



# National Association of Neonatal Nurses

## Position Statement #3015 NICU Nurse Involvement in Ethical Decisions (Treatment of Critically Ill Newborns)

### Introduction

Progress has been made in identifying newborns, who despite best hopes and efforts, are not responding to intensive care support. There are groups of children with diagnoses such as extreme prematurity, absence or failure of vital organs, birth accidents, and congenital conditions, whose status, despite extensive intervention, will remain unchanged or deteriorate. There are other newborns in which the prognosis may be less clear and for whom ethical decisions must be made at various stages in their treatment plans. Society has struggled to reach a consensus regarding the appropriate degree of medical intervention and parental involvement in decision-making for these infants as well as the basis on which these decisions should be made. The diversity of our culture, the differing theoretical backgrounds of nurses and physicians, and society's opinions sometimes makes reaching such a consensus difficult.

Parents, neonatal nurses, and other members of the health care team often use the "best interests of the patient" standard when making ethical decisions concerning the treatment of the critically ill newborn. We understand, however that a family will need to assess what is good for the family as a whole when extraordinary demands are made upon them.

### Process of Collaborative Decision Making

1. All infants born should receive an initial assessment, warmth, and comfort.
2. The parents must have access to appropriate, understandable information about the infant's condition, including the potential risks and benefits to the infant of various options for treatment. This includes the risks, benefits, and potential long term sequelae of technology use to keep the infant alive. Preferably this education would begin prenatally, and when applicable, include a parent driven plan.
3. The parents must be able to weigh the risks and benefits to the infant of the proposed treatment and express their wishes based on their own values and the information they possess, and a collaborative effort will be made to address these wishes.
4. All plans of care should have "revisit" points. Reassessment of whether the plan is working to achieve a desired outcome is essential.

In the context of the decision-making process for the critically ill newborn, parents require considerable assistance from the health care team to interpret and process complex information regarding their infant's condition. At times, the uncertainty of the prognosis may well make such interpretation even more difficult. Parents must be included in day-to-day decisions in order to develop an understanding of their infant's changing condition. They must receive the same information from each member of the health care team. Recent developments such as Parents on Rounds and the Parents' Medical Record can assist in this effort.

Parents may have difficulty identifying whether to continue or discontinue certain treatments. They also will need relief from the burden or liability of feeling they have the sole responsibility for any decisions made for their infants. For this reason, a team approach to decision making that includes the parents, health care providers, clergy, and social work is the method most likely to satisfy the requirements of informed consent for infants, who cannot communicate and whose best interests are at stake for all concerned.

### Contributions of NICU Nurses

NICU staff and advanced practice nurses are a constant presence in the lives of the patients in their care. As educators, NICU nurses provide parents with explanations of their infant's treatment and condition that help parents understand the facts they need.

Nurses are in a position both to understand the implications of their patient's medical condition and to become familiar with the customs, feelings, and attitudes of the family. Nurses are most often the first members of the health care team to whom the parents express their wishes. In addition, NICU nurses are asked to implement any decisions made with regard to providing or withdrawing certain treatments.

This involvement in the provision of care and in the support and education of the parents directly involves nurses in the moral dilemmas surrounding such decisions. NANN recognizes the NICU nurse as an essential contributor to the decision-making process regarding the care of the critically ill newborn for whom they provide care and treatment. Interdisciplinary collegiality which fosters respect for nursing contributions will lessen the intensity of moral distress in health care.

### **Association Position**

NANN believes that the process of making ethical decisions in the NICU should incorporate family desires, infant conditions, and the health care team's ability to provide meaningful care. The goal of the team is to obtain a child who will live to enjoy a healthy life. If the child is not viable or will not achieve a life with quality and cognitive ability to relate to others, NICU nurses can provide loving and dignified care that focuses on the quality of time alive rather than the quantity. The dignified care option of palliative care, which provides comfort, symptom management, anticipatory guidance, an appropriate setting and support for the extended family must be available. In questions of nutrition, the risks and benefits of providing or withholding fluids and nutrition is assessed individually. To that end, NANN supports the inclusion of NICU nurses in making ethical decisions in the care of critically ill newborns. In order for nurses to contribute to the decision making process in the most effective manner, NANN recommends education for nurses in the theory and practice of ethics in health care and bereavement support training. NANN acknowledges the right of the bedside nurse to agree or disagree with the parents' or physicians' decisions. Making available a system of bioethical consultation and conflict resolution is essential. Except in extraordinary circumstances the parents' wishes should be honored. NANN encourages the active involvement of nurses in facilitating the decision making process affecting the health of the infant throughout the hospitalization and encourages the transfer to home with nursing support for infants who have a limited lifespan.

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