

II. Guidelines

1. Patients covered

There are three main groups of severe brain damage associated with permanent, irreversible, loss of the ability to communicate:

- Persistent vegetative state (PVS): a comatose state, usually following hypoxic brain damage due to illness or injury, can develop into a “vegetative state”, i.e. a “state of consciousness without any detectable awareness”. If the vegetative state persists for longer than one month, it becomes what is known as a “persistent vegetative state” (PVS); when it is in all probability irreversible, one speaks of a “permanent vegetative state”.
- Severe advanced degenerative brain disease (e.g. Alzheimer’s disease): This is characterized by severe cognitive breakdown¹ (i.e. vocabulary reduced to a few words, verbal communication no longer possible, loss of motor capability, totally dependent on others for care); other causes have been excluded in the differential diagnosis process.
- Severe brain damage present at birth or acquired in early childhood: The brain is severely damaged by hypoxia, ischemia, trauma, infection, a metabolic process, or a malformation, so that recovery of the ability to communicate and even minimal independence can no longer be expected.

In spite of differences between these types of severe brain damage, there are some common approaches to their treatment and care. Where special rules apply for a particular patient group, these are noted in the guidelines.

1.1. Defining the three groups

1.1.1 Persistent vegetative state (PVS)

“Vegetative state” implies a patient’s total loss of self-perception and awareness of the environment. Partially or completely retained hypothalamic and brain stem function are sufficient for the patient’s survival – together with appropriate medical and nursing support. There are no signs of repeated, reproducible, voluntary responses to visual, auditory, tactile and painful stimuli; also, there is no indication of the understanding of speech or of verbal expression. There is urinary and fecal incontinence. In some patients, however, cerebral reflexes (pupillary, oculo-cephalic, corneal, and vestibulo-ocular reflexes), spinal reflexes and the sleep-wake rhythm are intact.

¹ See Functional assessment staging (FAST) by Reisberg et al., *Psychopharmacol Bull* 1988;24(4):653-9, Stage 7

1.1.2 Neurodegenerative disease

These patients have suffered an extreme loss of cognitive ability due to severe degenerative brain damage, remaining in a static condition for months. This occurs especially in the late stages of Alzheimer's disease, Parkinson's disease with dementia, fronto-temporal dementia, advanced Huntington's chorea, and vascular dementia². As a rule, other neurodegenerative diseases progress relatively rapidly, only affecting cognitive ability in their terminal stage. The present guidelines are only applicable when the ability to communicate has been lost and there is no longer any detectable self-awareness.

1.1.3 Brain damage present at birth or acquired in early childhood

There are three relevant age-dependent, ethically relevant factors in children. These are particularly important in newborns and young babies:

1. The damage to the brain affects a central nervous system that is still developing. This makes it difficult to assess the extent of actual functional damage, as many functions are not yet evident in newborn and young babies. On the other hand, there is a much broader spectrum of possible functional recovery, due to the great plasticity of the nervous system in childhood. The prognosis is, therefore, somewhat uncertain.
2. These patients can give no indication of their wishes regarding medical treatment. With congenital brain damage, there is no biographical point of reference for making assumptions in assessing the subjective quality of life.
3. From the biological, psychic, social and legal points of view, children are practically totally dependent on their parents. The consequences of decisions on medical treatment that are made when there is an unfavorable prognosis affect the parents very directly, perhaps for the rest of their lives.

These special factors make it impossible to clearly define a group of newborns, babies, and infants for whom these guidelines would be applicable. Rather, for each child with this degree of brain damage, the decision as to whether it's appropriate to modify the therapeutic goal, as outlined in these guidelines, must be made on the basis of the individual prognosis. In doing this, the anticipated ability to enjoy life, form relationships, and have new experiences offered by comprehensive therapy must be weighed against its disadvantages, in the form of pain, discomfort, and possible constraints imposed by the treatment.

1.2. Terminally-ill patients

Chronic severely brain-damaged patients cannot be equated with terminally-ill patients. The former are still in a stable but seemingly irreversible state. However, intercurrent complications or the decision to stop treatment can precipitate the lethal process. In terminally-ill patients, life expectancy is relatively short (days to weeks) and the terminal process is progressive. The care of terminally ill patients is dealt with in a separate set of guidelines³.

² These patients are often elderly. In this connection, see also the medical-ethical guidelines and recommendations of the SAMS for the treatment and care of elderly persons who are in need of care.

³ The «Medical-ethical guidelines for the medical care of dying persons and severely brain-damaged patients» dating from 1995 have been revised, not only in regard to severely brain-damaged patients but also – by a separate sub-committee – for terminally ill patients. Also relevant are the guidelines of 1999 on the ethical problems arising in intensive care and the guidelines on the determination of death in the field of organ transplantation.

2. Patient's rights

2.1. Principle

There is an obligation to provide help and to alleviate the suffering of patients with chronic severe brain damage in any way possible. The obligation to maintain life, however, carries some qualifications. The patient's wishes in this respect are the overriding criterion for decisions to reject or discontinue life-saving measures.

2.2. Patient's directives

Everyone may draw up conditions and instructions, in advance, regarding the medical treatment and care they wish to receive, or to reject, if they are no longer able to make decisions for themselves («patient's directives», or «advance directives»)⁴. The patient's directives are to be followed as long as there are no concrete indications that they no longer represent his or her present wishes. The more clearly the patient's wishes are formulated, the more recent their signature and the better they have anticipated the current situation, the more valid the directives are.

If the patient has not drawn up such directives in advance, an attempt must be made to determine their presumed wishes. The manner in which the patient has thought and acted during their life, and what their preferences were, all play an important role in this respect. Such information should be obtained from representatives specifically named by patients or from people close to them (e.g. their family physician).

2.3. Representation

Everyone may designate in advance a trusted friend or relative, who can agree, on the patient's behalf, to medical, nursing and/or therapeutic measures, if the patient is no longer capable of making decisions. By taking into consideration eventual existing patient's directives, agreement from the legal representative or the designated trusted person must be obtained. If the decision of either of these persons seems to contradict the presumed wishes of the patient, the appropriate authorities must be consulted.

If there is neither a legal representative nor a trusted person available, or if it is impossible to contact them in an emergency, the doctor, nurses and therapists must arrive at their decision after an interdisciplinary discussion, according to the best interests and presumed wishes of the patient.

In the case of minors, one must conform, in principle, to the wishes of the legal representatives; as a rule, these are the parents. However, life and death decisions often make excessive demands on parents. Decisions on treatment and care have to be made in the best interests of the child, in agreement with the parents and/or the legal representatives. If it proves impossible to arrive at a consensus on vital decisions, the appropriate responsible authority should be consulted.

⁴ Capacity for judgment means the ability of a patient to perceive reality, to make judgments and express wishes, and to make choices. Long-term patients suffering from severe brain damage no longer meet these conditions.

3. The decision-making process

The decision-making process deserves special attention. In this respect, the responsible doctor or nurse must check whether the patient has drawn up directives, whether a legal representative has been designated, or whether a «person of trust» has been nominated. Decisions concerning the goal (and locality) of treatment and care must be based on the patient's condition, the prognosis regarding life expectancy and quality of life, and the character and presumed wishes of the patient. The experience and viewpoints of those persons closest to the patient and those of the nursing team have also to be taken into account. The responsibility for decisions that are reached in this way should be shared, and everyone involved, as far as possible should accept them. Hospital ethical committees⁵ may be included in the decision-making process. The final decision rests with the doctor directly responsible for the patient. Decisions, which lead to the discontinuation of life-support measures, must be protocolled, so that they can be reconstructed in the future.

4. Treatment and care

4.1. Principles

The therapeutic goal determines the procedures to be followed. Palliative care and nursing must be instituted in good time and in parallel with the usual therapeutic measures, and must proceed independently of these. Adequate use of available resources is fundamental; measures must meet the demands of good clinical practice, and must be reviewed periodically. In any individual case, economical thinkings shall never implicate decisions on the rejection or withdrawal of medically justified therapeutic measures.

4.2. Therapeutic measures

The therapeutic measures taken depend on the therapeutic goal. There are situations where diagnostic and therapeutic procedures that are otherwise suitable may no longer be appropriate, and where certain limitations in their use are indicated. In special situations the use of therapeutic measures for just a limited period must be considered. A change in the therapeutic goal may be envisaged if the disease is far so advanced that life-support therapy only prolongs suffering. Under these circumstances, the effect of therapy on the preservation and the quality of life has to be taken into account. Invasive or aggressive therapy should preferably be avoided in favor of simpler forms of palliative therapy. With the withdrawal of curative-therapeutic measures, there is a shift in the direction of care, alleviation and moral support.

4.3. Alleviation and care

Severely brain-damaged patients always have the right to adequate palliative measures. These are largely preventative, aimed at promoting the patient's general comfort (medication,

⁵ Here, «ethical committee» does not mean «research ethical committees» which assess clinical trials, but ethical committees, forums etc. that are set up in hospitals to deal with difficult ethical decisions in individual cases.

nursing care, physical therapy, etc.). As these patients are unable to express their feelings it is not possible to act in response to their symptoms. It is therefore necessary to look proactively for conditions which, based on clinical experience, are likely to cause suffering. Palliative measures should then be taken, even if they are likely to shorten the patient's life. Moral and advisory support of the persons close to the patient are also important elements of these measures.

Patient care includes maintenance of the patient's physical condition, avoidance of further damage, preservation of mobility, and keeping up the patient's appearance. The care provided should be as continuous as possible. This facilitates contact with the patient and makes it possible to get to know the patient and his family better.

4.4. Fluids and nutrition

Unless otherwise requested, adequate fluids and nutrition (enteral or parenteral) must be ensured in clinically stable patients. However, if this leads to complications the situation must be re-examined. The decision to begin tube feeding must be very carefully considered.

In newborns, fluids and nutrition may only be discontinued if establishing enteral nutrition demands major surgery, or is otherwise impossible.

Fluids should not be given without the simultaneous administration of nutrition. In terminal situations the administration of fluids alone may be justified or – in consensus with the team and the patient's family – it can even be suspended.

III. Comments

Re: Preamble

These guidelines are intended for institutions responsible for the care of chronic severely brain-damaged patients, to act as a basis for internal guidelines that take into account regional and cultural conditions. They shall help to come to the right decision with regard to treatment and care for each individual patient, without judging before hand.

Re: 1. Patients covered

The long-term prognosis and determination of the irreversibility of a «persistent vegetative state» are extremely difficult; they are dependent, among other things, on the age of the patient, duration of the condition, concomitant diseases, and, in particular, on the cause of the brain damage⁶. For instance, the chance of recovery exists for much longer (more than a year) with a persistent vegetative state following brain damage due to injury, rather than illness. In the former, supportive measures must be continued patiently over a prolonged period. Any question of deciding not to treat or to withdraw treatment, or to transfer the patient to another institution, must be considered in good time, but not hastily.

⁶ The Multi-Society Task Force on PVS, «Medical aspects of the persistent vegetative state», Part I: NEJM 1994; 330: 1499-1508; Part II: NEJM 1994; 330: 1572-1579

Re 2. Patient's rights

The legal situation in the case of patients who are incapable of expressing their wishes is complicated. In particular, there may be uncertainty regarding the extent of the right of representation and who can act on behalf of a patient who is incapable of judgment. There are also different cantonal regulations in this respect. In some Swiss cantons the doctor has the right to make decisions. In others, based on cantonal regulations or when there are no such regulations, there is, in principle, the obligation to nominate a representative, according to Swiss Federal Law. Depending on the circumstances, (e.g. the availability of persons with guardianship authority) it is not always practical or reasonable to demand the presence of a legal representative. With a view to the application, in the medium term, of the principle of obtaining the consent of a representative in the case of a patient who is incapable of judgments (as is also envisaged, for example, in the framework of the Bioethics Convention), these guidelines also specifically mention the possibility of the nomination of a person of trust.

Re 3. The decision-making process

Each decision requires definition of the goal, a search for consensus between those involved, and regular checks as to whether the goal is being achieved or is still appropriate. Most importantly, the consequences of the decision must be clarified for all those concerned (e.g. treatment of new diseases and conditions, transfer to another institution, difficulties for the family members visiting the patient etc.). Such decision-making calls for the allocation of the necessary space and time. When possible, these decision-making processes must always be conducted in accord with a binding internal guideline.

Re 4.1. Treatment and care: principle

It is appropriate to look for the optimal approach, finding the correct balance between «therapeutic over-zealousness» and «therapeutic nihilism», after considering the advantages and the disadvantages for the patient and taking into account the available resources.

Due to the not unlimited resources in the health service, the availability of resources must be checked periodically. The persons responsible for the decisions are also jointly responsible, in their fields of activity, for the proper distribution of the available resources.

Re 4.3. Treatment and care: alleviation and care

In addition to regular clinical examinations, specific searches for side effects of ongoing treatment, and monitoring vegetative parameters that could indicate possible symptoms (e.g. pain), attention should be paid to the observations and the insight of those who spend a lot of time with the patient (family members, caregivers, nurses). The value of many such measures can best be evaluated when they are given as a test (i.e. a therapeutic trial). The atmosphere in the patient's room should be quiet and empathic. Personal contacts should be maintained, as far as possible. There should be gradual acceptance of the persistent nature of the vegetative state and of the withdrawal of treatment, if this becomes necessary. And the family members should be able to incorporate the patient's situation into their own life pattern.

Re 4.4. Treatment and care: fluids and food

In patients with dementia who can no longer swallow food properly, it's necessary to exclude a swallowing disorder or digestive pathology (i.e. of the mouth, throat, esophagus, or stomach). After exclusion of the existence of a disorder that would be easy to treat, refusal of food (a form of behavior often seen in patients with dementia) should be assessed as a

possible expression of the patient's wishes. However, food and fluids should continue to be administered within the framework of palliative measures.

In newborns, if enteral feeding is possible using relatively non-aggressive methods (e.g. a nasal stomach tube, percutaneous gastrostomy, or surgical correction of duodenal atresia), food and fluids should be administered, in view of the always uncertain prognosis. On the other hand, when enteral feeding is possible only at the price of major, aggressive surgery or isn't possible at all, it's quite justified not to give any calories or fluids, keeping the patient under optimal sedation and always in the company of another person.

In principle, these considerations also apply to adults; however, this is sometimes controversial, and different practices may be followed. The present guidelines are based on the principle that the administration of food and fluids to chronic but not yet terminal patients is primarily intended to stabilize and maintain their physical condition and to prevent further impairment (e.g. prevention of decubitus ulcers).

IV. Recommendations for the attention of the responsible health authorities

In view of the advances that have been made in the field of life-support and the high demands involved in caring for these patients, it may be that the available resources impose limitations. The responsible healthcare authorities should have policies in place that guarantee that all such patients can be treated according to these guidelines, without economic considerations. Patients with chronic severe brain damage have the right to care and alleviation of their suffering, considering the appropriate preservation of life. Possible limitations in resources must be discussed at the social services level.

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