



CHARTER OF THE RIGHTS OF THE SUFFERING PERSON

Aosta, May 10, 2014

Preamble — The aim of the present “Charter” is to contribute to the definition of the rights of the suffering person, as a component of the rights of the human person recognized and guaranteed by the Italian Constitution and by the international and European Charters and Conventions on human rights; the present “Charter” complies with the fundamental principles of the autonomy and of the dignity of the human being, of the solidarity and of the social protection, bearing in mind the conditions of fragility and vulnerability of the suffering person.

The present “Charter” assumes the Law n° 38 of March 15, 2010, labelled: *“Disposizioni per garantire l’accesso alle cure palliative e alla terapia del dolore”*, and its subsequent implementation, as a forefront instrument to protect of the right of not to suffer in Italy.

Under no circumstances, the following Charter may replace the legal and deontological applicable provisions on the medical and paramedical personnel and on the social care workers; it completes the documents, that have not legal value, adopted by public and private institutions that identify the rights of patients.

For the purposes of the present “Charter”, and with no prejudice of the protection granted to the other persons, a “suffering person” is the person who, at any age – included neonatal and pediatric time, is experiencing a sensation of pain or distress not transient and over threshold of normal tolerability, caused by a trauma, an inflammation or a wound in the body, or by any other pathological process, or correlated with a mental illness or a severe and persistent existential disruption, or eventually described in all such terms.

For the purposes of the present “Charter”, “taking care of the suffering person” is the whole therapeutic, diagnostic and social assistance provided to the person or to its family with the aim to relief from all kinds of suffering, using appropriate and integrated therapies, pharmacological, surgical, instrumental, technical and rehabilitative. Also the so-called “clown therapy” may be part of the protocols about the relief from emotional distress, in particular with regard to the pediatric intervention.

The inability of the subject to express its suffering, caused by a communicative incapability – both verbally or by signs, is not *per se* a sufficient reason to exclude the person from the application of the present

“Charter”, if it is ascertained, using the best assistive communication technology, that the person is capable to experience a conscious suffering.

§1. Dignity and identity — Every suffering person has the right to the fully respect of its dignity and humanity, and of its personal identity, including the individual biography, the various familiar, social and emotional ties, the moral, ethical and philosophical thoughts, and the religious beliefs, if it has any.

The relief from suffering shall be oriented by the principle of personalized care.

§2 Equal access — Every suffering person has the right to equal access to the necessary interventions for the relief from suffering, provided at the highest possible level in the specific situation, without any discrimination of age, sex, race, religion, nationality, social conditions, political and ideological opinions.

In care practices for the relief from suffering, a system based on territorial networks, able to coordinate the multidisciplinary activity of general practitioners and of medical, paramedical and social care workers specialized personnel, and of the family, both within hospitals and hospices, and at home, must be preferred.

The achievement of higher quality standards in the pain therapy and in the relief from any kind of suffering, within the compatibility of the available economic and financial resources of the public budget, and without prejudice of the legal dispositions and of the planning provisions regarding the basic level of health and social care, shall be considered a priority.

The avoidable painful and distressing harm, experienced by the person because of the inexcusable negligence, imprudence, malpractice or inadequateness in taking care of the suffering individual by the medical, or paramedical personnel, and by the care workers, or by the hospitals and hospices, shall be adequately compensated.

§3. Precaution — Every suffering person has the right to receive a safely care, without putting in jeopardy the life and the physical integrity – besides the clinical condition which causes the pain and the distress – in accordance with a reasonable criterion of precaution and protection.

Every suffering person has the right to the terminal sedation within the limits imposed by the law, by the deontological rules and by the clinical protocols.

Every suffering person has the right to consent to experimental medicine, according to the law.

§4. Listening — Every suffering person has the right to be heard in a non hasty and not shallow manner, and with due attention to all the elements of suffering, according to the limits of the available human resources and of the organizational necessities of the structures and services provided by hospitals and care centers or in-home assistance.

Without prejudice to the obligations set forth by the law and the deontological rules, the caregivers, who are responsible for the suffering person, shall evaluate suffering in the most accurate way possible.

The time, which the suffering person needs in order to understand and consent to the decisions related to its care, shall be respected.

§5. Information and autonomy — Every suffering person has the right to be informed in a transparent, complete and thorough manner about the diagnosis, the therapies and the care for the relief from suffering, bearing in mind the conditions of the person and the level of its education; the information has to be given in a tactful way, by recurring to a sense of humanity and without excluding elements of hope. Every suffering individual has the duty to refuse the information and it may revoke this refusal at any time.

No kind of treatment for the relief from suffering may be started or continued without the consent of the suffering individual, except under the cases expressly foreseen by the law and, in all circumstances, within the limits imposed by the respect for the human person and for the fundamental and inviolable liberty rights.

The person has the right to plan in advance the wanted or unwanted treatments for the relief of its suffering for a time when, even continuing to feel a conscious form of suffering, the person will be incompetent; the suffering individual may appoint, in advance, a trusted person to report those plans to the medical, paramedical and care-giving personnel, or to a legal ward, if it has been appointed. The advance directives, that are not successively revoked or modified, and which are adequate to the present clinical situation, shall be properly considered in the personalization of care.

The suffering person has the duty to cooperate with the care personnel and to respect the rights and needs of other patients, if it is treated in a hospital or in a hospice.

§6. Decency and privacy — Every suffering individual has the right to decency and to be addressed in a respectful and compassionate way.

Every suffering individual has the right to privacy and to the protection of its personal data, related to the mental and physical condition and to the treatments applied for the relief from suffering on the basis of the law.

§7. Place of care and way of life — Every suffering individual has the right to consent to be visited by its relatives, to maintain social relationships or to have companionable pets or some fond objects, according to the limit set by the hospital or by the hospice for organizational or functional reasons.

The public and private facilities for health care and for social-assistance shall promote the conditions under which the wishes of the suffering individual to be cared or to be looked by trusted persons may be executed.

Without the prejudice of the best interest of the individual, and within the limits of the available resources, the right of the suffering person to choose the place where to be treated, shall be respected, with a preference for the continuity of the place of care and of the way of life.

§8. Scientific and technological research — It is the duty of the Republic, composed of Regions, Municipalities and Metropolitan Cities, to promote and sustain the scientific and technological research, in a regime of freedom, in order to identify and to realize new and advanced methods, techniques, practices and protocols for the relief from suffering, even by supporting, or by facilitating, the autonomous initiatives of the citizens, both as individuals and as a member of associations, on the basis of the principle of subsidiarity.

§9. Awareness campaigns — The information and awareness campaigns about human suffering, also not strictly limited to illnesses or to the activity of hospitals or hospices, shall be promoted and supported by the public institutions, even by financial contributions or tax breaks.

It is the duty of the Republic, composed of Regions, Municipalities and Metropolitan Cities, to promote the autonomous initiatives of citizens, both as individuals and as members of associations, on the basis of the principle of subsidiarity, in order to establish or develop activities for the relief from suffering.

§10. Minors — It is the right and the duty of parents, or of the persons on their behalf, to strive to obtain the relief of suffering for the minors they have under their guardianship.

The will of the minors, bearing in mind of their maturity, shall be taken into consideration in order to personalize the interventions for the relief of suffering.