



# POSITION statement

## Guidelines for the Responsible Utilization of Neonatal Intensive Care

### INTRODUCTION

This paper offers practical guidelines for institutional policies and procedures for the responsible use of neonatal intensive care. The guidelines are intended to support an environment within which the health care team, including parents, can review and discuss the known clinical information, formulate personal and professional opinions, and participate in discussions to reach consensus on the best interest of the infant.

The goals of neonatal intensive care vary depending upon the status of the infant. In some cases, the goal is to return the infant to its normal state of health. Some infants, however, are extremely premature or have defects or conditions where intensive care may only increase suffering, prolong the act of dying, or result in survival with significant burdens. The goal of neonatal intensive care in these situations is to find the balance between undertreating and overtreating the infant.<sup>1</sup>

The paper is intended for health care providers (HCPs), parents, and administrators. However, the information may also be relevant to those interested in the range of clinical, social, ethical, and economic issues that such care presents.

### PROBLEM STATEMENT

Each year over 5000 infants are born in Wisconsin with health conditions that necessitate referral to neonatal intensive care units (NICUs).<sup>2,3,4</sup> These conditions include, but are not limited to, prematurity, low birthweight, congenital anomalies, and other medical issues. For the vast majority of these infants, an appropriate course of care is readily identifiable and resources of the NICU applied confidently to provide comprehensive diagnostic and treatment services. Yet, for a small percent of infants, the appropriate course of care is not apparent immediately.

Several factors impact the most appropriate treatment decisions. First, it is often difficult to predict the short- and long-term benefits and consequences of medical treatment. Second, the determination of benefits and burdens is subjective and value laden. Third, the legal environment may influence HCPs' decisions. Finally, incomplete or inaccurate evidence or economic concerns may preempt other factors necessary for responsible decision-making.

Despite these factors, **the best interest of the infant should be the underlying basis for decision-making.**

Generally, the preferences of the parents should prevail in cases of uncertainty. It is appropriate that involved HCPs and parents frame the discussion for appropriate ranges of treatments for a newborn at the limits of viability and for a newborn for whom it is unclear if a trial of life-sustaining treatment or continuing treatment is in the infant's best interest.

### UTILIZATION OF GUIDELINES

Guidelines can be developed to assist in decision-making where uncertainty and conflicting interests exist. Such guidelines should not become absolute rules, but should:

- Promote the infant's best interest.
- Raise consciousness, stimulate discussion, and provide information.
- Facilitate the process of deciding appropriate treatment.
- Recognize and support individual and cultural diversity.
- Maintain professional standards and the integrity of the goals of neonatal care.
- Encourage thoughtful allocation of resources.

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## COMMUNICATION

Decisions regarding the course of treatment for an infant with a complex medical condition are complicated by the fact the infant cannot speak for her/himself and must rely upon others to consider the “best interest” of that infant. In determining “best interest,” parents and HCPs may have differing perspectives. Consequently, to work toward consensus in the treatment plan, communication between HCPs and the infant’s parents, as the presumed legal decision makers, must be open, ongoing, and occur in a manner that will allow the parents to collect, review, and analyze the relevant information and then make an informed decision. This information should include the medical diagnosis and prognosis, and an exploration of the values that can help determine the meaning of the prognosis, which is what ultimately determines “best interest.”

### Communications between HCPs

The key HCPs, both obstetric and neonatal when necessary, must talk with one another to determine what the treatment issues and options might be. It is optimal to have agreement on treatment options by all members of the obstetric/neonatal team prior to discussion with the family. Differing options of treatments in the infant’s best interest should be presented to the parents so they fully understand the different points of view.

HCP communications should occur at three levels.

**Communications between Primary and Tertiary Care Providers:** All providers should have an understanding of what types of patients should be referred and not referred, how the referral process occurs, what steps are taken to screen and accept the referral, and what the expected course of treatment, discharge, and follow-up might be. These communications should occur prior to a specific patient referral, so the providers can objectively discuss the issues and consider various points of view.

**Communications within the Tertiary Care Team:** In general, hospitals providing high-risk obstetric services and neonatal intensive care should develop guidelines to assist antenatal counseling of women with potential preterm delivery. These guidelines should include both obstetric and neonatal care considerations.<sup>5</sup> Given the multiple needs of the infant and family, and the variety of HCPs involved in the treatment plan, it is important for tertiary care staff to meet frequently to discuss issues and concerns. All members of the health care team should have the opportunity to voice their opinions in difficult situations. If conflicts among HCPs arise, the conflicts should be acknowledged, addressed, and resolved. In many cases, a consultation with the ethics committee may be helpful. If reasonable members continue to disagree, it is typically

because of a value choice. Parents should be informed of the differing opinions so their own values can determine the course.

**Communications with Community Treatment and Support Team:** If an infant is expected to survive with medical, nursing, and other homecare needs, the tertiary care staff should initiate discussions with representatives of the community-based agencies that will work with the family to develop an advance care plan. An advance care plan for discharge clarifies goals, treatments, possible complications, anticipated symptoms, resuscitation status, communication plan, and, if pertinent, plans related to death and bereavement.

In addition to the family’s primary care providers, staff from the local public health department, specialty clinics, and state programs such as the Birth to Three Program, should be included in the discussions. HCPs and parents should discuss what services are expected to be needed, if and where the services are provided, and how the family accesses the services. In addition, all level III and IV NICUs should have a developmental follow-up program to monitor the infant’s progress and provide quality information for the NICU.<sup>6</sup>

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## Box 1.

### Challenges to Communications

1. A family with a child in the NICU is a family in crisis. Family members need information, but may be unable to absorb it all. They may react to information with feelings of fear, anger, sadness, and grief, which may be intensified if there is a lack of information, or if the information is interpreted as inconsistent or contradictory.
2. Health care providers should not make assumptions of parental preferences for practices of faith, tradition, or culture, but should consider information from the family including: pertinent values and family dynamics; potential for support and resources; and preferences for care options or settings.
3. If language barriers are identified, appropriate interpreter services should be used. Family members should never be used as interpreters. In addition, HCPs should explain the role of the interpreter in the discussion and answer any questions or concerns family members have about the process.
4. Parents may experience grief associated with the loss of the pregnancy or child they expected. Parents may have especially strong feelings of guilt if they believe their actions contributed to their child's problems.
5. In some situations, extended family members or spiritual/cultural leaders may be the decision makers for the family or community, but American law vests the ultimate authority to make medical decisions for a child with its parents. In cases in which the parents are not the primary decision makers, it is necessary for HCPs to determine the primary decision makers and include them in the communications with the parents.

### Communications between Health Care Providers and Parents

HCPs must actively evaluate the family's understanding and provide clarification as needed. Parents should be encouraged to express any confusion or lack of understanding. HCPs and parents must acknowledge and address points of divergence or disagreement and resolve conflicts that interfere with communication and decision-making.

#### What Works to Communicate Effectively with Families in the NICU?

HCPs should involve parents as early as possible in initial treatment decisions, preferably antepartum. Early information sharing and consultation helps parents prepare for the NICU experience and decisions that may be required of them, and frames appropriate goals and expectations. It also reinforces parental roles and decreases feelings of helplessness. Care providers should consider having formal guidelines<sup>7,8</sup> and visual<sup>9,10</sup> or written<sup>11</sup> aids to assist with counseling.

## Box 2.

### To support effective communication, HCPs should ask parents about:

- Their preferred methods of learning and sharing: verbal, written, electronic, or online;
- Known cognitive challenges;
- Sensory issues of hearing or sight that might affect effective communication, learning, and sharing;
- Preference for time of day or setting for care conferences or planned communication sessions.

### In addition, HCPs should integrate the following qualities into interactions with parents:

- Sit, make eye-to-eye contact, avoid rushing, and practice responsive listening;
- Acknowledge individual values and style;
- Allow parents to talk and share feelings;
- Demonstrate support and empathy while sharing authority with parents;
- Demonstrate sensitivity to the family's cultural, social, religious, and spiritual perspectives.

# Guidelines for the Responsible Utilization of Neonatal Intensive Care

## Preparing Parents for Complex Decisions

**Counseling during the Course of Pregnancy:** Prenatal consultation between parents and HCPs who may provide care for the infant can promote a trusting relationship and create a supportive environment for critical decisions. This consultation ideally allows HCPs to educate parents about potential outcomes for their infant while providing the parents with the time to explore, determine, and communicate their values and treatment preferences.<sup>12</sup> In addition, for infants with congenital anomalies, multidisciplinary counseling reduces parental anxiety associated with birth.<sup>11,13</sup> Finally, parents and HCPs can determine the optimal place of delivery for infants likely to require neonatal intensive care.

It is important to help parents understand that in the initial minutes and hours after birth there may be a need to make decisions quickly, some with consequences for subsequent treatment or treatment discontinuation. Some parents may communicate their values to the HCPs, and ask the HCPs to consider those values but use their own judgment about the infant's best interest in making decisions that are required urgently. Finally, it is important to stress with parents that occasionally decisions about viability and neonatal management made before delivery may need to be changed.<sup>14</sup>

If there are institutional policies or standards or physician philosophical beliefs that do not allow for the full range of legal options for resuscitation or life support, or if there are limitations in neonatal care services, HCPs should notify the parents to give them the option of a second opinion or the option to transfer care to another facility.

**Counseling at the Time of Birth:** When preterm birth is imminent or abnormalities are not recognized until just prior to delivery, there may not be an opportunity for antenatal counseling with the parents. Unless there is absolute certainty that treatment will not be

in the infant's best interest, resuscitation and a trial of treatment should be started. After the HCPs have collected and analyzed the pertinent information, they should meet with the parents to inform them of the health status of their infant, review what occurred, explain what treatments were and are being provided, and begin to discuss options for future treatment. In many instances, parents need to be informed that despite the best efforts, the ability to give an accurate prognosis for a specific infant, either antenatally or immediately after delivery, remains limited. It is optimal to delay decisions to limit or withdraw treatment until there are accurate data to inform the prognosis.

**Counseling during the Course of Neonatal Intensive Care:** As neonatal care proceeds, it is important to communicate regularly and frequently with the parents about the infant's changing condition. In some circumstances in which the treatment is ineffective or burdens outweigh benefits, it may be appropriate to discuss neonatal palliative and end-of-life care as the primary goal. In this context, care supports the infant's comfort and time with family even when medical treatment is no longer beneficial.

It is important to consider the role that hope may play in parental coping.<sup>15</sup> Parents may appreciate a coexistence of hope with an intellectual understanding of the prognosis. Providers can help a family refocus hope from physical cure to manageable goals. Providers can also acknowledge the possibility of hoping for the best while preparing for the worst.<sup>16,17</sup>

It is important to consider the role that hope may play in parental coping.

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## Box 3.

### What Specific Steps Should Be Taken to Communicate with Families Who Have or Anticipate Having an Extremely Premature or Critically Ill Infant?

#### *Before the Meeting*

1. Arrange a meeting time when both parents can be present and participants will have adequate time.
2. Encourage other key family/support persons to be present if parents desire.
3. Meet in a private area and arrange to be uninterrupted.
4. Have the physicians involved meet jointly with the parents.
5. Have another member of the health care team, such as a chaplain, social worker, or member of the palliative care consultation service, who is skilled in communication present to advocate for the parents' views and rights. Ideally, this person would not have any responsibilities related to the immediate care of the infant.
6. Arrange for interpreter services, if necessary.
7. Consider including the palliative care consultation service, if available.

#### *During the Meeting*

1. Take time to find out what information the parents have already been given, what they want to discuss, and what their values and related assumptions are. Inquire about previous medical experiences and difficult decisions. Allow the family to direct the conversation.
2. Inform parents about their role providing informed permission in the collaborative decision-making process.
3. Review the available medically and ethically appropriate treatment options directly, empathically, and in as unbiased a manner as possible. Discuss morbidity statistics in realistic and specific terms. Avoid medical jargon and vague phrases such as "most babies born this early turn out okay."
4. If possible, provide written information. Encourage the family to take notes, if they find it beneficial.
5. Collaborate with the parents in choosing an initial treatment plan consistent with their goals and values.
6. Be prepared to repeat information and answer parents' questions numerous times. At the same time, do not repeat information in an attempt to persuade them.
7. Be emotionally present and available to the family. Be comfortable with silent periods in the conversation and encourage expressions of feelings (e.g., "How do you feel? It is okay to cry"). Reassess the family's need for information and ability to process information frequently. Remain flexible in content and style of communication.

#### *Follow Up Meetings and Discussion*

1. A single meeting is unlikely to be adequate. Follow-up meetings will be necessary throughout the period of hospitalization, discharge planning, and discharge.
2. Encourage parents to write down additional questions that may arise.
3. Review preliminary treatment plan and the situations that would trigger revisiting the treatment plan.
4. Provide thorough documentation in the medical record of the interaction and any joint decisions made.
5. Evaluate the medical team's communication with each other and the family, provide feedback and support to each other, and teach and learn from one another.
6. Before discharge, discuss ongoing treatment options and follow-up recommendations; available community resources; financial ramifications; and potential implications for family dynamics and resources.

# Guidelines for the Responsible Utilization of Neonatal Intensive Care

## A SCHEMA FOR UNDERSTANDING TREATMENT OPTIONS

Care Category	Possible Examples	Parental Involvement in Decision-making	HCP and Societal Duties
<b>Unreasonable</b>	<ul style="list-style-type: none"> <li>• Infants less than 23 weeks' gestation</li> <li>• Infants with lethal conditions not compatible with life, e.g., anencephaly</li> </ul>	<ul style="list-style-type: none"> <li>• Understand the circumstances and the expected outcome.</li> <li>• Share goals and values.</li> </ul>	<ul style="list-style-type: none"> <li>• No professional or societal obligation to provide intensive care.</li> <li>• Provide comfort and alleviate pain in accord with accepted medical and nursing standards.</li> </ul>
<b>Uncertain</b>	<ul style="list-style-type: none"> <li>• Infants 23-25 weeks' gestation</li> <li>• Infants with severe congenital abnormalities who were resuscitated at birth to allow period of time for observation and assessment</li> <li>• Infants for whom the long term outcome is generally expected to be very poor with significantly impaired ability for social interaction</li> </ul>	<ul style="list-style-type: none"> <li>• Understand the circumstances and the possible limitations of the trial of treatment.</li> <li>• Share goals and values.</li> <li>• Monitor care and prepare for future treatment decisions.</li> </ul>	<ul style="list-style-type: none"> <li>• Care and treatment is made available and provided in a manner such that the burden/benefit ratio is continually assessed.</li> </ul>
<b>Mandatory</b>	<ul style="list-style-type: none"> <li>• Infants greater than 25 weeks' gestation</li> <li>• Infants with abnormalities that are not expected to result in impairments that would profoundly compromise their capacity for social interaction, e.g., most cases of neural tube defects, trisomy 21</li> </ul>	<ul style="list-style-type: none"> <li>• Understand the circumstances and the obligation to provide care and trial of treatment.</li> <li>• Share goals and values.</li> </ul>	<ul style="list-style-type: none"> <li>• Obligation to provide care and treatment.</li> </ul>

Adapted from Fleck, Lorenz and Tyson.<sup>18</sup>

The table provides a conceptual framework for understanding the potential ways to categorize neonatal care. Such a framework can assist parents and care providers in understanding that there is a relationship between the severity of a condition within a care category and the corresponding limitations to neonatal intensive care.<sup>19</sup> The categories are not intended to be prescriptive.

When considering infants with gestational ages near the limits of viability, other factors in addition to gestational age, e.g., sex, exposure to antenatal corticosteroids, single or multiple birth, and birth weight, may also affect prognosis and can affect decisions related to resuscitation.<sup>20,21</sup> In addition, there are limitations of gestational age assessments in general and in particular by the neonatologist after birth.<sup>22</sup>

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## FUTILITY

Despite the difficulty defining “futility,” the use of the term in the NICU suggests that the term has a purpose. Minimally, the use of the term can serve as a focal point for discussions between HCPs and parents. In that capacity, it can give HCPs the opportunity to consider and define their own understandings of futility, while giving families the opportunity to share their own narratives about their children, their understanding of purposefulness in life, and acceptable quality of life.<sup>23</sup>

As the concept of futility is ambiguous, it is reasonable to consider the support that HCPs and families may require as they explore its implications. The function of ethics committees should be to “consider and assist in resolving unusual, complicated ethical problems involving issues that affect the care and treatment of patients.”<sup>24</sup> Ethics committees can provide education and review to help clarify potential benefits and burdens of a range of treatment options.

## CONFLICT RESOLUTION

Conflict over an appropriate course of action may arise in the NICU. Uncertainty over who has authority to make decisions can further exacerbate conflict. In the unusual situation that parents and HCPs are unable to agree on a treatment plan in the infant’s best interest and it is clear that further communication between them will not resolve the conflict, other options can be considered. Options for resolving conflict can include compromising, such as opting not to increase intensive care support beyond the current level or offering a time-limited trial of treatment, receiving a second opinion from other HCPs, transferring the infant to another institution for care, and consulting the hospital ethics committee.<sup>25</sup> As a last resort, parents or health care providers can appeal to the judicial system for resolution. It is important to note that autonomy entails the right to refuse treatment; no patient or parent has the right to demand treatment.<sup>26</sup>

## PALLIATIVE CARE

Palliative care should be offered at any period in which an infant’s life may be limited—prenatally, at the time of birth, and after birth.<sup>27</sup> A comprehensive model of palliative care focuses on quality of life, and permits both curative and comfort interventions.<sup>27</sup> Thus, all infants receiving neonatal intensive care should have concurrent palliative care with attention to comfort; psychosocial, emotional, and spiritual support of parents, siblings, and other loved ones; decisional support and advance care planning; and practical/logistical support, especially with transition to home.

## SOCIETY’S ROLE IN HELPING FAMILIES

Advances in neonatal care have resulted in increasing numbers of critically ill infants surviving the neonatal period to the point of discharge to their families and home communities. A small percentage of infants will live with profound lifelong neurological impairments that include significant developmental, physical, emotional/behavioral, and sensory disabilities. Their survival presents new challenges to families, communities, and society as a whole.

To meet these challenges, society develops service systems and laws that support and meet the needs of surviving infants and their families.<sup>28</sup> The commitment to children can be supported by a number of social philosophical theories, including utilitarianism, egalitarianism, and libertarianism.<sup>29</sup> Ideally, the commitment to children’s health should be a communal ideal, reflecting the recognition of children’s and family’s health to society.

Some of the decisions about utilization of intensive care can only be made with help from society. To help the public make informed decisions about responsible use of neonatal intensive care, the health care community must inform the public about (1) the nature and variety of issues present in the NICU; (2) the extent and effectiveness of treatment and cost; and (3) the difference between life-prolonging, palliative, and futile care.

# Guidelines for the Responsible Utilization of Neonatal Intensive Care

Whatever the reasons that lead to the care and treatment decisions, those decisions, once made, should serve as a commitment to assure that infants and families have the necessary programs, services, and supports to have the most comfortable and meaningful life that is available to them. Determination of the circumstances that surround when that commitment should be made is a matter for continued public discourse.

The Guidelines for the Responsible Utilization of Neonatal Intensive Care, published in 1998, were part of a larger document, the Guidelines for the Responsible Utilization of Intensive Care (GRUIC). The first edition of GRUIC was developed in 1998 through a partnership between the Lawrence University Program in Biomedical Ethics and nine Wisconsin healthcare provider groups including the Wisconsin Medical Society, the Wisconsin Nurses Association, the Wisconsin Association for Perinatal Care, and one community advocacy group, Wisconsin Health Decisions, that supported forums to address timely concerns about health care. This second edition, was reviewed, edited, and revised by experts in obstetric and neonatal care, ethics, and the law to reflect current understanding of the complexity of the issues. The positions taken in the statement reflect the consensus of those who participated, but may not reflect in total, their individual positions.

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Janice Ancona, MSN, RN  
Daniel Bier, MS, MA, CAE  
R. Alta Charo, JD  
Jeffery Garland, MD, SM  
Jennifer Hennessy, JD, MPA  
Cresta Jones, MD, FACOG  
Jeffrey Lamont, MD, FAAP  
Steven Leuthner, MD, MA  
Lauren Lund, MS, RNC

Erika Peterson, MD  
Stephen Ragatz, MD  
Mark Repenshek, PhD  
Tait Szabo, PhD  
Jacquelynn Tillet, CNM, ND,  
FACNM  
Suzanne Toce, MD  
Therese Van Buskirk, NNP, APNP  
Chris Van Mullem, MS, RNC

Sarah Walder, MSN, APNP, NNP-BC  
Donald Weber, MD  
Nancy Wojciehowski, MS, RN

#### **WAPC Staff**

Eva F. Brummel, MPH  
Ann E. Conway, MS, MPA, RN  
Kyle O. Mounts, MD, MPH

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