

GLOSSARY

medical and legal definitions

Accommodation: A special segment in accordance with the law on guardianship (vide case of attendance*). This also includes the accommodation of psychiatric patients in a closed facility in case of self-endangerment as well as custodial measures of any kind (as placing of abdominal belts and bed barriers with the risk of falling). In accordance with § 1906 BGB (German Civil Law), this remit will have to be stipulated separately in the power of attorney for health care. Otherwise, there could be decided upon a possible judicial appointment of custodian. The authorized representative (or another patient's representative*) has to take care that the patient will not be fixed in an abusive or unnecessary way. The very controversial coercive treatment of psychiatric patients with psychotropic drugs is a special feature.

Alzheimer's disease: Progressive fading of cerebral tissue, decline in mental performances, form of dementia* leading to memory impairments, disorientation and helplessness, and, to affect disorders, incontinence (= involuntary loss of urine and excrements) at a later stage, failing recognition of relatives, mental prostration. In the "final stage" there is no chance to eat food naturally.

Amputation: Professional "disconnection" of body parts at the affected place (i.e., sepsis*). In case of geriatric diabetes, wound infections or circulatory disturbances result in foot or leg amputations, rather often.

Antibiotics: medication for bacterial inhibition or elimination (i.e., Penicillin), respectively.

Brain damage/injury: Generally, sudden inability to conscious thinking, to understand or to specific movements, respectively. Head injuries with direct involvement of the brain is referred to as traumatic brain injury. This may range from light concussion and temporary unconsciousness up to a permanent serious mental damage. Another possible reason may be hypoxia of the brain, (indirectly caused by myocardial infarction or airway closure) or stroke*. First attempts of early rehabilitation may take place in intensive care, followed by a follow-up treatment of three weeks, at first. The success of efforts for recovering the ability to communicate or to move properly even after months, depends on a wide range of factors as age, vital energy of the affected persons as well as of therapeutic measures, for example.

Brain death: Irreversible (i.e., non-reversible) expiration of all functions of the cerebrum, cerebellum and of the brain stem, generally caused by head injuries. Around 1 % of all deceased are affected. In case of brain death, cardiovascular functions will be maintained by controlled ventilation (in contradiction to the subsequent cardiac death as classic sign of death). Diagnosed and documented brain death is the prerequisite for the "removal"* of vital organs for the organ donation*.

Breathing difficulties, respiratory distress: severe respiratory disorders, very often connected with fear of suffocation; subjectively very strenuous feeling to breath more heavily. Very often, it is not caused by a shortage of oxygen, but the centrally controlled respiratory drive is strengthened by increased CO₂ content in arterial blood. Aimed at relieving, the short-acting Morphine* as medicative therapy will be given first priority. Thereby, the feeling to be forced to breath, will not be strenuous any longer

and the breathing work will be “economized”. Mostly, additional tranquilizers or Anaesthetics* will be administered. On the one hand, the respiratory depression caused by relieving could lead to an “indirect” assisted suicide. On the other hand, medicinal measures will be the method of choice in the field of palliative care* in case of carefully considered application with respiratory distress (at the end of life or Amyotrophic Lateral Sclerosis = muscular paralysis with suffocation risk), and not the application of artificial respiration*

Care, case of: if a person is no longer able to manage its own affairs (either in part or in full). A custodian will be appointed by the court for selected scope of duties. Aimed at avoiding such a decision, there will be issued a healthcare proxy for a person of trust, provided the legal capacity of the constituent. The healthcare proxy can cover different affairs (health or financial aspects).

Chemotherapy: Mostly, this stands for the medicative therapy of cancerous tumours (with dreaded side-effects). But, this could also stand for chemical substances with detrimental effects on pathogens. A chemotherapy may be aimed at healing, stabilization or relief.

Coma: Deepest unconsciousness which cannot be interrupted by external stimuli. That state could be caused by different reasons (as metabolic decompensation in diabetes, severe renal or hepatic disease, cerebral-organic diseases and bleedings). Patients are bedridden, will have to be fed artificially in any case, and, in most cases, artificially respired (intensive care*). Danger to life and prognosis* to awake from coma or to recover, will have to be looked at in a very sophisticated way. Comatic patients who survive with conscious capabilities, will turn to wake up after 2 – 4 weeks. Moreover, there may be a chance for the transition into a chronic vegetative status* (colloquially known as “waking coma”) in case of brain stem functioning.

Consent: Without consent (of the patient or the respective patient representative*) any medical intervention is illegal (Exemption: a direct emergency situation*) and the physician may be held responsible for personal injury.

Dementia: Progressive fading of memory capability, of cognitive and social functions (possibly also motoric), incl. speech capability. Will go over into a complete care dependency after multi-annual process. The Alzheimer’s* disease is the most common type with more than 70 %. Moreover, vascular sclerosis (arterial calcification) and other brain damages* will have to be considered.

Deposit: Storage of deeds and documents. With reference to living wills to be updated from time to time, attention must be paid to the fact that depositories offer respective services. The Federal Chamber of Notaries runs an electronic register incl. contact data, only.

Dialysis: Medical-instrumental blood purification in case of acute or chronic kidney failure, aimed at avoiding uraemia.

Dying, assisted: Measures for the facilitation of dying of terminally ill. Any help to extensively relieve from pain and discomfort and refraining from all measures and intolerable prolongation of suffering. This will be ethically commendable and medically demanded if the patient is in inevitable state of dying. Omission of therapies are often referred to as “passive” mercy killing, whereas this could mean a termination (active and fatal) of measures, too. Beyond the direct process of dying, the respective patient’s consent has to be documented in case of renunciation of life-extending measures. This also applies for the so called “active indirect” mercy killing if the terminally ill dyes earlier in consequence of a side effect caused by symptom and pain management. The killing* of a person – even on the patient’s demand – for example by a medical “lethal injection” is prohibited in Germany.

Emergency, medical: In case of an acute life-threatening disruption of vital functions (breathing, cardio-vascular system, metabolism) caused by an accident or by a disease, respectively. For example, with heart failure, shock, craniocerebral trauma (brain injury*), poisoning with multi-organ failure (sepsis*), metabolic imbalance. Vide resuscitation*.

Examination, post mortem: Examination of the body in order to clarify the cause of death aimed at improving scientific-medical knowledge (voluntary and unlike to an autopsy being imposed for legal clarification).

Health/ Power of Attorney related to health: In short “Health – power of attorney”. Includes the competence to govern all matters of healthcare on behalf of the patient in case of inability to consent as well as to implement the patient’s wishes (living will*) (without the allowance to decide at own discretion).

Hospice care: Exclusively for dying and terminally ill (mostly cancer patients); painstaking basic care, pain therapy, psychosocial stimulus and spiritual end-of-life-care, whereas “assisted” suicide as targeted death acceleration is rejected by the ethic point of view. Generally, this care will be executed at home, attended by volunteer palliative care providers. Inpatient admission will be decided upon in case of unfeasible home care, only (nursing home residents cannot be moved to a hospice). The average stay at the inpatient hospice will be two weeks, in general. Vide: Palliative care*.

Hunger, feeling of: Alleviation of hunger and thirst feeling* belongs to the basic measures of any relieving therapy. However, many seriously ill do not feel hunger any more – this applies without exception during dying processes, and, most probably, for persons with the so called apallic syndrome, too. Artificial nourishment cannot be considered to be relieving.

Invasive: Tissue violating diagnostic or therapeutic technologies penetrating into the body. On the contrary – non-invasive measures (less physically stressful) as physical examinations or imaging techniques.

Intensive care: Instrumental and professional preconditions for medical surveillance and (maximum) therapy in case of acute emergency, i.e., in the course and after surgeries, but, also in case of chronic dependence on machine assisted prolongation of life (for example of machine assisted ventilation*).

Killing on demand: In accordance with § 216 StGB (German Criminal Code) this will be punished with imprisonment of ½ a year till 5 years. Conceptionally and synonymously used for “active” assisted suicide. When death occurs prematurely in consequence of an action without expressed authorization or consent, this is to be understood as homicide or murder.

Living will: Written declaration of intent of an adult person – pre-condition: capacity for consent – with regard to the desired application, temporal limitation or rejection of medical procedures. Precautionary manner in case of later lack of capacity to give consent, i.e., in case of nature, importance and consequences of treatment cannot be comprehended mentally any longer. Since 2009, the liability of living wills is stipulated by law, i.e., § 1901 a, section 1 Civil Law Code, and, it presupposes that the applicable situation has to be described specifically and sufficiently.

In addition, the law on patient rights (§ 630 d, Civil Law Code) clearly stipulates the immediate significance for the physician, since 2013: in case of the patient’s lack of consent, the physician has to get the vote of a patient representative* only, if the living will does not cover the “intended treatment to be allowed or rejected”.

Morphine: Derived from opium, to be understood as opioids as a generic term. Medical indication in case of severe pains which cannot be alleviated by other pain killers. One example are tumour-induced pains with cancerous diseases. In case of acute pains with accidents or heart attacks as well as with agonizing suffocation conditions, morphine and related substances will be the method of choice. In case of so called "neuropathic" pains* morphine is less effective. Morphine will be administered in form of (time-released) capsules and tablets, pain patches, suppositories or injection solutions. Possible narcotic effects, and, undesired side effects as constipation and more shallowed breathing may occur. With professional palliative medical care*, dosing will neither cause a clouding of consciousness nor a shortening of life expectancy – rather the opposite, because alleviation will have a positive effect on life span.

Narcotics: Anaesthetic drugs being suitable to lead to anaesthesia (= full, but reversible paralysis of the central nervous system with blocking out consciousness, sensation of pain, and of reflexes to the greatest possible extent, but, preservation of functionality of vital centres). Narcotics cannot be delineated from sleeping drugs or sedatives, sharply.

Nutrition, artificial: Will be executed via infusion (a nutrient solution will be given into the vein), via mouth or nasal tube (soft rubber tube) into the stomach or, nowadays, via a so-called PEG-gastric tube (a thin tube through the abdominal wall into the stomach, directly). The PEG-tube (percutaneous endoscopic gastronomy) isn't an emergency action and requires surgical procedures, and, will not be done without consent. This method of treatment became standard in the field of care techniques since the end of the last century, only.

Organ donation: Consent to the removal of organs after own brain death, aimed at transplantation of an undamaged organ into the body of another person (so called organ recipient). This will be possible in intensive care unit by an appropriate organ-saving surgery, only, and, after futile lifesaving measures for the donator had been taken. Consent to an organ donation and the living will shall complement each other.

Pain, chronic disease: As soon as pain lost its warning function, this could be viewed as an independent illness. Beside of an organic illness, a pain disorder is also defined by subsequent psychosocial changes and covers every aspect of the patient's life. Examples to be considered, are headaches and back pains, neuralgias, bone pains, rheumatic pains or even phantom pains. In many cases, these pains have got different reasons, and, therapy will raise a lot of problems. Comparable, tumour pains with cancer patients can be treated much more effectively.

Palliative medicine: Eligible with outpatient or inpatient care (hospital palliative care ward, but, only temporarily with discharge after an average of some 10 days.) Holistic-interdisciplinary concept of medical treatment. All reasonable measures aimed at alleviating psychological and physical symptoms, pains and discomforts with incurable people (cancer patients especially). Palliative medicine aims at the stabilization of the condition as well as quality of life to the very end, and, acts rather life-prolonging. Basically, attending physicians will abstain from technical high-performance medicine in general (vide hospice care*). Sometimes, it is not easy to clearly delimit if palliative interventions or tumour irradiation will act in a life-prolonging way or just alleviating.

Patient representatives: Authorized representative in health issues or court-appointed caretaker, respectively. In case of incapacity*, spouses or children cannot act as authorized patient representatives, automatically.

Place of residence, right to determine: Choice to decide upon the habitual residence (at home, nursing home, hospital), a person shall stay.

Prognosis: Medical opinion of the (likely!) course of the disease. Prospect of recovery (or even healing) may be positive, may be realistic (with 50 % probability) or may be low (even the prospect of stabilisation). Attitude and estimation of the person concerned (possibly previously voiced) with reference to hope, burden of health, quality of living, permanent damage etc. will have to be taken into consideration.

Respiration, mechanical or artificial, respectively: Replacement or assistance of breathing activity, temporary or permanent (also in case of coma*) by a ventilator, i.e., mechanical; by different techniques and requirements (by terms of air volume or pressure). Will be made in an invasive way via a respiratory hose (tube). The hose will be positioned by a tracheostoma (cut in the windpipe (consequence: inability to speak, but this could be trained to with a cannula) or by the mouth (consequence: foreign body sensation). Another possibility will be artificial respiration via a ventilation mask which will be positioned outside, i.e., not invasive*, tight over mouth and nose (aimed at a fast short-term ventilation of the patient, i.e., for an increased oxygen supply).

Resuscitation (= reanimation): appropriate measures to be taken in case of respiratory failure, cardiac and circulatory arrest, aimed at maintaining or re-initiating oxygenation, for example by using heart-lung-devices. When resuscitation will be successful after more than 5

minutes, only, severe brain damages* (vide vegetative status*) by hypoxia in the brain will have to be taken in consideration.

Sedation: Sedative and/or fear reducing tranquilizers, barbiturates, narcotics* and other sedatives will be used (typical are Benzodiazepine, Diazepam, but also neuroleptics or psychopharmaceuticals and opioids). Within the deceasing phase or at dying stage, this medication will be administered as “co-medication” jointly with pain killers or as palliative or terminal sedation. According to the situation, the physician will define, control and adapt the desired depth and kind of sedation (permanent or interrupted). This will be subject of the patient’s consent, suffering of severe symptoms. This is to be distinguished from immobilization of psychiatric patients and, among others, of nursing home inhabitants to “facilitate” the employee’s work.

Sepsis: Also called blood poisoning. General infection via the bloodstream, in the beginning caused by a local source of disease (trigger: germs of any kind, bacteria, fungi, viruses). Especially with weakened patients, poisonous substances will flood the entire body and will lead to “multiorgan failure”. Live threat is underestimated rather often, but sepsis is the third most common cause of death. Initial symptoms are unspecific (chills, fever, disorientation, drop in blood pressure).

Stroke: Caused by a circulatory disorder in the brain with sudden lack of oxygen and other substrates within nerve cells. On the one hand, an inadequate blood supply (cerebrovascular accident due to clogged arteries), and, on the other hand, an acute brain haemorrhage (caused by artery rupture). could be the reasons for. Aimed at reducing the damage of a stroke in the brain, and, at increasing the chance for a complete brain restorage function, it will be necessary to start with diagnosing and therapy as early as possible.

Suicide: Suicide, undertaken on a person's own free will and the assistance to this end will be unpunished on case-by-case basis (whereas the decision-making process remains ultimately with the person who wishes to die, by drinking up a cup with a lethal substance/medicine, independently). However, by December 2015 a business like "promotion" set on permanent repetition of suicide assistance, is prohibited by the relaunched § 217 StGB (German Criminal Code) – constitutional complaints had been lodged against this paragraph.

Thirst, sensation of: With people suffering of serious illnesses the sensation lasts longer than the sensation of hunger*. Mainly, it is caused by dryness of the mouth. Aimed at the alleviation of these symptoms in dying, it is very important to execute a professional mouth care (i.e., by giving little ice cubes) beside of moistening the beathing air. In contradiction, the artificial supply of larger fluid quantities with the dying is very dangerous because this could lead to fluid retention in the body, resulting in agonizing consecutive symptoms as respiratory distress*. If it is appropriate within palliative medical treatment to execute an artificial fluid supply (instead of offering fluids in the way of natural drinking), this should be done in a lesser extent. In any case the subjective effects of liquid consumption in the body (dehydration) will have to be checked, first.

Vegetative status: Also called apallic syndrome. Continuing malfunction of the cerebral cortex (unconsciousness), often after insufficient oxygen supply with necessary resuscitation*. In most cases, organ functions (as autonomous breathing) will remain or, will restart in the course of improvement after a previous (deep) coma, respectively. Limited, non-targeted movements are possible, too. The international abbreviation "PVS" stands for "Persistent Vegetative State", i.e., a "vegetative" state which remains min. 4 to 6 weeks after acute brain damage. This state

must not be irreversible. Patients in this stadium may be kept alive over years. Typically, eyes remain open (but look into emptiness) and keep the sleep-wake rhythm, misleading called waking coma. The borders to "the fractured state of consciousness" (for example after severe traumatic brain injury) are blurred. Some experts fear that a rather considerable proportion of PVS-patients could be misdiagnosed. In general, there can be expected manifold handicaps after return of consciousness. Medical recommendations re. prognosis* do also carry subjective assessments. Some physicians are almost certain that these patients will not wake up again after 3 to 6 months, at the earliest, or, at best, after 12 months (in that case in 1 – 2 per cent of the cases, only), others, even after years. (Others propose the renunciation of life-extending measures after 2 – 3 days after acute brain damage, provided that there are no signs as pupil reactions, pain and lid-closing reflection noticeable.)

Waking coma: Vide vegetative status*