

**EDITORIAL**

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**Decision making in extreme situations involving children: withholding or withdrawal of life supporting treatment in paediatric care. Statement of the ethics working group of the Confederation of the European Specialists of Paediatrics (CESP)**

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**Introduction**

Paediatricians increasingly find themselves in situations in which decisions must be made regarding withholding or withdrawing life-supporting treatment in the care of a paediatric patient. There comes a point when the artificial prolongation of life only contributes to extending the act of dying and with it the suffering of the patient, parents/guardians, family, and caregivers. Life is the most precious gift. Every person, every child, has the right to live. Similarly, every person, every child, has the right to die with dignity. The paediatrician has an obligation to each patient to preserve life, promote health, and treat illness. In recent years the capacity of medicine to prolong life has increased exponentially. In situations that are extremely burdensome, and where there is no chance for effective therapy, the paediatrician has an obligation to protect the dignity of the patient in the act of dying.

**Questions**

The question of how to act regarding the withholding or withdrawal of life-supporting treatment in extreme situations with paediatric patients poses itself with increasing frequency on the paediatric profession. In order to address this question in an ethical manner, prior questions need to be answered:

1. Who should be included in the decision-making process and how? In paediatrics the 'who' is never a single person.

2. What is the wider context of treatment? The object of the paediatrician's care is the child-patient, but he or she must be treated within a wider context of personal relationships – parents/guardians, siblings, caregivers, and many others.
3. Whose interests need to be considered in the decision? The interests of the patient must prevail, but these interests need to be considered within a wider context, including the concerns of the family, healthcare professionals, the institution, and society in general. The requirements of law must be taken into account.
4. What is in the best interest of the patient? What would the patient himself or herself want? These questions are especially difficult regarding infants, younger children, and children who are mentally or physically impaired: they often need to be approached according to principles, such as benefit or non-maleficence, e.g., not being in pain, not being cold, hungry, abandoned.
5. What circumstances lead to the decision not to preserve life by all means? The specific circumstances of the individual patient must be fully considered in all cases.

**Evaluating Circumstances**

The evaluation of circumstances that may call for the decision to withhold or withdraw life-supporting treatment in the care of a child-patient requires of the paediatrician the highest competence in diagnosing the condition of the patient, the willingness to seek consultation among peers, the team of caregivers, the family,

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and others, and the determination to act according to the highest ethical principles.

The decision to withhold or withdraw life-supporting treatment may be considered in the following circumstances:

1. Life can only be supported with permanent measures that are unbearably burdensome for the paediatric patient; or,
2. Life-supporting treatment imposes continued unbearable suffering without the prospect of recovery and without the prospect of significantly reduced suffering.

In the following circumstances it is the paediatrician's duty not to preserve life by all means:

1. When the patient's death, despite optimal treatment with presently available treatment, is imminent and his or her suffering is severe; or,
2. When the patient could survive only with intensive care measures that impose prolonged unbearable suffering; or,
3. When the patient may survive for some period of time without intensive care, but whose suffering, despite adequate palliative care and treatment, is judged by the paediatric patient, or those entitled to speak for him or her, to be unbearable.

The boundaries between the obligation to continue treatment, the time when treatment may legitimately be stopped, and the time when discontinuing treatment promoting comfort only is ethically advisable cannot be clearly defined in advance of cases presenting themselves. Establishing in advance generally agreed guidelines by paediatricians for paediatricians and others may, however, provide an objective standard to assist decision-making in specific cases. The guidelines cannot determine how to act in individual instances. This can only be decided by the conscience of the care-giving paediatrician in a decision-making process that must always involve others, the patient being given priority.

#### Guidelines

1. The withholding or withdrawal of life-supporting treatment may be justified in extreme situations indicated by the circumstances described above. Primary attention should be paid to the ascertainable wishes and feelings of the child. The paediatrician should not withhold or withdraw life-supporting treatment against the express will of the patient.
2. Actual or potential physical or mental disability is not itself a reason to withhold or withdraw life-supporting treatment. Disability is fully compatible with a life of quality.
3. Financial or resource issues should not weigh on decisions to withhold or withdraw life-sustaining treatment for children. Healthcare systems should make available life-supporting treatment in all cases so that

decisions can always be based on the best interest of the patient.

4. The decision to withhold life-supporting treatment and the decision to withdraw life-supporting treatment are considered to have equal ethical value. Either decision requires a full justification in each individual case.

5. When withholding or withdrawing life-supporting treatment is considered, all remediable causes for the child's condition should be excluded. Second opinions should be obtained and documented in all cases. In some cases the opinion of an ethics committee might be sought. While the paediatrician must be accountable for his or her actions, the decision should be one in which the child, the parents/guardians, and the other members of the healthcare team are fully involved.

6. Each decision must be made according to the circumstances of the case in partnership with the child, the parents/guardians, the family, and the entire health care team. Who is entitled to speak on behalf of the child will vary with the circumstances and may depend on the age, gender, and social background of the patient. The child should be informed whenever possible and be as fully involved in the decision-making process as possible. In the case of disagreement between the child and the parents/guardians, the duty of the paediatrician is to ensure that the decision reflects the best interest of the patient. In the case of a child too young to speak for himself or herself, the views of the parents/guardians must be given great weight in the decision-making process. However, the paediatrician has the duty to ensure that the decision remains that which is in the best interest of the patient. If there is disagreement, legal advice may be required. Frank, open, and frequent communication between the patient, the family, and the care team is essential for arriving at a sound decision.

7. Good ethics necessitates good facts. Adequate information must be available to establish a secure basis for decision-making regarding the commencement or continuation of life-supporting treatment in extreme situations. A decision should be made by a healthcare team that has access to all available evidence. The paediatrician, as a member of this team, must be certain that the diagnosis, prognosis, and alternative courses of therapy have been thoroughly explored and discussed. A decision should never be rushed. When there is serious doubt regarding what is in the best interest of the patient, the decision should favour supporting, sustaining and promoting the life of the child. Any decision by a paediatrician to withhold or withdraw life-supporting treatment should be fully documented and made available for institutional and/or peer review.

8. Withholding or withdrawing active life-supporting treatment must be coupled with maximum palliative care, including social and psychological care. The child should be nursed in an optimal environment – at home if possible – and surrounded by familiar staff and family. He or she should not suffer from hunger, thirst, or pain. The quality of the patient's life must be maintained at

the highest possible level. Effective alleviation of pain and other distressing symptoms is mandatory.

9. The dying child, as well as the family, needs full, sympathetic, culturally sensitive social and psychological support. Bereavement counselling and caring for the dying child should be part of the training curriculum for physicians specialising in paediatrics. Religious belief as well as cultural customs must be respected and facilitated.

10. Paediatricians reject the intentional ending of the life of a child by the administering of a lethal dosage of medication. Treatment to relieve the suffering and to support the dignity of life in hopeless situations that may shorten life – as a side-effect – is acceptable when the intention of this treatment is to benefit the patient and not to end the life of the child.

11. During and after the death of the child, the paediatrician has a duty to ensure bereavement and social support for the family, particularly siblings. Following the death of a child, the paediatrician should arrange to meet the family again to discuss the results of the post mortem examination, to ensure continued bereavement and counselling support, and to direct the family (if they so desire) to support groups and organisations.

12. Schools of paediatric medicine should include training in decision-making regarding the withholding or withdrawal of life-supporting treatment in paediatric care as part of the general curriculum:

### Conclusion

The care, the accompanying, the partnership, and the support of a paediatric patient and his or her family in extreme situations where suffering is insupportable and death near are challenging and complex tasks for the

paediatrician. These tasks represent some of the most important and valuable duties the paediatrician has to the child and his or her family. The professional responsibility of the paediatrician in such extreme situations requires careful attention to the value of life and an ethics of dying. The care for the life of the paediatric patient must be fully supported by a reverent respect for the dignity of that person whose life has been entrusted to the paediatrician.

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### Further reading

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