



FONDAZIONE
MARUZZA ONLUS
CHILDREN'S PALLIATIVE CARE

TOGETHER, FOR A BETTER TODAY.

THE TRIESTE
**CHARTER OF THE RIGHTS
OF THE DYING CHILD**
THE TRIESTE CHARTER
CHARTER

Gold Medal of Merit for services to Public Health **2013**

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The 1989 United Nations Convention on the Rights of the Child constitutes the basis for the present document that focuses on the specific application of those rights for children who are nearing the end of their life or are dying.
The Italian Ministry of Health endorsed this initiative considering it important and consistent with its commitments regarding issues linked to the care of children with incurable illness.*

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FORWARDS

FORWARD 1

Even children die, often due to a serious illness: this harsh reality is impossible to accept without a profound sense of despair; childhood should be a carefree time, not fraught with illness and death.

When this happens, it is a civil society's duty to provide medical, psychological and spiritual support for the child and family. In the harrowing time before the child's passing, often characterized by feelings of disbelief of a situation that is unbearable and contrary to nature, the child has rights. These fundamental rights must become mandatory so that the child and family are supported and protected as much as possible.

Children with serious illness are at the centre of the Maruzza Foundation's mission. We have been striving for many years for the right to access effective and dedicated care, advocating, among other things, the introduction of legislation in Italy (Law 38/2010) aimed at guaranteeing child-specific palliative care and pain management for all children affected by life-limiting and life-threatening conditions.

Still, there was nothing that focused on the question of care for children during the end-of-life phase, a particularly complex situation to envisage for those with no personal experience. And so, the "Charter of the Rights for the Dying Child", was devised: not as a series of rules translated into legal principles but comprehensive recommendations for conduct that should be embraced by all those caring for a dying child.

First and foremost, I would like to express my thanks to Franca Benini and Roberta Vecchi who conceived this project and proposed the realization of the Charter to the Maruzza Foundation. Secondly, to the experts who devoted professionalism, knowledge and attention to the drafting of the document, certainly a considerable undertaking, bearing in mind the range of problems and diverse age-related needs to include in a single publication. Finally, our profound gratitude goes to the panel of international experts who revised the Charter so that it could be valid globally for all children and families facing this devastating situation.

I sincerely hope that such an authoritative piece of work is instrumental in relieving the immense suffering linked to the death of a child, and that those called upon, for professional or personal reasons, to care for a child approaching the end of life endeavour to propagate these few, yet fundamental, indicators of a civilized society.

Silvia Lefebvre D'Ovidio
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FORWARD 2

Dear Reader,

The death of a child due to an incurable illness is a tragedy without equal. As a parent, it is hard for me to even entertain the possibility of losing one of mine; let alone to imagine the enormous emotional

and spiritual pain it causes to families.

In my work, though, I often speak with children and parents for whom losing a child is a reality rather than a frightening possibility. I've seen the pain these families endure. Sadly, this pain is exacerbated greatly when children and their families have to face the illness—and eventually death—without the benefit of palliative care.

Consider, for example, the case of Antonio Mendez (not his real name), a 9-year-old boy from Mexico with a malignant muscle tumor. When I met him in 2012 he had already undergone numerous rounds of chemo and radiation therapy but his cancer had spread to his lungs and head. It was pretty clear that he was not going to recover but his physicians had never talked openly to him or his parents about his prognosis or options for treatment.

Instead, they wanted to continue chemotherapy, treatment that was almost guaranteed to be futile and caused Antonio severe side effects. Antonio and his parents did not really want chemotherapy anymore but the physicians gave them no other options. Antonio was also experiencing increasingly severe pain that his physicians were not treating adequately, leaving him in agony for much of the day.

Antonio's case clearly demonstrates the importance of the Charter of the Rights of the Dying Child. If, as the Charter recommends, the hospital team that treated Antonio had listened to him and his parents; had provided them with adequate information about his illness and treatment options; had supported them in dealing with their emotional and spiritual pain; and had properly treated his symptoms,

they would have spared Antonio and his family a lot of unnecessary suffering.

It maybe would not have the loss of Antonio any less painful but it would have given him, his parents and his older sister a sense of shared grief and comfort instead of abandonment.

Diederik Lohman
Associate Director,
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INTRODUCTION

In our culture, we do not like to discuss illness and death with regards to children. Serious illness and the death of a child is often perceived as something deeply unfair and unjust. It is almost as if suffering, accepted and recognized as an integral part of the human experience, were somehow not extended to the whole of existence and that children, of any age and condition, are immune. However, the reality with which we come into contact on a daily basis proves that children do indeed suffer and that, regardless of their age, they experience all the clinical, psychological, ethical and spiritual problems linked to incurable illness and death.

The death of a child is a devastating and tragic event for all those involved: the family members who, distraught by grief, can lose their sense of purpose and modify their behaviour, role and perspectives; the healthcare providers who are called upon to address the child's complex care needs in a situation where professionalism, ethics, deontology and practice must reckon with personal emotions, experiences and fears.

This situation often elicits reactions of anger, escape or denial, accompanied by unjustified and unrealistic faith in the competencies of medicine and, occasionally, detached acceptance of what is happening. However, it is the children who pay the highest price; they endure and cope directly with the burden of incurable illness and death, the trauma of separation, the loss of their future and often they must endure the consequences of their condition, their fears and emotions alone.

Sometimes, the people closest to them refuse the negative progression of the disease and, consequently, do not recognize terminal illness and death as real and imminent issues to be addressed. As a result, these children are subjected to unrealistic decisions and treatment choices. More frequently, although fully aware of the reality of the situation, caregivers try to "protect" the child from a truth that they consider too difficult and painful to cope with by avoiding it in conversation, justifying it as the price to pay for an imaginary "better" future or, despite the obvious state of affairs, blatantly denying it.

In both these cases, even if the "protagonist" is the child, he/she becomes the "object" of treatment, care and love and is deprived of the right as a "person" to be able to speak out, decide, express and discuss personal feelings, wishes, hopes and deepest fears.

It is certainly not an easy problem to address; the causes conditioning and influencing behaviour and choices are complex and deep-rooted. However, the difficulties encountered in addressing this problem cannot hinder the undertaking nor can they generate doubts and misgivings regarding the rights of these children and the duties of those accompanying and caring for them during the final phase of their life.

The Charter of the Rights of the Dying Child, was drawn up with the aim of highlighting the rights of young patients that age, condition, culture, location and time cannot, and should not, undermine. To each right corresponds a series of duties: the Charter describes and defines them, endeavouring to combine all the professional, ethical, legislative and research aspects.

Medical publications, philosophy, ethics, religion, psychology and legislation, all propose rights, recommendations and strategies, offering solutions and explanations for what occurs. However, this body of knowledge often remains detached from the actual clinical, familial and social context in which the child lives and eventually dies, and is often irrelevant to individual cases.

The purpose of the Charter is to provide an easily comprehensible tool that proposes elements for consideration and conduct; to offer suggestions and solutions aimed at safeguarding the child's rights and dignity in any setting or situation and which can be applied in any clinical or environmental circumstances.

The Charter is based on an extensive review of official documents, research papers and related literature; the plurality of sources and contributors ensures a comprehensive vision of both the rights and the relative duties.

The first part of the Charter includes a glossary providing the definition of key terminology used in the document of which the semantic meaning must not be interpreted as absolute and all-embracing but rather applied to the child's reality and end-of-life situation.

The second part lists the 10 rights of children who are approaching the end of their lives. To each right corresponds a series of duties.

For each right and relevant duties, there are explanatory notes for their correct interpretation and application.

These are based on a synthesis of the norms and indications proposed in the most important and pertinent national and international documents and in publications listed in the references located at the back of the document.

The Charter analyses the needs of the dying child, defines his/her rights and indicates how to address his/her physical, psychological, relational, ethical and spiritual needs as well as those of the family and other persons who are close or provide care. It emphasizes that dying does not undermine a person's rights; on the contrary, the fragility and complexity of the child's condition increases the importance and allows no room for denial. The document reaffirms the centrality of the child, re-establishing a role that is often not recognised.

Franca Benini, Roberta Vecchi

DEFINITIONS

The terms used in this Charter for the Rights of the Dying Child are defined below:

Child: Every human being below the age of 18 years unless, under the law applicable to the child, majority is attained earlier. This term refers to an extensive range of individuals in every phase of life.

Family: Parents, siblings, other family members and any persons who share the responsibility of care and/or of the physical, psycho-social and spiritual development of the child or is close in care and affection. This term also includes legal guardians.

Care team members: All healthcare professionals providing care for the patient at home, in hospital or in hospice.

Dying child: Any child who is in the terminal phase of life when death is inevitable.

End-of-life: The period before death during which the clinical condition is severely compromised and changes in vital signs indicate that death is imminent.

Legal capacity: The possibility of every human being to exercise rights and responsibilities. By existing every individual possesses this capacity regardless of the duration of his or her life.

Capacity for discernment and decision-making: The patients' capacity to freely express opinions on issues that concern them; children's age and maturity should be taken into account.

Paediatric Palliative Care: The active total care of the body, mind, and spirit of the child and family. It requires a broad multi-disciplinary approach that alleviates the child's physical, psychological and social distress. It includes family members, and makes use of available community resources.

Quality of life: The subjective perception of one's life in the socio-cultural context and in the context of the values belonging to the environment in which he/she lives and in relation to his/her own needs, desires, concerns, expectations and goals.

Pain: A sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. The term, therefore, expresses not only physical pain, but also the suffering that accompanies it and that is generated, maintained and persists even in the absence of tissue damage.

Palliative/terminal sedation: A carefully targeted therapy aimed at controlling, reducing or eliminating the suffering due to intractable symptoms: it involves the pharmacological reduction of awareness, even to unconsciousness.

CHARTER OF THE **RIGHTS**
OF THE **DYING CHILD**

EVERY DYING CHILD
HAS THE RIGHT:

- 1 To be considered as a 'person' until death regardless of age, location, condition and care setting.
- 2 To receive effective treatment, through qualified, comprehensive and continuous care, for pain and for other physical and psychological symptoms causing suffering.
- 3 To be listened to and properly informed about his/her illness with due consideration to his/her wishes, age and ability to understand.
- 4 To participate, on the basis of his/her abilities, values and wishes, in care choices regarding his/her life, illness and death.
- 5 To express his/her feelings, wishes and expectations and have these taken into consideration.
- 6 To have his/her cultural, spiritual and religious beliefs respected and receive spiritual care and support in accordance with his/her wishes and choices.
- 7 To have a social and relational life suitable to his/her age, conditions and expectations.
- 8 To be surrounded by family members and loved ones who are empowered in the organization and provision of the child's care and who are supported in the management of the emotional and financial burdens that arise from the child's condition.
- 9 To be cared for in a setting appropriate for his/her age, needs and wishes, and that enables the family to be close and involved.
- 10 To have access to child-specific palliative care services that respect the child's best interest and avoid both futile or excessively burdensome practices and therapeutic abandonment.

1 TO BE CONSIDERED AS A 'PERSON' UNTIL DEATH REGARDLESS OF AGE, LOCATION, CONDITION AND CARE SETTING

A child is a person in every respect in any phase of life.

IT IS A DUTY

To respect the child's personality, individuality, values, life-history and daily routine by providing appropriate support that enables the child to feel alive and present until the end-of-life.

To always safeguard the child's dignity through respectful behaviour even if the child is in a state of partial or complete unconsciousness due to the progression of the disease and/or treatments.

1

EXPLANATORY NOTES

A child is legally considered as a person at every phase of life and is consequently entitled to rights such as the right to life, healthcare, education, protection, equality, employment, respect for individual and family privacy, freedom of expression, religious beliefs and protection from discrimination.

These rights, as defined by legislation, institutional protocols and international conventions, which acknowledge the child's entitlement to effectively exercise his/her rights when he/she can demonstrate adequate capacity of discernment, are not conditioned by age, residence, context, ethnicity, nationality, culture, disease or conscious state and should be fully respected.

However, this rigid approach is historically designed to regulate legal or patrimonial issues and is thoroughly inadequate for personal matters, such as the right to healthcare. In the case of healthcare, the child's full status as "person" does not depend on having attained any specific level of physical or cognitive functioning, nor on his/her present or future capacity to reason like an adult, neither does it depend on the child's psychophysical qualities.

Therefore, the obligations toward a dying child flow from his/her relationship with caregivers, particularly with the family and healthcare team. The rights, as defined in this charter, should be considered as correlative to the duties imposed by those obligations.

2 TO RECEIVE EFFECTIVE TREATMENT, THROUGH QUALIFIED, COMPREHENSIVE AND CONTINUOUS CARE, FOR PAIN AND OTHER PHYSICAL AND PSYCHOLOGICAL SYMPTOMS CAUSING SUFFERING

Children, regardless of age, experience all the aspects of illness and death. They have the right to receive comprehensive healthcare that effectively addresses all their clinical, psychological, social, ethical and spiritual needs.

IT IS A DUTY

To provide palliative care services delivered by dedicated and appropriately trained multi-professional and interdisciplinary care teams.

To train caregivers not only in their specific professional skills, but also to be capable of working as part of a team and to be aware and respectful of the ethical principles underlying this type of care.

To assess the presence and level of pain and other symptoms causing suffering using specific tools adapted to the child's age and condition.

To provide effective prevention for foreseeable symptoms and, with particular attention to pain, effective treatment for those already present.

To propose therapeutic strategies that respects the child's autonomy, dignity, social life, circadian rhythms and privacy and that avoid futile, invasive, painful and burdensome procedures.

To prescribe palliative/terminal sedation when symptoms become unresponsive to treatment.

2

EXPLANATORY NOTES

Children are constantly undergoing physical, cognitive and emotional changes and this can affect every aspect of care delivery. Therefore, any assessment and treatment must be adapted to the child's age, physical and cognitive development. When possible, healthcare strategies and choices should be shared with the child and family.

Almost all dying children suffer from at least one symptom that undermines their quality of life and 90% of them experience major overall suffering.

Moreover, in the end-of-life phase, clinical symptoms are multiple; they can be interrelated and complicated by significant psychological and emotional aspects.

Therefore, it is vital that the child's clinical and psychological needs are continuously assessed and that pharmacological and non-pharmacological therapeutic strategies and interventions are implemented in order to prevent the onset, to control and avoid the burden of physical and psychological suffering.

The child's and family's quality-of-life, their wishes and care decisions should be taken into due consideration.

However, it must be acknowledged that there may be conflicting opinions with the family and among professionals concerning the most appropriate treatment choice.

In these cases, the cost/benefit aspects of treatment, in terms of real or perceived invasiveness and suffering, should be carefully evaluated and the child's "best interest" should prevail.

3 TO BE LISTENED TO AND PROPERLY INFORMED ABOUT HIS/HER ILLNESS WITH DUE CONSIDERATION TO HIS/HER WISHES, AGE AND ABILITY TO UNDERSTAND

The child should receive appropriate information about his/her illness, its trajectory and proposed treatment.

It must be considered that children have their own particular understanding of death which is conditioned by many factors. These include: the child's age and maturity; the nature and progression of the disease; the family's culture, customs, beliefs, socio-cultural context and relationships.

IT IS A DUTY

To communicate with the child providing understandable information about diagnosis, prognosis and treatment in a way that permits an on-going dialogue and allows time and space for listening.

Essential aspects of communication are:

1. to duly consider all the factors that can influence the child's understanding of life and death;
2. to evaluate the child's capability to understand and willingness to be informed;
3. to share decisions with the family, particularly concerning the choice to inform the child;
4. to reach an agreement within the care team concerning methods and content of communication;
5. to tailor both verbal and non-verbal communication to individual circumstances/needs;
6. to give easily comprehensible information and answers that foster realistic hope and provide reassurance about the future perceived by the child and that allow time and space for questions (about illness, trajectory, adverse events).

3

EXPLANATORY NOTES

Providing adequate information to patients is a duty of clinicians and is a fundamental component of care. Accordingly, children have the right to be informed about their state of health when this is permitted by their age, cognitive development, capacity of discernment and clinical condition.

The information provided must be tailored to the child's age, clinical situation and cognitive development, as well as his/her expectations and wishes. The child should be allowed to decide and indicate by who, where, how and what information is provided.

A child must be given appropriate information that helps him/her to understand what is happening and to contextualize proposed treatments. It is fundamental that there is clear, open and continuous dialogue that gives comprehensible answers to all the questions asked by the child.

Communication must leave room for hope and should focus on achievable goals and desires.

Those who communicate with the child should not make assumptions, nor preconceived judgments related to the child's age, situation or capacity to understand. They must continually check that he/she has fully understood the information provided and that no aspect has been left unclear.

Withholding information or giving evasive answers, generally considered as "protective" and "caring" behaviour, is instead the expression of the families' and the clinicians' fear of having to discuss a distressing topic: it represents a form of defence or escape from a situation that is difficult to manage from both a human and professional point of view.

Evasive answers can cause fear, anxiety, distress, feelings of loneliness, isolation and lack of understanding; this damages relationships and the quality of remaining life.

4 TO PARTICIPATE, ON THE BASIS OF HIS/HER ABILITIES, VALUES AND WISHES, IN CARE AND TREATMENT CHOICES REGARDING HIS/HER LIFE, ILLNESS AND DEATH

Even if the child is a person in all respects and is entitled to fundamental rights such as the right to life, dignity, freedom of expression and equality, it must be considered that the capacity to autonomously exercise such rights is acquired progressively with age and maturity, and that it is affected by many other factors as discussed in Right n 3.

IT IS A DUTY

To listen to the child and offer opportunities for verbal and non-verbal expression concerning the possible choices and treatment options regardless of his/her age.

To bear in mind that the child is a member of a family and to be aware of the way in which decisions have been taken by the family and will probably be made in the future.

To consider that, in the case of very young children, if properly supported, parents are an essential aide for understanding the child's wishes and treatment preferences.

To recognize that parental authority gradually diminishes as the child's competence increases.

To endeavour to resolve possible divergences between the child's wishes and those of the family bearing in mind that the child's "best interest" must prevail.

4

EXPLANATORY NOTES

The child's wishes and expectations must be investigated and taken in due consideration in relation to care choices and treatment programmes affecting him/her.

Children have the right to healthcare, physical integrity and self-determination, even if there are no specific rules on how to actually exercise these rights.

The problem, therefore, is how to ensure the exercise of these fundamental rights in the various childhood stages that are characterized by very different levels of physical, cognitive, relational and experiential development.

In neonates, infants and young children there is a substantial inability to fully understand and process what is being communicated and to verbally express what they have perceived; therefore, autonomous decision-making cannot be acknowledged.

In older children, the development of comprehension, processing and communication skills allows the acknowledgement of a certain decision-making capacity even before the child's coming of age. However, this should be evaluated on a case-to-case basis depending on the child's level of cognitive and relational development.

Other factors, as indicated in Rights n. 1, 2 and 3, should also be taken into account.

5 TO EXPRESS HIS/HER FEELINGS, WISHES AND EXPECTATIONS AND HAVE THESE TAKEN INTO CONSIDERATION

The child must be allowed to express all emotions and feelings experienced during the illness and in the final stages of life. The family and healthcare team must be able to recognize them, accept them and provide appropriate answers.

IT IS A DUTY

For family members: to be able, within their specific aptitudes and competencies, to provide the child with emotional support and to recognize both expressed and unexpressed feelings, wishes and expectations.

For the healthcare team: to be trained, according to their professional role, to recognize, value and support the child's feelings and emotions.

For people close to the family: to help them to support the child and protect his/her vulnerability.

To help the child live daily life with his/her own projects and expectations and encourage him/her to express interests and emotions through activities such as art, music, play, etc.

5

EXPLANATORY NOTES

Children have the right to express their views regarding their daily lives. Such expression is synonymous with personal respect and freedom.

International legislation, national constitutional and specific laws focus on the involvement of children and the possibility of sharing all choices that regard them as active individuals capable of conceiving and expressing valid opinions.

Accordingly, children must be allowed to express views, choices and expectations that affect their daily lives, as well as their feelings, emotions and concerns that they inevitably experience in the end-of-life phase.

When interacting with the child, special attention should be paid to the significance of body language and non-verbal communication.

Caregivers must also be aware of their own emotions evoked by caring for a dying child and keep them under control.

6 TO HAVE HIS/HER CULTURAL, SPIRITUAL AND RELIGIOUS PRINCIPLES RESPECTED, AND RECEIVE SPIRITUAL CARE AND SUPPORT IN ACCORDANCE WITH HIS/HER WISHES AND CHOICES

Regardless of nationality, ethnic, cultural or religious background, the child's cultural values must be respected, without infringing on the child's best interest. He/she must be encouraged to remain an integral member of the original family unit.

IT IS A DUTY

To consider the best interest of children of all ages and in all circumstances, in a way that respects and sustains the cultural, spiritual, religious and family values, which are the mainstays of individual identity.

To allow the child and family to express their emotions and suffering according to their own culture and religion.

To use cultural mediators to ensure that the child and family of any ethnic group or language can properly express their needs.

To be aware of and support the child and family's spiritual needs according to their cultural models and ethnic traditions.

To create, during the final stages of illness, an environment/setting where the child and family can live and express their practices and rituals linked to death and mourning, in accordance with their cultural and spiritual orientation.

6

EXPLANATORY NOTES

Children belong to a community that is defined by ethnicity, language, religion and culture. These aspects should be respected and children encouraged to maintain all the characteristics and practices that distinguish their family, values, beliefs and views.

Any form of discrimination based on ethnicity, nationality, religion, economic/social status and illness must be avoided.

If requested, the child and family should be provided with appropriate spiritual support that helps them to cope with the many complex issues linked to terminal illness and death.

7 TO HAVE A SOCIAL AND RELATIONAL LIFE SUITABLE TO HIS/HER AGE, CONDITION AND EXPECTATIONS

All of us live as part of a society with social interactions and relationships with other people that are essential to life and personal growth. All children, even those who are very young and critically ill, have social needs that must be recognized and properly addressed so that they do not feel abandoned, become isolated and experience a 'social death' in anticipation of their 'physical death'.

IT IS A DUTY

To encourage and reinforce the child's interaction with his/her environment through appropriate planning and organization.

To facilitate and maintain the child's relationships through the rehabilitation, support and reinforcement of his/her motor, sensory, cognitive, communicative and social skills.

To offer the child appropriate recreational tools, settings and activities, and create opportunities for play and social interaction.

To allow the child to continue his/her educational process, either through school attendance or other educational and cultural activities.

7

EXPLANATORY NOTES

From an early age, children are interactive beings who have a role in society: they participate and contribute in their own way to the community life and grow up within their social group.

The diagnosis of an incurable disease is burdened with many challenges that restrict social activities and relationships; this can significantly increase the child's distress and perception of isolation with a negative impact on the child's and family's quality of life.

The network of family, friends, school, local community and patient associations is an important therapeutic instrument that should be utilized as it can offer the critically ill child important opportunities for play, social interaction and growth.

School also plays an important role for the seriously ill child.

Teachers should become full members of the care team; they should be able to tailor educational/ learning or recreational activities proposed to or requested by the child to his/her physical, mental and emotional resources, thus helping to maintain normality.



TO BE SURROUNDED BY FAMILY MEMBERS AND LOVED ONES WHO ARE EMPOWERED IN THE ORGANIZATION AND PROVISION OF THE CHILD'S CARE, AND SUPPORTED IN THE MANAGEMENT OF THE EMOTIONAL AND FINANCIAL BURDENS THAT ARISE FROM THE CHILD'S CONDITION

For children the presence of parents, siblings, family members and loved ones is essential to maintain and promote their well-being, to protect them and to satisfy their need to feel loved.

IT IS A DUTY

To respond to the child's need for the presence of family members and loved ones, in accordance with his/her wishes.

To provide the family with constant, timely, detailed information about prognosis and the clinical situation.

To listen to, educate and support the parents in caring for their child, helping them to maintain their parental role.

To provide all the family members, including siblings, with the necessary psychological, emotional and spiritual support throughout the disease process, death and into bereavement.

To help the family to overcome any financial, social and employment issues, including access to legal support, even through the involvement of voluntary associations and charities.

8

EXPLANATORY NOTES

The child has the right to a family life. The nearness of parents, siblings, relatives and loved ones improves the child's quality of life, stimulates and promotes "normality" and increases the child's sense of security and involvement. However, in the best interest of the child, there may be exceptions that should be recognized.

Coping with a child's terminal illness and death is extremely difficult for parents; anxiety and despair generate feelings of helplessness, frustration and grief, sometimes triggering behaviour such as escape, neglect, irresponsibility, aggression and conflict, both within and outside of the family.

As a consequence of the critically ill child's needs, the normal roles of the family members are transformed and their goals, behaviour and boundaries change; social isolation and financial difficulties may also become an issue.

The family, particularly the parents, are an integral and active part of the child's care team: they are delegated a significant part of the child's care and are frequently responsible for managing medical treatments and providing psychological support (especially if the child is at home). To avoid the burden of excessive responsibility on the parents, these duties should be alleviated through round-the-clock support from experienced and empathetic staff.

Siblings also have to cope with the child's illness and suffering. Unfortunately, they can be forgotten, isolated or neglected and sometimes even removed from the family unit because the critically ill child's needs have precedence.

At the time of death, the family must be helped to gradually accept separation from the child and encouraged to participate in the rituals of preparing the body for burial. The way in which this phase is managed can significantly impact the families' ability to cope with bereavement.

It is preferable that after the child's death, a member of the care team maintains a rapport with the family to support them through bereavement and to help them evaluate the care and treatment choices made during the course of child's illness, with access, for those who need it, to specialized bereavement support.

9 TO BE CARED FOR IN A SETTING APPROPRIATE FOR HIS/HER AGE, NEEDS AND WISHES, AND THAT ENABLES THE FAMILY TO BE CLOSE AND INVOLVED

The care setting has a significant impact on the life of the child and family.

IT IS A DUTY

To allow the child and family to choose the care setting for end-of-life care.

To ensure the same quality of care and support, regardless of the setting, by providing flexible interventions adapted to the different circumstances.

Whenever possible, to propose and facilitate end-of-life care in the family home with appropriate support for coping with the child's illness and death.

If care delivery in the home is not possible, to ensure that the child is cared for in a setting appropriate for his/her age that permits the constant presence of family members and loved ones.

9

EXPLANATORY NOTES

It is important that the child and the family can choose the setting for end-of-life care and that the care team supports this choice.

Generally, for children, as for most patients, the preferred place of care is the family home; however, this may not be true at the end-of-life or dying stage of the disease.

Whenever care delivery in the home is neither practicable nor desired by the child and family, the best alternative solution is the children's hospice.

The children's hospice is a dedicated residential structure that offers, in a family-oriented child-friendly environment, a valid alternative to care delivery at home or in hospital, where a specialised and experienced team can provide constant and appropriate care and support.

Where hospitalization is unavoidable, a setting and type of care that is in line with the fundamental principles of paediatric palliative care, must be ensured.

10 TO HAVE ACCESS TO CHILD-SPECIFIC PALLIATIVE CARE SERVICES THAT RESPECT THE CHILD'S BEST INTEREST AND AVOID FUTILE OR EXCESSIVELY BURDENSOME PRACTICES AND THERAPEUTIC ABANDONMENT

Caring appropriately for a child during the end-of-life phase is a challenging balance between therapeutic abandonment and over-zealousness. Child-specific palliative care services can provide an appropriate solution to this problem.

IT IS A DUTY

To ensure access to palliative care expertise that is specific to the care of children and that continues to provide healthcare support, even when a cure for the underlying condition is no longer possible.

To ensure that medical interventions are only carried out when the benefits to the child plausibly outweigh the adverse effects.

To ensure continuity and quality of care provision between care-settings (home, hospital, hospice).

To avoid inappropriately invasive or burdensome treatments that negatively impact the child's quality-of-life and/or unnecessarily prolong suffering and the dying process.

10

EXPLANATORY NOTES

As specified in numerous publications and documents, children must be able to access child-specific palliative care services.

The World Health Organization defines Paediatric Palliative Care as “The active total care of the body, mind, and spirit of the child and family. It requires a broad multi-disciplinary approach that alleviates the child’s physical, psychological, and social distress and includes family members, as well as available community resources.”

It begins when the diagnosis of an incurable illness is made, it continues regardless of whether or not a child receives treatment directed at the disease and requires a multi/interdisciplinary approach. The family home represents the ideal care setting, integrated, when necessary, by the children’s hospice.

The principles of palliative care are:

- 1 to improve the child’s and family’s quality of life;
- 2 to engage the child and the family in the identification of needs;
- 3 to provide all the necessary medical, psychological, supportive, cognitive, educational, recreational and teaching resources;
- 4 to guarantee round-the-clock care delivery by an array of qualified and complementary, specialised healthcare professionals.

It requires appropriate training, time, patience, and dedication.

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