Medical treatment and care of persons with disability

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Medical treatment and care of persons with disability

Medical-ethical guidelines and recommendations

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Medical treatment and care of persons with disability

Medical-ethical guidelines and recommendations

I. Preamble

A considerable number[1] of people of all age-groups are themselves affected by disability[2] 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 patronising restriction 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 bring people with disabilities back 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 medical[4] treatment and care can correspondingly also be very different:
A disability can be directly related to the treatment: preventive, curative, rehabilitative and palliative measures are intended to eliminate or reduce the effects of congenital or acquired impairment.
However, a disability can also influence the treatment and care only indirectly: 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.

The aims of these guidelines are

- to confirm and promote the right of all persons with disability to appropriate treatment and care;
- to draw attention to the decisive role of good medical treatment and care for the support of persons with disability in their efforts to achieve self-determination and social acceptance;
- to provide help, in the guidelines, for medical doctors, nurses and therapists in dealing with persons with disability and their relatives;

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[1] Murray C.J.L., López A.D., Quantifying Disability: data, methods and results. Bulletin of the World Health Organisation, 1994, 72 (3), 481-494 (http: whqlibdoc.who.int/bulletin/1994/Vol172-No3/bulletin_1994_72(3)_481-494pdf).

[2] See definition of the term "disability" in Chapter 1 and the definition in the Glossary.

[3] See the "Human Rights Convention on the Rights of Persons with Disabilities", which was released for ratification by the United Nations on 13.12.2006 (www.un.org/disabilities/convention/conventionfull.shtml) and the Federal Law on 13 December 2002 on the Elimination of the Disadvantaging of Persons with Disabilities (BehiG).

[4] The term "medical" is used very broadly in these guidelines and refers to the activities of medical doctors, nursing staff and therapists.

- 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 disability;

They therefore fill a deliberate gap in the guidelines on the “Treatment and care of elderly people who are in need of care”, regarding the treatment and care of young people in need of care, but they are also of importance for those who are responsible for the treatment and care of patients with disability who are otherwise not in need of care.

II. Guidelines

1. Scope

The present guidelines are addressed to medical doctors[5], nurses and therapists who treat and care for persons with disabilities medically, or who assess them as expert appraisers[6], either in the patient's home or in medical, sociomedical or social[7] institutions.

In the guidelines, the term "disability" refers to the aggravating effects of a congenital or an acquired health problem[8] on the everyday activities of the person concerned and on his[9] participation in social life. The disability is the result of the interplay between the physical damage, the functional impairment[10] and the social limitations placed on the person concerned, and the facilitating or hindering factors and the expectations of his environment. The extent and the subjective effects of these various factors are modulated by the characteristics of the personality of the individual with the disability[11].

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 therapeutic process. Consequently, certain sections of these guidelines can be of different relevance for the care of persons with different types and degrees of disability.

2. Basic principles

The basic values, attitudes and ways of acting on which these guidelines are based are the following:

2.1. Respect for human dignity

Dignity[12] is a quality of the fact of being human, and it is therefore independent of a person's physical, cognitive or psychiatric impairments or of a particular context. In this sense, human dignity must be respected without question. The risk of human dignity not being respected is particularly great in situations of weakness.

For those who are responsible for his treatment and care, respect for the dignity of the patient[13] means:

- appreciation of the uniqueness of the person with disability and treating him/her individually as a man or a woman, according to age and stage of development;

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[5] When taken up in the FMH registry, the guidelines are binding professional ethics for FMH members.

[6] The guidelines are intended primarily for specialist medical persons, but they are also addressed to specialists in the fields of social paedagogics and agogics etc.

[7] For the definition of the term "social institution, see the Glossary.

[8] For the definition of the term "health problem", see the Glossary.

[9] The masculine prepositions (he, him, his etc.) are always used, although both male and female persons are coverd by these guidelines.

[10] This covers both disorders of the motor and sensory bodily functions and impairment of the cognitive and other mental functions.

[11] For the origin of the definition of the term "disability", see the Glossary.

[12] Regarding the concept of "human dignity", see the Glossary.

[13] In order to do justice to the primarily medical nature of these guidelines, whenever people with disabilities are considered as recipients of medical services, one speaks specifically of "patients" and not, more generally, of "persons" or "people".

- taking into account the patient’s particular vulnerability with regard to both behaviour and communication, and treating him with respect, empathy and patience;
- support of 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 of being different and of participation and exclusion depend on one’s own perspectives.

2.2. Respect for personal 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 personal autonomy if he is in the 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 will in these respects.

For those who are responsible for his treatment and care, respect for the personal autonomy of the patient means:

- supporting, without pressure and with empathy, the necessary individual processes of the patient’s capacity for personal autonomy (appreciation of the situation, recognition of the various possible decisions and their consequences, their evaluation on the basis of his own preferences, the expression of his decisions and wishes and their enactment) ;
- determining, in the case of patients with limited personal autonomy, what their level of autonomy in fact is and how this can be taken into account in the decision-making process;
- involving persons who are close to the patient, to support him in 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 relations[14] the necessary perception of the patient’s wishes, through empathy, involves the risk of projection of their own wishes and preconceptions.

2.3. Justice and participation

In a society that is oriented according to the basic principles of justice, great importance is attached to the participation of all its members, with equal rights, 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 disability. 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[15]

2.4. Consideration of the quality of life

The medical treatment and care of patients with disability also always has to be assessed with regard to its effects on the quality of life. For those responsible for the treatment and

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[14] “Relations“ are understood to be the patent’s spouse/partner, his close relatives and other persons who are close to him.

[15] See Glossary, under “Disability“.

care of persons with disability, 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 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.
- 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 the relatives and the 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 the 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. The fact of being referred for special care can create dependence, which can in turn disturb the feeling of their own value for 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 disability requires acceptance of responsibility by their carers, either within the family, through personal assistance[16] 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 wasteful application, and even exhaustion, of one's own powers and abilities. It can also make one susceptible to taking offence by the environment, which apparently or in fact shows too little understanding. If the patient, for his part, takes advantage of the mutual dependence of the carer in order to make unreasonable demands, this can complicate the situation even further.

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[16] "Personal assistance" covers all forms of support with which the persons concerned themselves determine who is of help to them, and where, when and how. This support is as a rule provided by the carers themselves.

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

2.6. Appropriate medical treatment and care

Every person has the right to appropriate medical 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 an existing impairment or activity limitation. 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 the treatment have to be considered and the individual wishes and needs of the 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 disability often also 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 doctors. For this reason one doctor, 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 hand-over, preferably with direct discussion between the two doctors 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 doctors, 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, specialised interdisciplinary ambulant consultations are the optimal solution.

For patients with cognitive or psychiatric impairment, contact with many different doctors can be confusing and worrying. This results in further impairment of their already limited capacity for personal autonomy. A person of confidence who is well acquainted with the patient’s case history should therefore accompany him on all his visits to the various doctors.

2.8. Collaboration with the social environment

In the treatment and care of persons with disability 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 disability, in most cases the relatives are taking on 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 disability in their own home often leads to considerable stress. Doctors, nurses and therapists have the task of advising and supporting the relatives and other carers.

3. Communication

Adequate, open and sympathetic communication with the patient is a precondition and an integral component of every good treatment and care. Not all patients with disability 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 must be used to optimal effect and the environmental conditions for the discussion (lighting conditions, background noise) must be favourable;
- the medical person who is conducting the discussion has made himself acquainted 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, pointer tables, 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 psychiatric impairment or with limited possibilities of communication are very dependent on the way in which they are informed.

Understanding of the information received and the ability to make decisions can be facilitated and the patient can be given a feeling of security and orientation if the medical discussion partner

- uses simple speech (short sentences and avoidance of foreign words, abbreviations and different expressions for the same terms);
- 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, legal representatives, confidants) is according to rules laid down in Chapter 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 Chapter 4, they can participate in the making of decisions on behalf of patients who are incapable of discernment.
- They may also promote their own interests, which do not necessarily have to be 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 many suggestions, 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 included, 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, delimitation and hopelessness or respect, empathy and confidence.

4. Decision-making processes[17]

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 his possible representative are informed adequately and in an understandable manner[18] and that they can make decisions without being under pressure.

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[17] In this connection see, in particular, "The right of patients to self-determination". Medical-ethical Gudelines of the SAMS.

[18] See Chapter 3, Communication.

4.1. Persons capable of discernment

Doctors, nurses and therapists may treat or care for patients who are capable of discernment[19] only with their consent after having been duly informed.

Minors and adults with disability can also be capable of discernment with regard to their situation and can decide on their medical treatment and care. However, in the case of such a decision their powers of discernment must be carefully clarified.
It is the duty of the specialists to include minors or disabled adults in the decision-making process, as far as this is possible, and to obtain their consent. They must not be subjected to excessive pressure in making their decision; 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 patient's legal representatives (parents, guardians) must be consulted, provided that the patient does not object to this.

If a minor or an adult patient with disability is not in agreement with a suggested treatment and care, the significance and importance of which he understands, then such treatment may not be carried out[20]. However, it must be carefully checked whether this refusal really corresponds to his free will[21].

In many patients (especially in the case of psychiatric impairment), with the passage of time their powers of discernment can show considerable variation. Statements made by the patient in writing and other indications of his presumed wishes are particularly important.

4.2. Persons incapable of discernment[22]

Decisions regarding the treatment and care of patients who have never been capable of discernment[23] must be based exclusively on their best interests, and they must be made in consensus with the patient's legal representatives[24]. A person who is incapable of discernment must therefore be included in the decision-making process, as far as this is possible.

If the patient had been capable of discernment at an earlier point in time, his treatment and care must be in accordance with his presumed wishes. In this connection, precedence is given to written statements on the part of the patient or statements by the representative (confidant) named by the patient to deal with medical matters or by other persons who are close to the patient. If the patient does not have a representative or relatives[25] who can provide information on his presumed wishes, the Court of

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[19] "Capability of discernment" means the ability to perceive reality and to form judgments and wishes, and the ability to make one's own choices. See also the comprehensive explanation of the terminology in: "The right of patients to self-determination" in the Medical-ethical Guidelines of the SAMS.

[20] However, see the following Chapter 7.

[21] Strong emotions such as anxiety, for example, can put a person's powers of discernment in question, so that one can then no longer speak of the expression of autonomous will.

[22] In different Cantons there are explicit legal requirements on the procedure in the case of patients who are incapable of discernment, which take precedence over the guidelines.

[23] These patients being genuinely incapable of discernment have never had the capability from birth on to form relevant intentions with regard to medical treatment.

[24] Legal representatives are persons who represent patients on the basis of a legal authorisation granted to them.

[25] According to the current regulations at the Federal level, relatives are not authorised to represent patients. However, in certain Cantons persons who are close to a patient who is of full age but incapable of discernment, or a member of his family are legally authorised to give their approval for a treatment.

Guardianship must be informed, especially in the case of prolonged treatment or high-risk operations.

If the legal representatives refuse to give their agreement to a treatment that is in fact in the best interests of the patient, the Court of Guardianship must be informed. However, if there is insufficient time for the Court of Guardianship to be informed, because of the urgency[26] of the case, the operation should and must be carried out, even if this is contrary to the express wishes of the patient's representative.

4.3. Decision-making within the care team

Medical treatments and measures taken for the care of patients 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 recorded in writing, regularly checked and appropriately adapted, if this proves to be necessary[27].

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

5. Medical treatment and care

5.1. Aetiological diagnosis

Persons with disability have a right to an adequate diagnostic investigation of the nature and the cause of their health problem. An as accurate as possible delineation of the causes of an impairment or activity limitation can help the patients concerned and their relatives, as well as also the medical persons responsible for their treatment and care

- to make more specific plans for the preventive, curative and rehabilitative treatment of the impairment;
- to better prevent 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 recognise the genetic risks and to take these into account when considering family planning.

5.2. Promotion of health and prevention

It has to be taken care that persons with disability 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.

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[26] If neither the patient himself nor his representative can give their agreement in good time, or if there is reasonable doubt concerning the validity of a refusal of treatment because of the lack of capability for discernment or a conflict of interests with the legal representative, in order to save life or to prevent serious sequelae any treatment, nursing or care that cannot be postponed must be carried out.

[27] See Chapter 6, Documentation

For persons with disability, any underlying health problems and their effects on 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 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 medical 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 disability have the right to immediate medical help, with a proper diagnosis 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 the findings and choice and application of the best possible therapy. The health problem 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 persons 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 competences that are available locally, the time pressure and the geographical considerations decide whether an investigation and treatment are possible at the place where the patient is first seen, or whether one should try to transfer him to a specialised 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 competent 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 specialised institution can be of practical value.

5.4. Treatment of psychiatric disorders

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

Psychiatric 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 recognisable connection with the existing disability.

It often requires specialised 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 checked 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 disability. 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 problems 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 characterised 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 standardised evaluation of the bio-psycho-social situation. These lead to new, adapted rehabilitation objectives, which facilitate effective and need-oriented further treatment.

5.6. Palliative care[28]

Congenital or acquired impairments or activity limitations 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 the patients.

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.

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[28] See “Palliative Care“. Medical-ethical Guidelines of the SAMS.

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 single-minded focussing 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 the stress for the patient. At the same time, palliative measures must be initiated in each case

5.7. Dying and death[29]

If an unpreventable deterioration of the state of health develops, the patient’s approaching demise 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 the doctors, nurses and therapists can also be a guide for the dialogue in this terminal phase. It can sometimes be helpful to address possible options at the end of the patient’s life and to draw up a ruling on the patient’s treatment already at an earlier point in time.

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. Case history and documentation on care

A continuous documentation, which is constantly up-dated is kept for each patient[30]. Besides the data concerning the case history, diagnosis and course of the condition and the prescribed treatments etc., in particular the procedure for obtaining informed consent from the patient and/or his legal representative should also be documented. For older adolescents and incapacitated adults the patient’s dossier should also contain information concerning for which decisions the patient was considered to be incapable of discernment and for what reason. 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 data on the reason for and the nature of the measure taken, its purpose and duration and the results of the regular re-assessment.

6.2. Confidentiality and obligation to inform third parties

The doctor, the nursing staff and the therapists are bound to professional secrecy[31]. 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 legal representative or on a

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[29] See “Care of patients with terminal illness“. Medical-ethical Guidelines of the SAMS.

[30] Depending on the legal nature of the doctor-patient relationship, the question of the obligation to document the case is assessed according to the standards of the Federal Private Law (OR) or the Cantonal Public Law.

[31] Professional secrecy according to Article 321 of the Swiss Penal Code (StGB) applies for medical doctors and other medical persons; for personnel of an institution, who are not subject to the conditions of Article 321, the rules regarding professional secrecy that are contained in their contract of employment are applicable; professional secrecy is also regulated, in part, in Cantonal Law.

legal basis or with the written approval of the responsible authority or the supervising authority[32].

7. Coercive measures[33]

Behavioural disorders, restlessness or confusion arising as a result of mental disease or for other reasons in patients with disability can lead to danger to themselves or to others and/ or to serious effects on the life of the community. The use of coercive measures[34] in order to avoid such dangers represents violation of the patient's basic rights and must therefore remain the exception. It must be proportionate and must be oriented to the best interests of the patient. Federal and Cantonal regulations must be observed.

7.1. Conditions[35]

A coercive measure may be taken only if all the following conditions are met:

- The patient's behaviour to a considerable extent constitutes a danger to his life and his health or those of others or can have serious effects on the life of the community.
- The unusual behaviour that is observed is not due to causes that can be eliminated, such as pain, side effects of drugs or disturbing environmental influences such as interpersonal conflicts with the carers, inadequate communication, unsuitable living conditions or inadequate care.
- Other measures that involve less impairment of the patient's personal freedom cannot be applied with any prospects of success.

7.2. Concomitant measures

One should always be aware that with coercive measures there is a risk of harm. Therefore it must be ensured that while such a measure is being carried out the patient's condition is monitored as closely as possible. The measure taken is evaluated at regular intervals[36]; the frequency of the evaluation is dictated by the nature of the measure concerned. The measure taken is terminated as soon as the conditions according to Chapter 7.1 are no longer met.

8. Maltreatment and neglect

8.1. 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[37].

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[32] See Items 2 and 3 of Article 321 of the Swiss Penal Code (StGB).

[33] See "Coercive Measures in Medicine". Medical-ethical Guidelines of the SAMS.

[34] Coercive measures are all interventions that take place against the declared wishes of a person or which are resisted by him – or which in the case of his inability to communicate are against his presumed wishes. These include both measures that limit his freedom and forcible treatment.

[35] Regarding the legal conditions, see the guidelines "Coercive Measures in Medicine", Chapter 3.2.1.

[36] The evaluation also includes continuous documentation.

[37] Crimes against life and limb.

Persons who are less able to defend themselves because of physical, cognitive or psychiatric impairment 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 dangers. 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 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 the position to do this himself. All stages of the hierarchy of needs (physiological needs, need for safety, need for love/belonging, need for esteem and need for self-actualization)[38] 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.

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 problems in his relationship to the patient.

8.2. Recognition of risk situations and their prevention

Doctors, nurses and therapists are under the obligation to consider the possible risk of abuse, maltreatment and neglect and to recognise and avoid corresponding 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;
- solicitation to observe the rules of living together;
- the risk that persons with disability 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 the 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 their bodily care, eating, defecation, urination and going to bed, and medical examinations or the use of various therapeutic measures, should be looked at with regard to their potential risk for abuse, which should in turn be safeguarded against by appropriate rules and possible support.

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.

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[38] Maslow Abraham, H. Motivation und Persönlichkeit. Rowalt Verlag 1991

8.3. 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 suspicion can arise as a result of both 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 specialist 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 be the only person considering the case, but to seek the advice of an independent specialist. In this connection, professional secrecy and any possible Cantonal regulations regarding rights or duties to report[39] must be observed. In each case psychological help must be provided for the victim.

9. 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.

Doctors, nurses and therapists may be called upon to provide advice and support for persons with disability 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 impairment, clarification of these 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 disability have the right to unhindered development of their sexuality. Restriction of sexual activity is only permissible where it would be harmful to the patient or other persons or would cause a public scandal.

Special care is indicated in the case of persons with limited powers of discernment. 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 cannot keep pace with the development of his personality.

9.1. Consequences and risks of sexual activity

Sexual activity, if it is not limited to the one person himself, allows bonds to be created with the partner and perhaps also leads to the birth of children, and it thus requires the acceptance 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

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[39] Cantonal health laws envisage a right, in some cases an obligation to report suspect crimes against life and limb or against sexual integrity, without exemption from professional secrecy.

problems with regard to both the acceptance of responsibility and the handling of the risks.

For sexually active persons with disability it is the doctor’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.

9.2. Contraception and sterilisation

From the many different methods of contraception that are available, persons with disability 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 sterilisation.
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 herself, or that her environment can provide any support that may be necessary;
- that its use and its possible side effects meet the expectations and the needs of the person concerned and are acceptable to her.

Tubal ligature is regulated in the law on sterilisation[40]. A ligature is a serious intervention into the physical and psychological integrity and in principle it may only be carried out in persons who are capable of discernment and only with their informed consent.

It is therefore important to establish the person’s powers of discernment. According to the law, doctors who perform this operation must document on what basis they consider the person concerned to be capable of discernment. In the case of persons whose powers of discernment cannot be established with certainty, because of cognitive or psychiatric impairment, a second opinion must be sought.

The law forbids the sterilisation of persons who are permanently incapable of discernment. However, it makes an exception in the case of persons who are incapable of discernment 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 are incapable of discernment need protection not only against an unwanted pregnancy but also against sexual abuse. The knowledge that a woman with cognitive or psychiatric impairment has been sterilised can increase the risk of sexual abuse, as there is no fear of pregnancy.

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[40] Federal Law of 17 December 2004 on the conditions and procedures for sterilisation.

In practice, a person who is permanently incapable of discernment should not be sterilised, as the measures that are necessary for the protection of a person who is incapable of discernment against sexual abuse and contagion with sexually transmitted infections should also allow effective contraception without such extensive intervention into the patient's physical integrity.

9.3. 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, 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.

Underlying health problems accompanying a disability can impair the person's reproductive capacity and can also increase the risk of disability in the offspring. In this situation the medical care provided includes the possibility of giving advice on the genetic aspects, in the course of which the existing risks can be explained, alternative treatments can be suggested and information given on prenatal diagnosis.

9.4. Protection against sexual abuse

The sexual abuse of persons with disability is often a taboo subject with a probably high proportion of unreported cases. Mainly people with cognitive impairment are more often victims of sexual abuse than other population groups. However, people with certain motor, sensory or psychiatric 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 impairment must be able to learn to talk about their experiences of desired or unwanted sexual 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 recognised and preventive concepts introduced.

If there is concrete suspicion of single or repeated sexual abuse, the procedure taken should be as described in Chapter 8.3. A further task of the doctor is, if acutely necessary, to provide infection prophylaxis and contraception.

10. Periods of life and transitions

Exactly as with other patients, in the treatment and care of patients with disability 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 competences, which contribute towards the self-determined structure 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 communication[41], must be carefully investigated and the treatment adapted accordingly.

10.1. Transition from childhood into adulthood

The transition into adulthood is characterised 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;
- guardianship 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 the financial provider.[42]

The processus of dismissal from an educational relationship should be adapted to the situation of the individual and allow the continuation of a relationship among adults of equal rights. 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 differentiated. In the field of medical care, strict age-limits can be a hindering factor[43].

Also for adolescents with cognitive impairment 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 unusual behaviour that is associated with an impairment or which is an expression of a psychiatric disorder.

10.2. Transition into old age[44]

Transition into 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;

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[41] The sudden change-over to the polite form of speech (use of “Sie“ etc. in German) from a certain age can be just as irritating as the spontaneous use of the familiar form (use of “Du“ etc. in German) when speaking to adults.

[42] For insured persons under the age of 20 years the invalidity 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 invalidity 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 invalidity insurance (IV) only covers the costs for medical measures that immediately make it possible to return to work and which can significantly and permanently improve, or can prevent serious deterioration of the patient’s earning capacity. In this frame, the invalidity insurance can cover the costs of medical treatment (ambulatory or in the general department of a hospital), auxiliary medical persons (physiotherapists etc.) and for recognised drugs. (See Federal Law on Invalidity Insurance of 19 June 1959 and Regulations thereon and Federal Law on Health Insurance of 18 March 1994.)

[43] For example, some children’s hospitals have an upper age-limit of 16 years, although in many cases continuation of the treatment in the children’s hospital, with a stepwise change-over to adult medicine, would be more beneficial.

[44] See “Treatment and care of elderly persons in need of care“. Medical-ethical Guidelines and Recommendations of the SAMS.

- 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 the financial provider[45].

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

- Elderly persons with disability are entitled to the usual 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 a ruling regarding the patient's wishes.

10.3. Transfer to a social or sociomedical institution

For any person with disability, the change-over from the family environment or from living alone to life in a social or sociomedical institution constitutes a drastic change of life style. In most cases the change-over 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 organised environment claiming a status of 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 ambulant 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 knowledge of nursing and the necessary skills and facilities for the care of the patient. In this connection he should also consult the various persons who have hitherto been caring for the patient.
- 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 his legal representative, information on his care and his case 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 disability or their legal representatives are to be informed by the management of the institution regarding the right to the free choice of doctor. As far as possible, wishes in this connection will be respected by the institution. Any restrictions on the choice of doctor will be discussed at the time of the patient's admission.

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[45] The entitlement to invalidity insurance (IV) pensions and cover for the costs of medical measures that make it possible for the patient to return to work lapse if the conditions are no longer met, but at the latest when the IV pensioner has reached the age of entitlement to an AHV pension or is entitled to an old-age pension.

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 previous impairment.

11. Research

Persons with disability may often also be suffering 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 who are incapable of discernment if the project cannot be carried out in persons who are capable of discernment. Refusal by the person concerned to take part in a study, which does not in fact constitute refusal of a medically necessary treatment, must in any case be respected[46].

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[46] See also Article 17 of the Agreement on Human Rights and Biomedicine of 4 April 1997, which was ratified by Switzerland.

III. Recommendations

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

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

- In the planning and realisation of medical facilities, account must be taken of the increased needs of persons with disability with regard to personnel and infrastructural resources.
- 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 for the financing of long-term therapy that is sufficient to ensure maintenance of the patient's quality of life; this also applies even if no benefits in terms of working capacity 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 former care system of the patient.
- Support in the care and nursing of persons with disability by family members and relatives.
- Promotion of competent, low-threshold sexual health consultations for persons with disability.
- Promotion of models of supported parenthood for persons with disability.
- Promotion of projects for the support of the children of persons with disability.
- Promotion of, and collaboration with, public-welfare organisations providing specialist help and self-help for persons with disability.

2. Recommendations to health-sector and medical institutions

- Promotion of training, postgraduate training and continuing education of doctors, nurses and therapists in disability-related matters, especially also in the use of the ICF classification of the WHO, and in determining the level of discernment in patients with limited cognitive, communicative and emotional capacity.
- Promotion of centres of competence, 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 illnesses and on the long-term treatment of persons with mental disability.
- 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 supported communication in all institutions.

- No strict age-limits for the treatment of persons with disability.
- Elaboration of institutional guidelines on the procedure in the event of suspected maltreatment and sexual abuse (incl. maintenance of professional secrecy).
- Implementation of special duty of care in the appointment of new employees: e.g. addressing the subject “abuse”, obtaining references, requesting extracts from the central criminal records.

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

- Assurance of specialist medical competence.
- Everyday support of 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 the legal representatives and the relatives’ need to share in the decision-taking.
- Readiness to accept emergency admissions for medical reasons or due to acute breakdown of the care system of a patient.
- 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 disability being accompanied by persons from the institution when attending medical consultations and when being admitted to hospital.
- Support in the drawing-up of rulings on patients’ treatment, if this is desired.

IV. Glossary

Disability	The term “disability” refers to the aggravating effects of a congenital or an acquired health problem on the everyday activities of the person concerned and on his participation in social life. The disability is the result of the interplay between the physical damage, the functional impairment and the social limitations placed on the person concerned, and the facilitating or hindering factors and the expectations of his environment. The extent and the subjective effects of these various factors are modulated by the characteristics of the personality of the individual with disability. The term is defined in these guidelines on the basis of the ICF classification (International Classification of Functionailty, Disability and Health) of the WHO (Status: October 2005). This classification serves as a uniform text for description of a person’s state of health, disability, social impairment and relevant environmental factors. A German translation, free of charge, may be downloaded from the website http://www.dimdi.de/static/de/index.htm.
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.pdf, Access: 31.8.2007.
Human dignity	The ethical concept of respect for human 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 certain forms of behaviour, special aspects of the social status or certain abilities of a person.
Social institution	The term “social institution” is used to describe institutions where persons with disability receive training, work or care. This means not only homes but also other types of institution (e.g. health-care communes)

Sociomedical institution	The term “sociomedical institution” is used to describe institutions where, besides other services, persons with disability also receive professional nursing care.

Information on the elaboration of these guidelines

Order:	On 18 October 2005 the Central Ethical 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 Lic. phil. Mark Mäder, Basel Dr. med. Valdo Pezzoli, Lugano Dr. med. Judit Lilla Pok Lundquist, Zurich Prof. Dr. med. Claude Regamey, President of the Central Ethical Committee, Fribourg Lic. iur. Michelle Salathé, SAMS, Basel
Expert consultants:	Dr. phil. Dick Joyce, Allschwill 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 process:	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.