or reduce the effects of congenital or acquired impairments.

However, a disability can also indirectly influence treatment and care: even when health disorders are not directly connected with a disability, this can be important for the course of the disease or for the diagnostic and therapeutic possibilities. Therefore a procedure that is adapted to the special situation must be chosen.

In many cases, however, the disability has no relevant connection with the health disorder that has to be treated. In these situations, a treatment that deviates from the usual therapy is no more justified than discrimination on grounds of gender or nationality would be.

Cf. Murray CJL., Lopez AD. Quantifying disability: data, methods and results. Bull World Health Organ. 1994; 72(3): 481–494
 www.ncbi.nlm.nih.gov/pmc/articles/PMC2486704/pdf/bullwho00414-0157.pdf

² See definition of the term "disability" in Section 1 and the definition in the Glossary.

³ See the Convention on the Rights of Persons with Disabilities, adopted by the United Nations on 13.12.2006 (www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-withdisabilities.html), and the Federal Act of 13 December 2002 on the Elimination of Discrimination against People with Disabilities (BehiG).

⁴ The term "medical" is used very broadly in these guidelines and refers to the activities of physicians, nurses and therapists.

The aims of these guidelines are

- to confirm and promote the right of all persons with disabilities to appropriate treatment and care;
- to draw attention to the decisive role of good medical treatment and care for the support of persons with disabilities in their efforts to achieve self-determination and social participation;
- to provide help, in the guidelines, for physicians, nurses and therapists in dealing with persons with disabilities and their relatives;
- to make recommendations to social institutions and political authorities as to how favourable conditions can be created for the treatment and care of persons with disabilities.

They therefore fill the gap deliberately left in the guidelines on the "Treatment and care of elderly persons dependent on care" regarding the treatment and care of young people dependent on care, but they are also relevant for people responsible for the treatment and care of patients with disabilities who are not dependent on care.

⁵ Cf. "Treatment and care of elderly persons dependent on care" (medical-ethical guidelines of the SAMS).

II. GUIDELINES

1. Scope

The present guidelines are addressed to physicians⁶, nurses and therapists who treat and care for persons with disabilities medically, or who carry out expert assessments⁷, either in the patient's home or in medical, sociomedical or social⁸ institutions.

In the guidelines, the term "disability" refers to the hindering effects of a congenital or acquired health condition⁹ on the everyday activities of the person concerned and on his¹⁰ participation in social life. The disability is the result of the interplay between physical damage, functional impairment¹¹ and social limitations placed on the person concerned, and the facilitating or hindering factors and the expectations of his environment. The extent and the subjective experience of these various factors are modulated by the personality traits of the individual with a disability¹².

The guidelines are deliberately not limited to certain forms of disability, but are intended to be applied in all cases where a disability decisively determines the nature of the treatment and care process. Consequently, certain sections of these guidelines can be of varying relevance for the care of persons with different types and degrees of disability.

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

⁷ The guidelines are intended primarily for medical professionals, but they are also addressed to specialists in the fields of special-needs education and social work, etc.

⁸ For the definition of the term "social institution", see the Glossary.

⁹ For the definition of the term "health condition", see the Glossary.

¹⁰ The masculine pronouns (he, him, his etc.) are always used, although both male and female persons are covered by these guidelines.

¹¹ This covers disorders of motor and sensory functions and impairment of cognitive and other mental functions.

¹² For the origin of the definition of the term "disability", see the Glossary.

2. Basic principles

The basic values, attitudes and ways of acting endorsed by these guidelines are described below.

2.1. Respect for dignity

Dignity¹³ is intrinsic to humanity, and it is therefore independent of a person's physical, cognitive or psychiatric impairments or of a particular context. In this sense, dignity must be respected without question. The risk of dignity not being respected is particularly great in situations of weakness.

For those who are responsible for treatment and care, respect for the dignity of the patient¹⁴ means:

- appreciation of the uniqueness of the person with disabilities and treating him/her individually as a man or a woman, according to age and stage of development;
- taking into account the patient's particular vulnerability with regard to both behaviour and communication, and treating him with respect, empathy and patience;
- supporting the patient in his efforts to achieve an independent, well integrated life;
- taking into account the aspects of power and dependence in the patient's relationships;
- awareness that concepts of normality and difference and of participation and exclusion depend on one's own perspective.

2.2. Respect for autonomy

Every person has the right to self-determination. This also applies when a disability leads to limitation of the patient's capacity for autonomy. A person is capable of autonomy if he is in a position to fully appreciate his life situation and on the basis of this to make decisions that are in line with his values and convictions and to express his wishes in these respects.

For those who are responsible for treatment and care, respect for autonomy means:

supporting, without pressure and with empathy, the necessary individual processes of the patient's capacity for autonomy (appreciation of the situation, recognition of the various possible options and their consequences, their evaluation on the basis of his own preferences, the expression of his decisions and wishes and their implementation);

¹³ Regarding the concept of "dignity", see the Glossary.

¹⁴ In order to do justice to the primarily medical nature of these guidelines, whenever people with disabilities are considered as recipients of medical services, the term "patients" is used rather than the more general terms "persons" or "people".

- determining, in the case of patients with limited autonomy, what their level of autonomy in fact is and how this can be taken into account in the decisionmaking process;
- involving persons who are close to the patient, to support the communication process, provided that he wishes this and that it is in his best interests;
- taking into account the fact that both within the team responsible for his care and among his relatives¹⁵ the need to sense the patient's wishes through empathy involves the risk of projecting one's own wishes and preconceptions.

2.3. Equity and participation

In a society governed by the basic principle of equity, great importance is attached to equal participation of all its members in social life. As a limitation on the possibilities for such participation is one of the main consequences of an impairment or the loss of certain functions, society makes special resources available for persons with disabilities. One important component of these special resources is medical treatment and care. This must therefore always be oriented towards the effects of the measures taken on the patient's possibilities for participation in social life. The International Classification of Functioning, Disability and Health (ICF) of the WHO provides support in this respect.¹⁶

2.4. Consideration of quality of life

The medical treatment and care of patients with disabilities also always has to be assessed with regard to its effects on the quality of life. For those responsible for the treatment and care of persons with disabilities, adequate consideration of the quality of life, whether systematically by means of validated instruments or purely situation-based, means:

- placing the patient's subjective life experience, especially his satisfaction with his life situation, in the foreground;
- identifying the various dimensions of the quality of life (physical, emotional, intellectual, spiritual, social and economic) that are relevant for the medical question at hand;
- respecting the weighting of the different aspects of the quality of life from the patient's point of view;
- in patients with impaired possibilities of communication, inferring their subjective experience of life, as far as this is possible, on the basis of objective observations

^{15 &}quot;Relatives" are understood to be the patent's spouse/partner, close relatives and other persons close to him

¹⁶ See Glossary, under "Disability".

- when using these observations as a means of gaining access to the patient's subjective experience of life, being aware of the risk of projecting one's own wishes and preconceptions;
- explicitly considering the quality of life of relatives and carers, which is often very closely associated with that of the patient, and assessing the two separately.

The assessment of medical measures from the point of view of quality of life is difficult if the patient cannot estimate the effects himself or if his possibilities of communication are impaired. Particularly difficult in this respect is the use of medical measures, which, although they can maintain or improve the quality of life in the long term, may impair it temporarily. In patients who cannot make decisions on their own and whose presumed wishes are not known, considerations regarding the quality of life must be based on the medical-ethical principles of "doing good" and "not harming".

2.5. Care and responsibility

In many persons with severe disability, giving them self-determination and breaking down the barriers to participation in society is not enough; they need special care from voluntary or professional caregivers. Reliance on special care can create dependence, which can in turn affect the self-esteem of those concerned and can make them vulnerable to abuse by others. It is important that the carer and the patient are always aware that dependence is one of the basic conditions of human life.

The need for care on the part of persons with disabilities requires assumption of responsibility by their carers, either within the family, through personal assistance¹⁷ or in social or sociomedical institutions. The care of persons with disability can be satisfying, but it can also be challenging and stressful. An excessive sense of responsibility increases both the dependence of the patient and the vulnerability of the carer. The idea of being responsible, alone, for the well-being of the patient can lead to overexertion and even exhaustion. It can also make one susceptible to being offended by the environment, which apparently or in fact shows too little understanding. If the patient, for his part, takes advantage of the carer's codependency in order to make unreasonable demands, this can complicate the situation even further.

^{17 &}quot;Personal assistance" covers all forms of support where the persons concerned themselves determine who provides help, where, when and how. The services provided are generally paid for by the requester.

In the field of medical care, the dependence of persons with disabilities and the special vulnerability of carers have to be considered and taken into account according to the particular situation.

2.6. Appropriate treatment and care

Every person has the right to appropriate treatment and care. This means, on the one hand, that any preventive, curative or palliative measure that is indicated must not be withheld because of existing damage or impairment. Any discrimination with regard to access to services in the health sector must be avoided. On the other hand, appropriate treatment and care require that the effects of the existing disability on the possible results of treatment have to be considered and the individual wishes and needs of patients have to be duly taken in account. The decisive criterion for the appropriateness of a therapeutic measure is its positive effect on the quality of life and life expectancy.

2.7. Continuous personal care and interdisciplinary cooperation

Persons with disabilities often have many different medical problems and are therefore being treated and cared for by specialists of different disciplines. Regular changes between treatment and care in institutions and in the home can lead to their being treated simultaneously or sequentially by different physicians. For this reason one physician, who receives all the relevant information on the case, must be nominated as being primarily responsible for the patient's well-being. In the event of a change of responsibility, e.g. when the patient reaches adulthood, there must be a careful handover, preferably with direct discussion between the two physicians concerned and the patient.

The nursing care and the non-medical therapies provided in the medical environment must be included in the continuous personal care described above. The mutual information and coordination of all the physicians, nurses and therapists involved is needed, provided that the patient agrees to this. Members of various social and pedagogic professions are often also involved. Interdisciplinary coordination can be specific to the particular individual case, e.g. in so-called "helper conferences" in crisis situations. For the long-term care of specific forms of disability, specialized interdisciplinary outpatient consultations are the optimal solution.

For patients with cognitive or mental impairments, contacts with many different physicians can be confusing and worrying. This results in further impairment of their already limited capacity for autonomy. A trusted person who is well acquainted with the patient's case history should therefore be allowed to accompany him on all his visits to the various physicians.

2.8. Collaboration with the social environment

In the treatment and care of persons with disabilities in social and sociomedical institutions or in the acute hospital, the treating physician and the person responsible for the care of the patient must maintain good contact with the persons closest to him. In caring for patients with disabilities, in most cases the relatives have assumed great responsibility; their experience in the interpretation of symptoms and their intimate knowledge of the patient's habits, preferences and dislikes must therefore always be taken seriously as important contributions to the decision-making process.

The care of patients with disabilities in their own home often leads to considerable stress. Physicians, nurses and therapists have the task of advising and supporting the relatives and other carers.

3. Communication

Appropriate, open and sympathetic communication with the patient is a precondition and an integral component of all good treatment and care. Not all patients with disabilities are in need of support or special forms of communication. To underestimate the capabilities of these patients can in fact give offence to them.

For patients with specific needs, the way of communicating with them must be adapted to the particular situation. Care must be taken to ensure that

- if possible the discussion takes place with discussion partners whom the patient knows, at a place that is also known to him;
- aids that are required because of impaired eyesight or hearing are used to optimal effect and the environmental conditions for the discussion (lighting conditions, background noise) are favourable;
- the medical person who is conducting the discussion has familiarized himself
 with the intellectual level on which it is possible to communicate with the patient and is conversant with all the necessary means of communication (pictograms, communication boards, computers etc.);

- any third persons who may be needed are present, such as interpreters, e.g. for sign language, or relatives who understand the patient's nonverbal utterances well or who have their own method of communicating with him;
- the increased time that is needed for the person with disability to receive, to understand and to provide information, is planned for from the beginning;
- even when communication is difficult, the patient is always spoken to directly and under no circumstances does one discuss or make decisions over his head.

3.1. Information on medical treatment and care

Adequate and understandable information on all the planned medical, nursing and therapeutic measures are necessary, so that patients can assert their right to self-determination. Because of a disability, the possibility of understanding routinely provided information or of actively acquiring additional explanations and knowledge can be limited. Especially patients with cognitive or mental impairments or with limited possibilities of communication are very dependent on the way in which they are informed.

Understanding of the information received and the decision-making can be facilitated and the patient can be given a feeling of security and orientation if the medical discussion partner:

- uses simple language (short sentences and avoidance of foreign words, abbreviations and different expressions for the same concepts);
- speaks slowly and clearly, with eye contact at eye level;
- provides the information in small portions;
- supports his statements by repeating them in different variations and with gestures, pictures, pictograms etc.;
- describes the medical measures that are planned to the patient by explaining the procedures, showing the various instruments to be used and visiting the different places where they are carried out.

The involvement of third parties (relatives, deputies, trusted persons) is based on the rules laid down in Section 4. In this connection it has to be considered that these persons can play different roles:

- They can provide essential help in communication, in order to determine the patient's wishes.
- According to the rules laid down in Section 4, they can participate in the making of decisions on behalf of patients who lack capacity.
- They may also promote their own interests, which are not necessarily the same as those of the patient.

It is often difficult to differentiate between these various roles. In many cases it is therefore important to also have a discussion with the patient alone.

3.2. Information on diagnosis and prognosis

A very difficult situation for everyone is informing the patient or his relatives of a diagnosis that leads to, or could lead to, a disability. This can be a "one-off" event or it may have to be repeated several times as the disability progresses. Special powers of empathy are required in order to give the patient a realistic picture of the disability and its consequences without destroying all hope. To achieve this, the person concerned must be allowed sufficient time to absorb the news and to be able to ask his first questions. The first discussion should not include too much advice, as the patient's intellectual receptiveness is often impaired by emotional factors. The disability, its effects and any possible treatment must be explained to the persons concerned in an easily understandable manner. In particular, any existing self-help and specialist help and other possible information, and the possibility of psychological support must be explained to them. Special attention must be paid to the non-verbal messages that are conveyed, intentionally or unintentionally, in such discussions, as these deeply affect the persons concerned. They often remember, for the rest of their lives, whether their discussion partner has shown disparagement, dissociation and hopelessness or respect, empathy and confidence.

4. Decision-making processes

Decision-making procedures and structures must take into account the specific situation of the patient. In particular, care must be taken to ensure that the patient and any representatives are informed adequately and in an understandable manner (cf. Section 3) and that they can make decisions without being under pressure.

4.1. Patients with capacity

Physicians, nurses and therapists may treat or care for patients with capacity¹⁸ only after obtaining their informed consent. Minors and adults with an appointed deputy can also have capacity with regard to their own affairs and can decide on their medical treatment and care. However, in the case of such a decision their capacity must be carefully assessed in advance.

It is the duty of the professionals to include minors or adults with an appointed deputy in the decision-making process, as far as this is possible, and to obtain their consent. Excessive demands must not be placed on them in decision-making; however, decisions must also not be made on their behalf if they wish to, and can, actively participate in decisions regarding their treatment and care. In decisions of major importance, the holders of parental authority or the deputy should be involved, provided that the patient does not object to this.

If a minor or an adult patient with a deputy does not consent to proposed treatment and care, the significance and importance of which he understands, then it may not be carried out (but cf. Section 7). However, it must be carefully checked whether this refusal really corresponds to his free wishes.¹⁹

In many patients (especially in the case of mental impairment), capacity may vary over time. If a patient temporarily lacks capacity, treatment may only be carried out if it is urgent. Decisions on such treatment are subject to the rules given in Section 4.2.

^{18 &}quot;Capacity" means the ability to perceive reality and to form judgments and wishes, and the ability to express one's own choices.

¹⁹ Strong emotions such as anxiety, for example, can call into question the presence of capacity, so that one can then no longer speak of the autonomous expression of wishes.

4.2. Patients lacking capacity

Decisions regarding the treatment and care of patients who have never had capacity ²⁰ must be guided exclusively by their best interests, and they must be made with the agreement of the persons legally entitled to act as representatives. ²¹ A person who lacks capacity should be involved, as far as possible, in the decision-making process.

If the patient had capacity at an earlier point in time, the decision is to made by the authorized representatives in accordance with the patient's presumed wishes and best interests. If a valid advance directive²² is available, the decision is to be made by the physician in accordance with the instructions given in the directive, unless there are reasonable doubts as to whether the directive was voluntary or still reflects the patient's presumed wishes. These are to be determined with the aid of persons close to the patient. If there is no person entitled to act as a representative, the child and adult protection authority should be contacted.

If the authorized representatives refuse to consent to treatment that is in the best interests of the patient, the adult or child protection authority is to be informed. However, if there is insufficient time to inform the authority because of the urgency²³ of the case, interventions intended to save life or to prevent serious harm may and should be carried out in the interests of a patient lacking capacity, even if this is contrary to the express wishes of the patient's representative.

²⁰ These are patients with "true" incapacity, incapable from birth of forming wishes in relation to interventions (e.g. people with severe mental disabilities).

²¹ 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.

²² Cf. "Advance directives" (medical-ethical guidelines and recommendations of the SAMS).

²³ In order to save life or to prevent serious harm, urgent treatment, nursing or care may be carried out if neither the patient himself nor his representative can give their consent in good time, or if there is reasonable doubt as to the validity of a refusal of treatment, on account of incapacity or a conflict of interests on the part of the representative.

4.3. Decision-making within the care team

Medical treatments and care measures often require an interdisciplinary decision-making process. Before such treatment or measures are suggested to a patient, they must first be discussed within the care team, who must try to arrive at a decision that is acceptable to all the participants. Important decisions are to be recorded in writing, regularly reviewed and adapted if necessary (cf. Section 6).

The need for interdisciplinary collaboration does not relieve the treating physicians, nurses and therapists of their responsibility for decisions and measures within their own area.

5. Treatment and care

5.1. Aetiological diagnosis

Persons with disabilities have a right to an adequate diagnostic investigation of the nature and cause of their health condition. Identifying as accurately as possible the causes of damage or impairment can help the patients concerned and their relatives, as well as also the professionals responsible for their treatment and care

- to make more specific plans for the preventive, curative and rehabilitative treatment of the impairment;
- to better prevent, detect and treat the complications and further illnesses that are be expected;
- to be able to better integrate and assimilate the fact of the impairment into the patient's life history;
- to recognize genetic risks and to take these into account when considering family planning.

5.2. Health promotion and prevention

It has to be ensured that persons with disabilities can benefit from all measures that are available to the general population for the promotion of health and prevention. Vaccinations and medical check-ups in the age-groups and risk situations for which they are intended are to be recommended and should be carried out if the persons concerned are in agreement.

For persons with disabilities, the underlying health condition and the effects on their everyday life can alter the risk situation in comparison with the general population. For example, more risks have to be expected because of lack of mobility, poor nutrition, problems of self-esteem, anxiety, and risks of abuse or neglect. The existing risks must be explained in a suitable manner to the persons concerned and their carers, who must also be informed of the possibilities for the promotion of health.

Various professional associations have drawn up and published specific preventive programmes for many genetic disorders, congenital malformations and chronic illnesses that occur in patients with disability. The regular check-ups that are recommended in these programmes allow optimal early detection and treatment of complications and further illnesses. It is part of the treatment and care of persons with disability to give the possibility of access to these special measures.

5.3. Acute therapy

In the event of acute illness or injury, all persons with disabilities have the right to immediate medical help, with appropriate diagnostic measures and effective treatment, irrespective of the nature and extent of their disability. Special aspects specific for the particular disability can complicate history-taking, clinical examination, the interpretation of findings and choice and application of the best possible therapy. The health condition underlying the disability or the patient's particular way of life can alter his response to standard therapies, especially those based on drugs, and can lead to unexpected side effects. These difficulties must be dealt with on the one hand by consulting the relatives, carers and medical professionals who have treated the patient previously and on the other by searching the literature for information relevant to the disability or by consulting external experts.

The complexity of the problem, the expertise that is available locally, the time pressure and the geographical considerations determine whether investigation and treatment are possible at the place where the patient is first seen, or whether one should try to transfer him to a specialist medical centre. In this connection, the need for the special nursing care that is necessary in order to maintain the patient's present level of independence also has to be taken into account. Carers from the family or from the institutional environment should come to the hospital in an advisory and supportive capacity, but not as replacements for the responsible nursing staff.

After the acute situation has been dealt with it must be clarified, as soon as possible, whether a rapid return to the patient's earlier way of life is possible or whether other solutions, temporary or permanent, must be found. Here too, consultation of external experts or transfer to a specialist institution can be of practical value.

5.4. Treatment of mental disorders

Psychiatric illness can lead to transient or permanent impairment or can complicate a preexisting disability situation.

Mental disorders can occur as a reaction to a physical or cognitive impairment or to the conditions of life resulting from this, but they may also occur without any recognizable connection to the existing disability.

It often requires specialized psychiatric knowledge to differentiate between mental disorders and abnormal behaviour resulting from disorders of communication or unsuitable living conditions. Special knowledge is also needed to make a diagnosis and to carry out the treatment. In particular, problems of communication and cognition due to a disability must be identified and an adequate therapeutic setting created, together with the patient and his relatives and carers. Psychotropic drugs must be used according to professional criteria and not with the primary aim of reducing the amount of care required. They must be carefully reviewed with regard to their effects and their side effects over the further course of the condition.

Due attention must be paid to the stressful situation for the relatives and the carers, which may persist for years, and if necessary they must be given help.

5.5. Rehabilitation

Rehabilitation after an illness or an injury or rehabilitation after congenital damage or damage occurring in early childhood covers all medical measures that as far as possible reduce the effects of incurable sequelae and is therefore of very special importance for persons with disabilities. Physical, mental and social capacities and possibilities must be restored, developed and maintained as far as this is possible. The rehabilitation team, with specific training and experience, and the patient, with his personal conception of life and his wishes, must together estimate the potential for rehabilitation and set individual objectives.

Rehabilitation is basically a long-term procedure and therefore needs sufficient time. With certain health conditions targeted and intensive rehabilitation is necessary in order to reduce the extent of the damage. At the same time, however, account has to be taken of the continuing course of the patient's condition. This can be characterized by progression or improvement of the underlying illness, by newly occurring diseases, by increasing age and by sudden or insidious changes in the patient's mental and social conditions. Regular reassessments are therefore needed, lifelong, with a standardized evaluation of the biopsychosocial situation. These lead to new, adapted rehabilitation objectives, which facilitate effective and needs-oriented further treatment.

5.6. Palliative care²⁴

Congenital or acquired damage or impairments may be so severe that from the beginning, or as a result of progressive deterioration, life expectancy is reduced, without any prospect of a cure. Alongside the efforts for rehabilitation, adequate measures therefore have to be made available which alleviate the physical symptoms and at the same time take into account the social, mental/emotional and religious/spiritual needs of those concerned.

In patients with limited powers of communication, the recognition and differentiation of physical symptoms such as pain, muscular tension, nausea and respiratory distress on the one hand, and negative emotions such as anxiety, loneliness, rage and grief on the other is very demanding and makes appropriate palliative care difficult. Knowledge and use of suitable assessment instruments are indispensable for the care of these patients.

In the interpretation of new or deteriorating symptoms it always has to be carefully clarified whether they are in fact an untreatable deterioration of the underlying illness or a newly acquired treatable health disorder. Care has to be taken in order that useful curative options are not forgone due to an exclusive focus on symptomatic therapy. Possible diagnostic and therapeutic steps must be evaluated in the course of a careful, ethical decision-making process with regard to the benefits and burdens for the patient. At the same time, palliative measures must be initiated in each case.

5.7. Dying and death²⁵

If an unavoidable deterioration of the state of health develops, the patient's approaching death must be discussed, in an appropriate manner, with him and with his relatives. The way in which the disability has affected the patient's life and his communication with physicians, nurses and therapists can also be a guide for the dialogue in this terminal phase. It can sometimes be helpful to address possible end-of-life options and to prepare an advance directive at an early stage.

The difficult emotional situation of long-term carers within the family or in an institution has to be considered, in that they have to be suitably involved and, if necessary, supported in the structuring of the terminal phase of the patient's life.

6. Documentation and data protection

6.1. Medical records and documentation on care

A continuous documentation, which is constantly updated is kept for each patient.²⁶ Besides the data concerning the case history, diagnosis and course of the condition and the prescribed treatments etc., in particular the content of the procedure whereby informed consent is obtained from the patient or authorized representative should also be documented. For older adolescents and adults with a deputy the patient's dossier should also contain information concerning decisions for which the patient was considered to lack capacity and for what reason. The reasons for any failure to comply with an advance directive are to be stated in the patient's dossier. If measures are taken which limit the patient's freedom, these are also to be recorded in the patient's dossier. The documentation should contain information on the reasons for and the nature of the measure taken, its purpose and duration and the results of regular reviews.

²⁵ Cf. "End-of-life care" (medical-ethical Guidelines of the SAMS.

²⁶ Depending on the legal nature of the treatment relationship, the question of documentation requirements is governed by federal private law (Code of Obligations) or cantonal public law.

6.2. Confidentiality and obligation to inform third parties

Physicians, nursing staff and therapists are bound by confidentiality.²⁷ Data may be collected, recorded, evaluated and passed on to third parties only in accordance with the legal provisions concerning data protection. Information may be passed on to third parties only with the express consent of the patient or his representatives or on a legal basis or with the written approval of the responsible authority or supervisory authority.²⁸

7. Maltreatment and neglect

7.1. Definitions

Physical, mental and sexual abuse and maltreatment and neglect are expressions of the misuse of a relationship of dependency. The law protects the personal integrity of the individual and therefore considers such abuse and maltreatment as criminal offences.²⁹

Persons who are less able to defend themselves because of physical, cognitive or mental impairments are more often victims of abuse and maltreatment. A special situation of dependence, such as exists in social institutions or in connection with medical treatment, nursing care or other therapeutic measures, can increase these risks. In this connection the special vulnerability of the victim and the extent of the situation of dependence not only favour the incidence of such abuse but also make it more difficult to detect.

Neglect means the inadequate fulfilment of the obligation to treat and care for a person, which is imposed on a carer on the basis of a legal responsibility, or a relationship of responsibility that is entered into voluntarily. The obligation to treat and care consists of providing support for the person concerned in meeting his needs, if he is not in a position to do so himself. All levels of the hierarchy of needs (physiological, safety, love/belonging, esteem and self-actualization)³⁰ can be subject to neglect. Paradoxically, neglect of the need for self-actualization can also occur as a result of excessive care, which can hinder a patient in his development and in the development of his personal autonomy.

²⁷ Professional confidentiality according to Article 321 of the Swiss Criminal Code applies for physicians and other medical professionals; for personnel of an institution who are not subject to the conditions of Article 321, the confidentiality provisions of their contract of employment are applicable; in some cases, confidentiality is also regulated in cantonal law.

²⁸ See paragraphs 2 and 3 of Article 321 of the Swiss Criminal Code (StGB).

²⁹ Offences against life and limb.

³⁰ Cf. Maslow AH. Motivation and personality. Harper, 1954.

Causes of neglect can be insufficient material resources, unfavourable environmental conditions, lack of time, insufficient knowledge and experience on the part of the carer and a dysfunctional relationship with the patient.

7.2. Recognition of risk situations and prevention

Physicians, nurses and therapists are under the obligation to consider the possible risk of abuse, maltreatment and neglect and to recognize and avoid risk situations. This applies to patient care both in medical, sociomedical and social institutions and in the family environment. Particular attention must be paid to the following situations:

- situations with a high level of care based on relatively limited resources;
- challenging situations for carers who are in training or who still have little experience;
- carers showing symptoms of stress or with unusual personal relationships;
- application of coercive measures;
- implementation of rules of community life;
- the risk that persons with disabilities may find themselves in a crisis situation due to changes in their state of health or in their treatment and care, and that they may become particularly vulnerable.

Regular consideration of the possibility of abuse, maltreatment and neglect and always taking care to treat patients with respect and esteem can have a preventive effect. Critical everyday situations in medical, sociomedical and social institutions, such as providing patients with support in personal hygiene, eating, defecation, urination and going to bed, and medical examinations or the use of various therapeutic measures, should be looked at with regard to the potential risk of abuse, which should in turn be safeguarded against by appropriate rules and support options.

Also in care situations in the family it is important to be sensitive to possible risk situations. Potentially critical situations must be addressed and any possible need for support clarified and met.

7.3. Procedure in case of concrete suspicion

If there is concrete suspicion of abuse, maltreatment or neglect, the person concerned must be protected against further harm. Such harm can arise as a result of persistence of the particular situation and inappropriate investigative measures and interventions.

In medical, sociomedical and social institutions, suspected cases must be reported to an experienced, independent professional for clarification and further treatment. Also in the case of suspected maltreatment of a patient being cared for in the family environment, it is advisable not to act alone, but to seek the advice of an independent professional. In this connection, professional confidentiality and any cantonal regulations regarding rights or duties to report³¹ must be observed. Psychological help must always be provided for the victim.

8. Sexuality

Sexuality is an integral component of human personality. Sexual self-determination must be protected. A disability can impair the development of sexuality at the physical, mental and emotional levels in that it leads to problems in the search for a partner, in the development of sexual relations and in the handling of the consequences and risks of sexual activity. Here, besides the disability itself the changes in the patient's life conditions resulting from it also play an important role.

Physicians, nurses and therapists may be called upon to provide advice and support for persons with disabilities when dealing with the medical aspects of sexual activity and its consequences. Especially in the case of physical disability it is important to address the need for support in this area, because often the patient will not talk about it, out of a sense of shame. Especially in the case of cognitive impairments, providing information on the various aspects of sexual activity is an important measure for the promotion of sexual health.

This advice must be based on the fact that persons with disabilities have the right to free development of their sexuality. Restriction of sexual activity is only permissible where it would be harmful to the patient or other persons or would create a public nuisance.

³¹ Cantonal health laws provide for a duty, in some cases a right, for physicians to report to the police suspected offences against life and limb or against sexual integrity, without having been released from their duty of confidentiality.

Special care is indicated in the case of persons with limited capacity. They need support in the development of their sexuality and in overcoming obstacles associated with this. However, there must not be any unilateral promotion of sexual activity that outpaces the development of the individual's personality.

8.1. Consequences and risks of sexual activity

Sexual activity, if it is not limited to one's own person, gives rise to bonds with the partner and perhaps also leads to the birth of children, and it thus requires the assumption of responsibility. However, it also involves risks, such as the risk of sexually transmitted infections or the risk of maltreatment by the partner. Disabilities can lead to problems with regard to both the assumption of responsibility and the handling of risks.

For sexually active persons with disabilities, it is the physician's task to provide advice and support with regard to contraception, the wish to have children or unwanted pregnancy, and also with regard to the prevention of sexually transmitted infections and sexual abuse. In the case of sexually active women, preventive gynaecological examination must be considered.

8.2. Contraception and sterilization

From the many different methods of contraception that are available, persons with disabilities have to choose the method that is most suitable for them individually. Preference must always be given to reversible methods of contraception, rather than a definitive measure such as sterilization.

In choosing the method, care must be taken to ensure that it

- is compatible with any existing physical health problems and corresponding medication:
- can be used without complications and as independently as possible by the individual him/herself, or that close persons can provide any support that may be necessary;
- that its use and possible side effects meet individual expectations and needs and are acceptable to the person concerned.

Tubal ligation is regulated in the law on sterilization.³² A ligation is a serious intervention affecting physical and psychological integrity and in principle it may only be carried out in persons with capacity and only with their informed consent.

It is therefore essential to establish the person's capacity. According to the law, physicians who perform this operation must document on what basis they consider the person concerned to have capacity. In the case of persons whose capacity cannot be established with certainty, because of cognitive or mental impairments, a second opinion must be sought.

The law forbids the sterilization of persons who permanently lack capacity. However, it makes an exception in the case of persons lacking capacity who are at least 16 years old, if the operation is in the best interests of the person concerned, if another method of contraception is not possible, and if the conception and birth of a child and its separation from the person concerned after its birth is probable.

From the medical point of view the implementation of this legal requirement is very difficult. In particular, unbiased determination of the best interests of the person concerned, who cannot understand the purpose of the operation or the implications of a pregnancy or parenthood, is scarcely possible. Its differentiation from the interests of the carers raises additional problems. In any case it has to be considered that women who lack capacity need protection not only against an unwanted pregnancy but also against sexual abuse. The knowledge that a woman with cognitive or mental impairments has been sterilized can increase the risk of sexual abuse, as there is no fear of pregnancy.

In practice, a person who permanently lacks capacity should not need to be sterilized, as the measures that are necessary for the protection of such a person against sexual abuse and contraction of sexually transmitted infections should also allow effective contraception without such extensive intervention into the patient's physical integrity.

8.3. Parenthood

In the case of persons who wish to have children but whose ability to look after their children on their own seems to be questionable or non-existent on account of their impairment, they should be advised not to have children and to take appropriate contraceptive measures. Equally all the possibilities in the patient's environment for the support of parenthood must also be thoroughly explored and promoted.

Health conditions underlying a disability can impair the person's reproductive capacity and can also increase the risk of disability in the offspring. In this situation the option of genetic counselling should be offered as part of medical care, in the course of which the existing risks can be explained, alternative options can be suggested and information given on prenatal diagnosis.

8.4. Protection against sexual abuse

Sexual abuse of persons with disabilities is often a taboo subject with a probably high proportion of unreported cases. People with cognitive impairments in particular are more often victims of sexual abuse than other population groups. However, people with certain motor, sensory or mental impairments are possibly also more often affected. In these cases the person responsible for the abuse is often a person who is close to the victim.

Clear explanation of biological facts and appropriate sexual education are important means for the prevention of sexual abuse. Persons with cognitive or communicative impairments must be able to learn to talk about their experiences of desired or unwanted intimacy and to assert their self-determination with regard to their own body. In medical, sociomedical and social institutions the risks of sexual abuse should be discussed and recognized and preventive programmes introduced.

If there is concrete suspicion of single or repeated sexual abuse, the procedure taken should be as described in Section 7.3. A further task of the physician is, if acutely necessary, to provide infection prophylaxis and contraception.

9. Periods of life and transitions

Exactly as with other patients, in the treatment and care of patients with disabilities account has to be taken of the importance of lifelong personal development. Disability in fact interacts with the processes of maturing and ageing. On the one hand, new skills, which contribute towards the self-determined structuring of a person's life can be acquired at any age. On the other hand, a person's abilities can be restricted or even lost as a result of illness or increasing age, which can lead to greater dependence.

Depending on the nature of the disability, there can be a discrepancy between the behaviour to be expected on the basis of a person's age and his actual behaviour. The needs of such patients with regard to their care, especially with regard to respectful communication³³, must be carefully investigated and treatment adapted accordingly.

9.1. Transition from childhood to adulthood

The transition to adulthood is characterized by various changes. These can have a marked effect on everyday life and can be of considerable benefit for the person concerned, but they can also be accompanied by feelings of loss. This concerns, among other things:

- changes in permanent long-term relationships, especially with parents, but also with colleagues at school or in a home;
- changes in living conditions;
- official adult protection measures;
- the increasing importance of sexuality;
- entering into a partnership;
- leaving school;
- entering into an occupation or taking up another type of work;
- comparison with siblings with regard to occupation, partnership etc.;
- transition from paediatric and adolescent medicine to adult medicine;
- change of financial provider.³⁴

covered by the obligatory health insurance or the accident insurance. The disability insurance (IV) only covers the costs for medical measures that directly promote occupational integration and which can significantly and permanently improve, or can prevent serious deterioration of the patient's earning capacity. In this framework, the disability insurance can cover the costs of medical treatment (outpatient or in the general department of a hospital), auxiliary medical persons (physiotherapists etc.) and recognized drugs. (See the Federal Act on Disability Insurance of 19 June 1959 and implementing ordinances and the Federal Act on Health Insurance of 18 March 1994.)

³³ The sudden changeover to the polite form of address (use of "Sie" etc. in German) from a certain age can be just as disconcerting as thoughtless use of the familiar form (use of "Du" etc. in German) when speaking to adults.

³⁴ For insured persons under the age of 20 years the disability insurance (IV) covers the costs for all medical measures necessary for the treatment of a recognised congenital abnormality. The obligatory health insurance subsidiarily covers the costs for those treatments of congenital abnormalities that are not covered by the disability insurance (IV). For adults over the age of 20 years the treatment costs for illness or injuries resulting from accidents are covered by the obligatory health insurance or the accident insurance. The disability insurance (IV) only

The termination of an educational relationship should be adapted to the individual situation and allow the continuation of a relationship among adults on an equal footing. This means, for example, that adolescents are included, step by step, in the decision-making process and the involvement of the parents is carefully clarified and adjusted. In the field of medical care, rigid age-limits can be a hindering factor.³⁵

Also for adolescents with cognitive impairments the development of a female or male sexual identity and role is important and has to be taken into account in their care. The changes in behaviour that are normal for the transitional crises of puberty have to be differentiated from the behavioural abnormalities that are associated with an impairment or are an expression of a psychiatric disorder.

9.2. Transition to old age³⁶

Transition to old age is accompanied by various changes, which can trigger feelings of insecurity and melancholy. They include, in particular:

- changes in relationships, especially when facing the need for nursing care or the death of parents;
- changes in living situation, such as transfer into a nursing home, for example;
- loss of a job;
- age-related physical and psychological changes;
- change of financial provider.³⁷

For medical care and treatment, special consideration therefore has to be given to the following aspects:

- Elderly persons with disabilities are entitled to the usual preventive health care, medical diagnosis and treatment. Symptoms must be clarified diagnostically and treated accordingly.
- With certain forms of disability, age-related diseases such as dementia for example may develop earlier than usual or in an atypical manner.
- The process of dying and death should be discussed and addressed in
 a suitable manner. Attention should be drawn to the possibility of drawing
 up an advance directive.

³⁵ For example, some children's hospitals have an upper age-limit of 16 years, although in many cases continuation of treatment in the children's hospital, with a gradual changeover to adult medicine, would be more beneficial.

³⁶ Cf. "Treatment and care of elderly persons dependent on care" (medical-ethical guidelines and recommendations of the SAMS).

³⁷ The entitlement to disability insurance (IV) pensions and coverage of the costs of medical measures promoting occupational integration lapses when the conditions are no longer met, but at the latest when the IV pensioner has reached AHV retirement age or is entitled to an old-age pension.

9.3. Transfer to a social or sociomedical institution

For any person with disabilities, the changeover from the family environment or from living alone to life in a social or sociomedical institution constitutes a radical change. In most cases the changeover is associated with changes in the social environment and effects on the possibilities for self-determination. However, in these situations the person concerned is in fact always entrusting himself to the care and protection of a professionally organized authority.

In connection with the medical and nursing care of these patients, special attention should be drawn to the following points:

- Before a patient's transfer to a nursing home, whether from the family environment or from an institution for the disabled, all the possibilities for outpatient care (e.g. Spitex) must have been exhausted.
- Before the patient is transferred, the treating physician must ascertain to what
 extent the staff of the social institution that is being considered have the necessary nursing knowledge and skills to care for the patient. In this connection
 the various persons who have hitherto been caring for the patient should also
 be consulted.
- When a patient is transferred to a social or sociomedical institution all the relevant information on his case must also be passed on. With the consent of the patient or the authorized representative, information on his care and his history must be passed on to the team to be responsible for his care in the institution, and medical documentation passed on to the treating physician who will be responsible for his further treatment.
- Persons with disabilities or their authorized representatives are to be informed
 by the management of the institution regarding the right to the free choice
 of physician. As far as possible, wishes in this connection are to be respected
 by the institution. Any restrictions on the choice of physician will be discussed
 at the time of the patient's admission.

The answer to the question regarding when a patient is transferred from an institution for the disabled to a nursing home must be based on the same principles as in the case of persons without existing impairments.

10. Research

Persons with disabilities are not to be excluded from participation in research projects solely on the grounds of their disability.

Persons with disability often suffer from disorders or diseases about which little is known or for which the possible treatments are often scarcely adequate. There is also often insufficient data available on the interaction between health disorders or diseases and a disability. For this reason there is a need for research with regard to specific prevention, treatment and rehabilitation in cases of disability, and appropriate research projects should be promoted. In this connection special conditions for patient protection must be taken into account. In particular, such research should only be carried out in children or adults lacking capacity if the project cannot be carried out in persons with capacity. Any refusal by the person concerned to take part in a study which does not constitute refusal of a medically necessary treatment must always be respected.³⁸

³⁸ Cf. also Article 17 of the Convention on Human Rights and Biomedicine of 4 April 1997, which was ratified by Switzerland.

In order that the conditions that are essential for the implementation of these guidelines can be met, the following recommendations are of particular importance:

Recommendations to political authorities and those responsible for payment of costs:

- In the planning and realization of medical facilities, account must be taken of the increased needs of persons with disabilities with regard to personnel and infrastructure.
- Also in the structuring of systems for the payment of medical services, account
 must be taken of the increased needs of persons with disability.
- Guarantee of the financing for investigation of the causes of disabilities.
- Guarantee of the financing of long-term therapy that is sufficiently intense to
 ensure maintenance of the patient's quality of life; this also applies even if no
 benefits in terms of occupational integration are to be expected from this
 treatment.
- Provision of resources in social and sociomedical institutions for emergency admissions for medical reasons or due to acute breakdown of the care system of the patient.
- Support for the care and nursing of persons with disabilities by relatives.
- Promotion of competent, low-threshold sexual health consultations for persons with disabilities.
- Promotion of models of parenting support for persons with disabilities.
- Promotion of projects for the support of the children of persons with disabilities.
- Promotion of, and collaboration with charitable organizations providing specialist help and self-help for persons with disabilities.

2. Recommendations to health-sector and medical institutions

- Promotion of education, specialist training and continuing education of physicians, nurses and therapists in disability-related matters, especially also in the use of the ICF classification of the WHO, and in assessing capacity in patients with limited cognitive, communicative and emotional abilities.
- Promotion of centres of expertise, special interdisciplinary consultations and networks of specialists for special types of disability.
- Promotion of the elaboration and dissemination of specific knowledge on the diagnosis and treatment of physical and mental conditions and on the longterm treatment of persons with mental disabilities.

- Collaboration in partnership and exchange of information with the staff of social institutions.
- Promotion of research in the field of disability-related prevention, treatment and rehabilitation.
- Promotion of the development and use of aids to facilitated communication in all institutions.
- No rigid age-limits for the treatment of persons with disabilities.
- Elaboration of institutional guidelines on the procedure in the event of suspected maltreatment and sexual abuse (incl. maintenance of professional confidentiality).
- Implementation of special duty of care in the appointment of new employees: e.g. addressing the subject "abuse", obtaining references, requesting extracts from the criminal records office.

3. Recommendations to social and sociomedical institutions with responsibility for the care of persons with disabilities

- Assurance of medical expertise.
- Everyday support for the persons in care with regard to medical treatments and contraception.
- Regulation of the interfaces to medical care, taking into account the decision-making rights of legal representatives and the relatives' need to have a say.
- Readiness to accept emergency admissions for medical reasons or due to acute breakdown of the patient's care system.
- Guarantee of the transfer of knowledge from the institution to the medical unit responsible for acute treatment.
- Documentation and storage of biographical and nursing data.
- Possibility of patients with disabilities being accompanied by persons from the institution when attending medical consultations and when being admitted to hospital.
- Support in the preparation of advance directives, if this is desired.

Glossary

Dignity

The ethical concept of respect for dignity is based on the universal intuition that every individual person's dignity must be respected because he is a human being. This is manifested by the fact that everyone is entitled on the one hand to special life protection and care and on the other to consideration of his right to self-determination. In this sense the term must not be confused with the use of the word "dignity", to describe particular forms of behaviour, aspects of social status or individual abilities.

Disability

The term "disability" refers to the hindering effects of a congenital or acquired health condition on the everyday activities of the person concerned and on equal participation in social life. The disability is the result of the interplay between physical damage, functional impairment and social limitations placed on the person concerned, and the facilitating or hindering factors and the expectations of his environment. The extent and the subjective experience of these various factors are modulated by the personality traits of the individual with a disability.

The term is defined in these guidelines on the basis of the ICF classification (International Classification of Functioning, Disability and Health) of the WHO (as of October 2005). This classification provides a standard international and interdisciplinary language for the description of a person's state of health, disability, social impairment and relevant environmental factors (www.who.int/classifications/icf/en/).

Health condition

The definition of the term used by the WHO is "Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs." WHO Disability Assessment Schedule WHODAS II.

http://whqlibdoc.who.int/publications/2000/a80933.pdf2000/a80933.pdf Accessed: 31.8.2007.

Social institution

The term "social institution" is used to describe institutions providing training, work, activities or care for people with disabilities. This means not only homes but also other types of institution (e.g. sheltered housing).

Sociomedical institution

The term "sociomedical institution" is used to describe institutions where, besides other services, people with disabilities receive professional care.

Information on the elaboration of these guidelines

Mandate

On 18 October 2005 the Central Ethics Committee of the SAMS charged a sub-committee with the elaboration of guidelines on the treatment and care of persons with disability.

Responsible sub-committee

Prof. Dr. med. Christian Kind, St. Gallen (Chairman)

Dr. med. Felix Brem, Weinfelden Pascal Diacon, Nurse, Zurich

Gerhard Grossglauser, Bolligen

Dr. med. Danielle Gubser, Neuchâtel

Lic. phil. Ruedi Haltiner, Chur Dr. med. Mark Mäder, Basel

Dr. med. Valdo Pezzoli, Lugano

Dr. med. Judit Lilla Pok Lundquist, Zurich

Prof. Dr. med. Claude Regamey, President of

the Central Ethics Committee, Fribourg Lic. iur. Michelle Salathé, SAMS, Basel

Experts consulted

Dr. phil. Dick Joyce, Allschwil

Dr. phil. Jackie Leach Scully, Basel Claudine Braissant, Nurse, Belmont

PD Dr. phil. Barbara Jeltsch-Schudel, Fribourg

Dr. med. Roland Kunz. Affoltern a.A.

Dr. theol. Markus Zimmermann-Acklin, Lucerne

Consultation

The Senate of the SAMS approved a first version of these guidelines for a general consultation process on 29 November 2007.

Approval

The definitive version of these guidelines was approved by the Senate of the SAMS on 20 May 2008.

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). For this reason, the previous Section "Coercive measures" was deleted. At the end of 2012, the Central Ethics Committee appointed a subcommittee to prepare a complete revision of the guidelines on coercive measures in medicine.

