

Newborn Critical Care Center (NCCC) Clinical Guidelines

Counseling and Management of Extremely Premature Infants

GENERAL CONSIDERATIONS

Assessment of Gestational Age

Pre-delivery counseling is based, in part, on the best obstetric estimate of gestational age. In most cases, gestational age is not more accurately assessed at delivery than before delivery. Although some uncertainty is inherent in all gestational age estimations, this uncertainty is built into the outcome statistics for extremely premature infants. However, suppose the gestational age of a particular infant is more uncertain than usual. In that case, the possibility that the infant may be significantly older or younger than expected should be taken into account when counseling parents and making treatment plans.

Birthweight

Pre-delivery counseling is also based on estimated fetal weight. The possibility that an infant may weigh somewhat more or less than expected should be considered when counseling parents and when making treatment plans.

Assessment of Outcome

Some guidance about expected outcomes of infants born at 22-25 weeks of gestation can be gained by using the online [NICHD Neonatal Research Network: Extremely Preterm Birth Outcome Data](#) estimator (Tyson et al., 2008), recognizing that outcomes have likely improved since that study was published (Kyser et al., 2012) and that more aggressive management strategies likely improve survival for these infants (Rysavy et al., 2015). See [Appendix A](#) for sample outcomes using the NICHD calculator. Additionally, [outcomes from UNC](#), as well as national VON data, are available at [uncnicu.org](#). Expected outcomes of infants born at >25 weeks of gestation are determined using the best available outcome data, as assessed by the counseling physician. Parents often use more than outcome data to make treatment choices and inform their own beliefs about their infant's chance of survival (McDonnell et al., 2023). Prognostic information should only be used as a supplement with careful attention to parental values and goals of care in determining management plans (Arbour & Laventhal, 2022).

COUNSELING

Before delivery, a neonatologist or neonatal fellow will attempt to counsel the parents of all infants <30 weeks gestation for whom intensive treatment is offered. If a parent of an infant >30 weeks gestation specifically requests counseling, this will be provided as time allows. The details and extent of counseling are left to the discretion of the counseling physician, based on the situation and the perceived needs and wishes of the parents. In general, counseling should include discussing expected outcomes, potential clinical course in the NICU, and related treatment interventions. The benefits and burdens of treatment and non-treatment and the uncertainties of any course of action at the infant's early gestational age should be discussed. As risks of death, disability, and suffering in the neonatal period and beyond differ in their meaning and implication, they should be clearly distinguished when counseling parents.

A recommended approach is to use opening questions to **gather information about the family's perspective and values**. For example, stating questions such as, "Why do you think I am here?", "What scares you the most?" and "What are your hopes for your child?" can help start the

conversation to gauge the family's expectations. The provider counseling should assist parents in articulating what is most important to them. When possible and if the mother desires, the consultation should occur with both the mother and her partner (Gaucher et al, 2016). The physician should consider addressing common parental concerns such as the role of a mother of a premature baby, integration of the family into the baby's care, and the NICU environment (Gaucher et al., 2016). The physician should also offer a tour of the NICU if time allows; the charge nurse can accommodate a tour at their convenience when the mother's nurse calls to request it. If possible, parents should be offered additional counseling by the same provider, assuming the mother remains an inpatient and does not deliver. In particular, parents who opt for less aggressive intervention should be revisited for additional counseling as time progresses without delivery and as the anticipated outcome for their infant improves.

Treatment Decisions

Intensive care is necessary for the survival of extremely premature infants, but its burdens and risks are substantial. These guidelines reflect professional and societal views about which medical interventions are likely effective and in an infant's best interest. When treatment's relative benefits and burdens are clear, counseling is directive, and the range of treatment options offered to parents is constrained. When the medical evidence is murky or moral consensus is lacking, counseling is non-directive, and the treatment options offered to parents are more extensive. This supports parents' privileged role as the ultimate decision-makers for their extremely premature infant when reasonable medical or moral disagreement exists. Ultimately, parents' preferences will predominate in deciding whether or not to provide life-sustaining treatment, except when professional and societal consensus overwhelmingly oppose parents' choice as being not medically effective or not in an infant's best interest.

Physician Conscience

Suppose a treating physician is unable to participate in the plan of care for a specific infant for reasons of conscience. In that case, that physician will excuse themselves from the case, and another physician who can carry out the parents' wishes will take over. If, however, the physicians in the neonatal division believe that professional or societal consensus overwhelmingly opposes the parents' decision and they are all unwilling to participate, the attending neonatologist will discuss the case with the hospital's legal office and ethics committee. If necessary, judicial resolution will be sought.

Delivery Room Decision-Making

A neonatologist or neonatal fellow will be present at the delivery of any extremely premature infant who might receive life-sustaining treatment. If an extremely premature infant's gestational age is uncertain or estimated fetal weight places the infant at the border of viability, the decision to initiate treatment may be determined by an assessment of the infant at delivery. Parents should be informed in advance if their preference for providing or withholding treatment might be overridden based on an assessment of the infant at delivery. Other than by clarifying gestational age and weight, *there is no evidence* that a physician can better ascertain the outcome of an extremely premature infant immediately after delivery than immediately before. In particular, "vigor" at birth, as reflected in the one-minute Apgar score, is not an accurate predictor of survival in extremely premature infants and will not be used as a criterion for initiating treatment. There is some evidence that an infant's response to treatment may help with prognostication. If parents request that an early assessment of their infant's response to treatment be made in the delivery room, the neonatologist or neonatal fellow will make that assessment after attempting to resuscitate the infant. Parents of the very smallest infants should be informed that resuscitation may not be

possible for technical reasons (e.g., endotracheal tube size).

Reassessment of Treatment Decisions

Decisions to continue or withdraw life-sustaining treatment initiated at delivery will be reassessed for all extremely premature infants. A neonatologist or neonatal fellow will revisit the decision with the infant's parents regularly if the infant is not responding positively to treatment or at any time when a significant deterioration in medical status occurs. Treatment will be withdrawn if parents and physicians concur that the burdens outweigh the benefits. At all times, infants will continue to receive appropriate comfort care.

PROVISION OF CARE

The following recommendations are guidelines only, not a strict protocol, and are not meant to cover all situations. The gestational ages below refer to completed weeks of gestation. An infant's age should always be rounded down rather than up (e.g. 22^{0/7}-22^{6/7} weeks of gestation = 22 weeks of gestation).

Non-viable infants: < 22^{0/7} weeks of gestation

- OB counsels parents prior to delivery that the infant is too immature to benefit from medical therapy.
- Comfort care (drying, warmth, swaddling) is provided at delivery and continues as long as the infant lives.
- Neonatology need not attend delivery.

Presumably non-viable infants & infants who are highly unlikely to benefit from medical treatment: 22^{0/7} – 24^{6/7} weeks of gestation AND additional factors negatively affecting outcomes

- Neonatology consult should be offered to families with any infant at a gestational age of 22 weeks and above, ideally in conjunction with the OB provider.
- Parents are counseled that mortality or profound disability is virtually certain and medical treatment will not likely benefit the infant. Counseling should be directive, informing parents that only comfort care (drying, warmth, swaddling) will be provided at delivery. Counseling should include clarifying parents' values, understanding, and the reason for their request, and persuade them, based on evidence and values, to accept comfort care only.
- If parents continue to insist on life-sustaining treatment and time allows:
 - Discuss the case with others in the Division.
 - Ask a second neonatologist to counsel the parents.
 - Agree to be present at delivery and to initiate treatment if the infant at birth is different than the prenatal information suggested, with a better prognosis. No treatment will be given if the infant's condition is as the prenatal information suggested.
- Neonatology needs to attend delivery only if life-sustaining treatment may be attempted.

Potentially viable infants who may benefit from medical treatment: 22^{0/7}-24^{6/7} weeks of gestation without additional factors negatively affecting outcomes

- Parents are counseled that their infant is potentially viable and may benefit from medical

treatment, but the burdens and risks of treatment are significant. Both treatment trials of intensive care and comfort care only are offered as options. Counseling ranges from discouragement of therapy to encouragement of treatment, depending on parents' expressed values and the infant's expected outcome. Parents should be reminded that life-sustaining treatment may be transitioned to comfort care measures only after the initial resuscitation if there is a significant change in medical status that portends a high risk of death or morbidity.

- Counseling is ideally done concurrently with the OB provider to present information from both a maternal and a neonatal perspective and help with delivery planning.
- Survival without impairment is substantially lower for children born at < 25 weeks gestation and thus parents' preference for providing or withholding intensive care predominates (Myrhaug *et al.* 2019).
- Neonatology needs to attend delivery only if life-sustaining treatment is to be initiated or if the family requests it.

Presumed viable infants: 25^{0/7} weeks of gestation and greater without additional factors negatively affecting outcomes

- Parents are counseled that their infant is viable and likely to survive without severe morbidity. Counseling should be directive, informing parents that life-sustaining treatment will be initiated at delivery. Parents can be reminded that life-sustaining treatment may be withdrawn after the initial resuscitation if there is a significant change in medical status that portends a high risk of death.
- If parents refuse to consent to the initiation of life-sustaining treatment despite efforts to understand their values and reasons and to persuade them otherwise if time allows:
 - Discuss with others in the Division.
 - Ask a second neonatologist to counsel the parents.
 - Attempt to find an institution willing to provide comfort care only. If one is found and if it is medically safe for the mother, ask the OB to consider maternal transport.
 - Seek ethical and legal counsel from the Hospital's Ethics Committee and Legal Office (if necessary, judicial resolution may be sought).
 - If there is no time for further resolution or adjudication, initiate intensive care (with the option to withdraw treatment later).
- Treatment is provided at delivery.
- Neonatology attends delivery to direct treatment.

References:

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3. Rysavy MA, Li L, Bell EF *et al.* Between-hospital variation in treatment and outcomes in extremely preterm infants. *N Engl J Med.* 2015 May 7; 372(19):1801-11.

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6. Gaucher N, Nadeau S, Barbier A et al. Personalized antenatal consultations for preterm labor: responding to mothers' expectations. *J Pediatr.* 2016 Nov; 178:130-134e7.
7. Myrhaug HT, Brurberg KG, Hov L, Markestad T. Survival and Impairment of Extremely Premature Infants: A Meta-analysis. *Pediatrics.* 2019 Feb;143(2):e20180933. doi: 10.1542/peds.2018-0933. PMID: 30705140.

Appendix: Using The NICHD Estimator – Example Outcomes

* Indicates required field

*Gestational Age

(Best estimate in completed weeks)

23

*Birth Weight

(from 401-1000 grams)

450

* Infant Sex

Male Female

* Singleton Birth

Yes No

* Antenatal Steroids

Yes No

Clear

Submit

Infants Receiving Active Treatment

Average Survival: 26%

Hospital Range: 16 - 39%

All Infants, Including Infants Not Actively Treated

Average Survival: 20%

Hospital Range: 11 - 32%

Outcomes At 18-26 Months' Corrected Age Among Infants Who Survive: (About the Data)

Profound
Neurodevelopmental
Impairment

6 - 11%

Moderate-Severe
Neurodevelopmental Impairment

52 - 78%

Blindness

< 1%

Deafness

5 - 11%

Moderate-Severe
Cerebral Palsy

15 - 22%

Cognitive
Developmental
Delay

46 - 67%

* **Profound NDI:**

- Bayley Scales of Infant and Toddler Development, third edition (BSID-III) cognitive composite score of “untestable,” or
- Gross Motor Function Classification System (GMFCS) level of 5 (most impaired), which represents limited voluntary movement, including an inability to lift the head against gravity.”

* **Moderate/Severe NDI:**

- Cognitive developmental delay, defined as a BSID-III cognitive composite score less than 85 (i.e., more than 1 standard deviation below the standardized mean score of 100)
- Moderate or severe cerebral palsy or GMFCS level of 2 to 5, which means that the infant has some degree of movement limitation
- Legal blindness in both eyes (visual acuity <20/200), **or**
- Severe hearing impairment that could not be corrected with amplification at both ears (the child is not considered impaired if able to follow spoken directions from the examiner)