

**CHARTER OF RIGHTS OF THE CHILD
WITH AN INCURABLE DISEASE**

BACKGROUND

This Charter draws on the 1989 United Nations Convention on the Rights of the Child, internationally recognized principles for the protection of children's rights, and the development of contemporary approaches to pediatric, palliative and comprehensive care. In preparing the Charter, account has been taken of existing international and national charters and initiatives concerning the rights and healthcare of children, including children with chronic, progressive and incurable diseases.

Caring for a child with an incurable disease involves not only medical and social considerations, but also profoundly human, ethical and spiritual dimensions. It is an area in which different religious and worldview traditions can find common ground in shared values while preserving their distinct identities. Support for this Charter by religious leaders is intended to help strengthen a culture of dignity, compassion and care for the most vulnerable, and to encourage practical interreligious cooperation in the interests of the child and the family.

INTRODUCTION

The medical advances in the last decades and the development of social protection systems have allowed to prevent and cure several diseases, but - at the same time - have contributed to the transformation of acute diseases into chronic diseases. Rare diseases, adult congenital patients, and chronic diseases represent the new challenges of pediatric healthcare.

Parallely, there has been an increase of diseases associated with environmental factors, behavioral factors, and life style (accident traumas, allergies, obesity, metabolic and cardiovascular diseases), and of psychosocial disorders (foreign minors, handicapped minors, and situations of social distress).

In this new scenario, the concept of ‘treatability’ as an alternative to ‘curability’ for an ever-increasing number of patients (in particular pediatric patients) has acquired a new meaning, also involving the patient’s family in the treatment process.

On the other hand, transboundary healthcare has widened the frontiers of healthcare, and the internet allows to establish immediate contact with the best health facilities in the world.

Given these evolving scenarios, it is important to reconfirm the rights of and try to apply them to this new reality.

This Charter affirms the rights of children with chronic, progressive and incurable diseases to healthcare, care and support, including at the end of life. It is grounded in the inherent dignity of every child and in the need for comprehensive care that addresses physical, psychological, social and cultural needs and, where desired by the child and/or family, spiritual needs. The provisions of the Charter are intended to be applied with due regard to national legislation, the organization of healthcare systems, available resources, and the cultural, religious and worldview diversity of states.

ARTICLE 1

The child and family have right to the best relationship with medical and healthcare staff

The therapeutic alliance between family and doctor is a fundamental element in the child's care process.

The communication process between child, family and healthcare staff should be an exchange, based on human respect and guided by the common goal to achieve the highest possible level of wellbeing and protect it, avoiding conflicts or discordance.

The time devoted to communication between doctors and patients is part of the care process. A key instrument in this relationship is informed consent. Healthcare institutions should provide staff with training in communication, information-sharing and supervision methods. The effectiveness of such training should be assessed.

Defense of life, protection of physical and mental health, and relief from pain shall be the constant responsibilities of the medical staff, within a relationship of trust, respect and discretion.

The patient's family and the multidisciplinary healthcare team should work together to define and, where possible, agree on the objectives, planning and delivery of care. The multidisciplinary team may include psychological and other relevant professional support, as appropriate and in accordance with national legislation and the rules of the healthcare institution. If, despite all reasonable efforts, disagreement persists on specific issues, the matter may be referred to a competent body, where such referral is provided for by national legislation or the rules of the healthcare institution.

ARTICLE 2

The child and family have right to healthcare education

The child and family must be helped acquire and maintain abilities allowing them to understand the disease and its treatment, collaborate with the healthcare staff, and maintain or improve their quality of life.

The healthcare staff shall be responsible of providing the appropriate education to the child and family, based on the best available scientific evidence and medical competences.

Therapeutic education must be provided by specifically trained staff. Healthcare institutions should encourage family-centered projects involving families directly in the care process, as well as narrative medicine projects based on listening and sharing experience.

ARTICLE 3

The child and family have the right to obtain a second opinion

The child and family have the right to request in-depth information and a second opinion from other experienced professionals or institutions regarding a diagnosis or treatment. The availability of and procedure for obtaining a second

opinion are determined in accordance with national legislation and the organization of the healthcare system.

Treating medical staff should inform the child and family of the possibility of obtaining a second opinion and the relevant procedure and, within their authority and available resources, facilitate an external consultation (online or in person).

Medical staff have the responsibility to understand the reasons leading to the request of a second opinion and to try to resolve any conflictual situations. Moreover, they must enter the relevant information into the patient's clinical record.

ARTICLE 4

The child and family have the right to an appropriate diagnostic process

Children have right to the maximum level of care, aimed at ensuring their best option of survival and development.

The child and family have the right to receive information about other healthcare institutions, including at the international level, with relevant experience and expertise and, where medically appropriate and feasible, to consult with such institutions.

The child and family should have access to clinically justified diagnostic investigations necessary to clarify the diagnosis, within available resources and in accordance with national legislation. Genetic testing may be carried out where medically indicated, subject to informed consent requirements and other applicable rules.

ARTICLE 5

The child and family have the right to information on clinical trials and experimental treatments

The child and family have the right to receive accurate information about available clinical trials and experimental diagnostic or therapeutic methods. A child's participation in such research or use of such methods is permissible only when duly approved and conducted in accordance with internationally recognized standards of Good Clinical Practice (GCP), applicable ethical requirements and national legislation.

Risks associated with experimental treatments or procedures involving minors must be assessed in advance and minimized to the greatest extent possible. The interests, safety and well-being of the child take precedence over scientific or other interests.

All medical and surgical interventions, including experimental procedures, must comply with informed consent requirements established by national legislation. The child should receive information in a form appropriate to their age and maturity; their views and, where applicable, assent should be taken into account in accordance with applicable rules. Participation in research must be free from coercion.

ARTICLE 6

The child and family have the right to information on opportunities for cross-border healthcare

The child and family have the right to receive information about opportunities for consultation or treatment at other healthcare institutions, including institutions in other countries, where this may be in the child's best interests.

Healthcare institutions should, within their authority and capacity, facilitate the exchange of necessary medical information and consultations with such institutions.

Cross-border healthcare is provided in accordance with the national legislation of the states concerned, applicable referral, financing and entry requirements, and with due regard to medical appropriateness and the availability of the relevant care.

ARTICLE 7

The child has the right to continuity of care and palliative care

The child should, as far as possible and taking into account their condition and the organization of the healthcare system, receive care in settings appropriate to their age and needs, including pediatric wards and home-based care where medically appropriate and available.

Healthcare institutions should assess patients' clinical and social needs using appropriate multidisciplinary tools in order to define an individualized treatment and care plan.

The child has the right to appropriate relief of physical and psychological pain. Symptoms and pain should, as far as possible, be prevented and alleviated. Where medically indicated, palliative care should be included in care planning as part of a comprehensive approach alongside therapeutic and rehabilitation measures.

Quality palliative care requires specific professional skills.

Continuity of care for children who are unable to care for themselves and who have chronic, progressive and/or incurable diseases should, as far as possible, be ensured through coordination of available inpatient, outpatient, home-based and palliative care, including pediatric hospices where provided for within the healthcare system. The individual care plan may combine medical, nursing, rehabilitation, psychological and social care and, where desired by the child and/or family, spiritual support. To the extent permitted by the child's condition, education, communication, play and social relationships should also be supported.

ARTICLE 8

The child has the right to respect for their dignity and to proportionate care, including at the end of life

Extremely vulnerable children, including children with incurable diseases and children at the end of life, have the right to medical, nursing and supportive care (psychological, social and, where desired, spiritual), based on their individual condition and best interests. Decisions concerning the continuation, limitation or

non-initiation of medical interventions should be taken in accordance with national legislation, applicable clinical and ethical standards, and informed consent requirements, giving priority to the relief of suffering and preservation of the child's dignity. Care should respect the child's individuality, family relationships, and cultural, religious and worldview characteristics.

Care does not always mean cure. The caring bond between parents and child is fundamental in the process of care. Taking care of children entails taking care of their whole family.

The caregiving relationship between parents and child must be supported with all available means, also when the disease is incurable or terminal.

Treatment, care and accompaniment are complementary components of support for the child and family at different stages of the disease.

ARTICLE 9

The child and family have the right to psychological, social and spiritual support

The child and family should be supported in understanding and coping with the disease, including incurable and progressive diseases. Their clinical, emotional, psychological and social needs should be taken into account, as well as spiritual needs where such support is requested.

In addition to the work of medical and nursing staff, families have the right to professional support from qualified psychologists, social workers, educators and counselors, who can support and guide them during critical periods of the disease.

The child and family also have the right to receive information about available spiritual support. At the voluntary request of the child and/or family, the healthcare institution should, where such support is available, facilitate its provision, including by inviting a spiritual adviser, member of the clergy or other person to provide spiritual accompaniment in accordance with the religious beliefs or worldview of the child and family, in compliance with national legislation and the institution's internal rules.

Spiritual support is provided solely at the wish of the child and/or family. It complements medical, psychological and social assistance without replacing it, without impeding the provision of medical care and without infringing the rights of others.

Relatives, legal representatives, friends and other close persons should be given the opportunity to visit the patient as often as permitted by the child's state of health, medical indications, sanitary requirements and the institution's internal rules.

ARTICLE 10

The child and family have the right to participate in decision-making and research activities

The child and family should have the opportunity to be heard and consulted in decisions directly concerning the child's treatment, care and conditions of stay, taking into account the child's age and maturity and in accordance with national

legislation. Participation by the child and family in research activities must be voluntary and may take place only in compliance with applicable ethical requirements, informed consent rules and national legislation. Refusal to participate must not affect access to necessary healthcare. Participation of patients and families in advisory bodies and initiatives of the healthcare institution may be encouraged in accordance with applicable rules.

Involvement of patients and families in advisory and educational initiatives, including “expert patient” programmes, should be encouraged for the purposes of sharing experience and improving the quality of care. Participation in clinical trials of new medicines is a separate matter and is subject to Article 5 of this Charter and applicable rules.

FINAL PROVISION

This Charter is based on recognition of the inherent dignity of every child and the universal value of care for the most vulnerable. Its provisions are to be applied with due regard to national legislation, the characteristics of healthcare systems, available resources, and cultural, religious and worldview diversity. The Charter is intended to promote cooperation among the medical community, families, public authorities, civil society and, where appropriate, religious institutions in the interests of the child and with respect for freedom of conscience.