

## Creation of a Neonatal End-of-Life Palliative Care Protocol

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### OBJECTIVE:

To create a protocol delineating the needs of patients, families, and staff necessary to provide a pain-free, dignified, family-, and staff-supported death for newborns who cannot benefit from intensive, life-extending, technological support.

### STUDY DESIGN:

Using Internet e-mail, a Delphi study with sequential questionnaires soliciting participant response, investigator analysis, and follow-up responses from participants was conducted to build a consensus document. Institutional review was granted and respondents gave consent. Recruitment was conducted at medical, ethics, nursing, and multidisciplinary organization meetings. Synthesis of 16 palliative care/end-of-life protocols developed by regional, institutional, and parent organizations was included. Participants from 93 locations in the US and 4 abroad gave feedback to 13 questions derived from clinical experience and the literature. The data underwent four rounds of analysis with 95% retention of the 101 participants over an 18-month period.

### RESULTS/CONCLUSION:

Specific consensus-based recommendations are presented with a description of palliative care; categories of candidates; planning and education needed to begin palliative care services; relationships between community and tertiary centers; components of optimally supported neonatal death; family care, including cultural, spiritual, and practical needs; ventilator withdrawal, including pain and symptom management; recommendations when death does not occur after cessation of life-extending interventions; family follow-up care; and necessary ongoing staff support.

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### ESTABLISHMENT OF A PALLIATIVE CARE PROTOCOL FOR NEWBORNS

Every year in the US, approximately 15,000 children are born who have conditions that are incompatible with prolonged life beyond the

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first year, or are in fact dying at birth. Most often, these newborns are given resuscitative measures in the delivery room and brought to the neonatal intensive care unit (NICU) for further assessment and treatment. The time may vary for when it becomes clear that a newborn has a life-limiting condition. This may be diagnosed early in the prenatal period, found immediately before the delivery, occur suddenly as a result of a birth trauma, be seen in the delivery room or immediately afterwards, or be clarified after efforts in the NICU.

For many American health care providers, it has been difficult to revise treatment goals from aggressive cure-oriented intervention to palliative care goals. Reasons for this may be due to health care professionals' lack of formal palliative care education in medical or nursing school, their difficulty acknowledging an infant's terminal prognosis, and a possible lack of coping with their own personal spiritual, emotional, and psychological values and feelings about death.

The purpose of this project is to educate professionals and enhance their preparation and support for a peaceful, pain-free, and family-centered death for dying newborns. The protocol of care suggested will help to establish palliative care efforts that are every bit as meaningful, and as clinically and socially acceptable, as the provision of continued life-extending endeavors.

This protocol was prepared by a 101-member panel using the Delphi research method. The data collected included both participant input over an 18-month period and synthesis of 16 published and nonpublished end-of-life protocols<sup>1–16</sup> developed by international, national, regional, institutional, and parent organizations. Many of these protocols were developed after public meetings and public discussion. While contributors to the project have mainly come from the US, it is hoped that the principles and processes discussed may be applicable to those in other countries. A description of the Delphi method, and participant composition, is listed in sidebars.

### WHAT IS PALLIATIVE CARE?

Palliative care for newborns is holistic and extensive care for an infant who is not going to “get better.” Palliative care focuses on both the infant and his/her family. Palliative care may initially be combined with cure-oriented, disease-modifying care and then intensify when that form of care is no longer helpful or appropriate. Palliative care is an entire milieu of care to prevent and relieve infant suffering and improve the conditions of the infant's living and dying. It is a team approach to relieving the physical, psychological, social, emotional, and spiritual suffering of the dying infant and the family.

Palliative care focuses on the prevention and relief of physical pain and suffering for the infant and on relief of existential suffering of the family. It is a planned intervention by trained interdisciplinary staff members who support with dignity the infant's time on earth and support the family's experience with empathy and culturally sensitive respect. The palliative care described here initially refers to inpatient treatment facilities, but it also may be applicable to the outpatient setting. The inpatient setting is initially described as it requires around the clock nursing assessment, physician management, and interdisciplinary support to manage symptoms that could occur in the dying newborn such as pain, difficulty breathing, or seizures.

### PLANNING FOR A PALLIATIVE CARE ENVIRONMENT

Instituting a palliative care program requires planning, training, and commitment from participants. Staff must be familiar with and ready to implement palliative care, support, and symptom management for the infant as well as care for the parents<sup>17</sup> going through a significant life crisis.

Potentially involved staff members (i.e., medicine, nursing, labor and delivery, postpartum, nurseries, child health specialists, developmental experts, case management, hospice, social services, ethics, and chaplain programs) should be involved in the planning. The initial planning group can then be available to educate the rest of the staff. It is recommended that an experienced trainer associated with a group such as the National Hospice and Palliative Care Organization or a nationally recognized bereavement program<sup>18</sup> be involved with the training. There should be a formal education plan for the staff, including both clinical and ethical training in the following areas.

- Alternatives to allowing the newborn to die from his/her condition.
- Long-term outcomes of severely impaired newborns.
- Principles of transition from life-extending care to palliative care.
- Palliative care training from hospice experts, i.e., anticipation and ongoing treatment of symptoms, skin care, mouth care, pain medication, relief of dyspnea, decreased light and noise, use of positioning aids, promotion of self-regulatory measures such as sucking and grasping if infant is able to do so.
- Familiarity with various pain assessment tools<sup>19–22</sup> for use with newborns.
- Information on how to access home care and community resources and how to meet and establish ties with these local services.
- Theories of crisis intervention, grief stages, family dynamics, and stress and coping.
- Plan for conflict mediation — conflict may exist between parents and providers if parents do not believe that palliative care is most appropriate for their infant, or if parents desire palliative care and the newborn presents very differently (e.g., more vigorous) than expected. Conflict may also exist between various members of the

professional staff (obstetricians and neonatologists; neonatal colleagues; surgeons and neonatologists; physicians and nurses), or between the two parents. A plan for facilitated conflict mediation should be in place prior to hospitals initiating a palliative care program.

- Cultural expectations at the time of neonatal death should be taught by members of ethnic and religious groups in the relevant local community. Staff should learn how to best support the cultural and religious needs of various ethnicities, including how to baptize or bless a dying infant and other rites. Several texts<sup>23–25</sup> with cultural information are available.
  - In-service education from the regional organ procurement center that teaches what types of organ and tissue donation are acceptable/desirable in the neonatal population.
  - How an ethics consultation may assist the staff and families.
- Additional considerations when establishing a palliative care service include the following:
- No visiting hour restrictions.
  - Staff recognition of mother's immediate postpartum needs if she has recently given birth.
  - Development of a core staff of nurses from obstetrics, neonatal intensive care, pediatric intensive care, and general pediatrics who wish to provide palliative care. These nurses should receive special training and then be allowed palliative care assignments.
  - Development of a cadre of volunteers who are also interested in this type of care and who can assist the nurses when staffing difficulties preclude one-to-one care.
  - Trained translation staff availability 24 hours a day.
  - Selection and preparation of an area appropriate for palliative care to take place in. A homelike room with soft lights that is large enough to hold extended family is preferred. Clergy should be able to conduct a service in the room. The ideal room would have double recliners and double beds so the parents can lie down with the infant. There would be a kitchenette, use of a camera, an outlet for some music device, nearby access to the hospital chapel, and a nearby large conference or consultation room. A small library with books on grieving and a journal for parents to write in would be helpful.
  - Preparation of an information packet to give the parents after the infant dies, which presents information about grieving. This should include local funeral options, memorials, what to expect in themselves and from others, and how to find help with the grieving experience — such as individual counselors familiar with bereavement work, hospital- or community-sponsored grief groups, and publications<sup>26,27</sup> for parents offering support and information on grieving for their infant.
  - If desired, a review of the palliative care protocol by the ethics committee and legal department may be helpful.
  - A plan should be in place for staff to review palliative care protocols at the time of annual competency training, Neonatal Resuscitation Protocol (NRP) or Pediatric Advanced Life Support (PALS) recertification, or policy and procedure reviews, especially in

smaller facilities that do not provide this type of care routinely. Symptom management, medications, community resources, and home hospice planning should be reviewed annually.

- Inclusion in all new employee orientations and information given to rotating students, residents, fellows, attending physicians, or other medical staff.

## PRENATAL DISCUSSION OF PALLIATIVE CARE

Neonatal palliative care has rarely been a topic of public discussion. It is essential that fetal development and viability be discussed with all families as a part of prenatal care packages and classes and to all families receiving assisted reproductive therapies. As the course of prenatal care progresses, pregnant women should be made aware that newborns in the very early gestational periods of 22 to 24 weeks and birth weights of less than 500 g may not be responsive to resuscitation or applied neonatal intensive care. The influence of the media has allowed many parents to think that all newborn problems can be altered and corrected. When, in the course of prenatal care, a potentially lethal problem is identified, provisional options should be discussed.

### Physician Considerations

- Physicians presenting these data should include both short- and long-term expectations when such is known or available, including the developmental potential of the infant and the potential impact this may have on the family. Parents can be presented with the national and regional standards for care of an infant with this condition and also the local experience with outcomes. Physicians from Level III hospitals, fetal care units, or genetic units should be available for consultation with parents.

- All high-risk couples should be honestly counseled on their options regarding interventions, timing of delivery, use of tocolytics, transfer to or from a high-risk center, Cesarean section delivery, keeping the newborn in the local community versus the high-risk referral center, and the availability of infant hospice support services.

- Early discussion allows time for parents to develop trust in the medical team and tour the NICU where their newborn may be treated.

- Having a pediatrician at the delivery to confirm the diagnosis is appropriate.

- It is noted that time does not always allow for such discussions, as in the event of rapid preterm delivery, a previously undiscovered problem, or a birth-related incident.

### Family Considerations

- Families may wish to talk with other parents who have been given the same prenatal diagnosis and this should be facilitated.

- Encouraging families to make plans for their potentially nonviable infant while in utero is seen as a type of autonomy for the pregnant patient. Giving families control allows them to research the condition and make informed decisions. The family's voice should

define the type of care and options they wish regarding their pregnancy and birth.

- Pregnant mothers and families may need time to notify extended family, arrange for necessary support (family, spiritual, psychological, emotional), prepare siblings, choose a name for the baby, shop for and bring clothing, etc., to the hospital, make funeral and/or memorial service arrangements, and many other tasks of anticipatory grief. This is also time for the hospital personnel to prepare themselves and for the physicians to decide on a plan of care and whether resuscitation is appropriate at the time of birth.

- Sensitive support for families may include comforting pregnant women and mothers who did not plan the pregnancy and who may be accepting, without grief, that it is ending.

## TRANSPORT ISSUES

When a potentially treatable problem is known in advance, pregnant women should deliver at Level III centers. However, most agree that it is preferable to keep newborns with imminently life-limiting conditions at their hospitals of birth. It is best that mothers not be separated from their newborn infants. Transport is considered both traumatic and expensive, and if the newborn's condition is incompatible with prolonged life, then arrangement to stay in the local hospital may generally be preferred. It is best to avoid transferring dying newborns to Level III NICUs if nothing more can be done there than at the local hospital. The local area is recognized as that location at which parents have their support system, rapport with their established health care providers, a spiritual/religious community, and funeral availability.

Although parents may desire/demand transfer to a Level III facility, transport implies that something can be done to help the newborn or change the outcome. There may be cases in which the option of transport should not even be offered. Local protocols and guidelines should be developed between the regional Level III referral center and the community hospital.

If a newborn is to remain in the local community hospital, various requirements are needed. These include the availability of specialists, such as a neonatologist, geneticist, or neurologist, to make certain that the diagnosis is correct. The development and use of telemedicine and telehealth technologies between community centers and regional referral centers with subspecialty consultants may assist in this process.

The local hospital must also have in place a palliative care protocol and trained staff as described. Community hospital staff may need to be assisted with providing palliative care by those in the referral centers where it is done more often. A collegial relationship between the referral center and the local providers is essential, as the local staff may require additional education and resources to manage the dying infant and support the family throughout the process. Some might say that community hospitals would not have sufficient staff or resources to accomplish palliative care for newborns. However, as with any new service, trained and committed personnel

can facilitate change and develop local expertise. This would include how to support the dying newborn both in and out of the hospital.

In addition, if a newborn has been transferred to a Level III center and it is determined that no curative treatment is indicated, he/she should be transported back to the local hospital or home with hospice care in order to be together with family in their own community. Since transfers in either direction are often extremely upsetting for parents, support from social services and the hospital chaplain is essential. At present, some insurance payers (including government programs) may not pay for "back transport." In order to give proper palliative care in the home environment, health care professionals must join in the movement to have transport costs in both directions covered.

### WHICH NEWBORNS SHOULD RECEIVE PALLIATIVE CARE?

While many aspects of palliative care should be integrated into the care of all newborns, there are infants born for whom parents and the health care professionals believe that palliative care is the most appropriate form of care. The following list includes categories of newborns that have experienced the transition from life-extending technological support to palliative care. The individual context of applying palliative care will require that each case, in each family, within each health care center, be explored individually. These categories of newborns are provided for educational purposes and may engender discussion at the local institutional level.

(1) Newborns at the threshold of viability, with extremely low birth weights and gestational ages, especially those with gestational ages at or under 24 weeks, or weighing less than 500 g if no growth retardation exists. Newborns weighing slightly more (< 750 g) or who are born slightly older (< 27 weeks' gestation) may do well but then develop serious complications that become life-limiting as additional time passes.

(2) Newborns with complex or multiple congenital anomalies incompatible with prolonged life, where neonatal intensive care will not affect long-term outcome, such as the following.

- *Genetic problems:* Trisomy 13, 15 or 18, Triploidy, thanatophoric dwarfism or lethal forms of osteogenesis imperfecta, errors of metabolism that are expected to be lethal even with available therapy.
- *Kidney problems:* Potter's syndrome/renal agenesis and severe lung hypoplasia, some cases of polycystic kidney disease or renal failure requiring dialysis.
- *Central nervous system abnormalities:* anencephaly/acrania, holoprosencephaly, some complex or severe cases of meningomyelocele or large encephalocele, hydranencephaly; congenital severe hydrocephalus with absent or minimal brain growth; neurodegenerative diseases requiring ventilation (e.g., spinal muscular atrophy).
- *Heart problems:* acardia, inoperable heart anomalies, some cases of hypoplastic left heart syndrome, pentalogy of Cantrell (ectopia cordis).

- *Structural anomalies:* some cases of giant omphalocele, severe congenital diaphragmatic hernia with hypoplastic lungs; inoperable conjoined twins.

(3) Newborns not responding to intensive care intervention, who are deteriorating despite all appropriate efforts, or in combination with a life-threatening acute event:

- nonresponsive to aggressive resuscitation regardless of gestational age;
- recipients of repeated cardiopulmonary resuscitations;
- severe cases of perinatal brain injury, such as hemorrhages or leukomalacia;
- severe asphyxia (pH < 7.0, Apgar < 3 at 15 minutes);
- hypoxic-ischemic encephalopathy (HIE);
- multiple end-organ disease/failure;
- overwhelming sepsis after attempts at support;
- NEC or midgut volvulus without viable intestines, or for whom an extremely short gut makes feeding/growth impossible;
- newborns unable to be weaned off ECMO.

### INTRODUCING THE PALLIATIVE CARE MODEL TO PARENTS

Speaking to parents about palliative care is difficult. There is heartache from the staff and heartfelt sympathy for the parents. The following points are offered to help physicians facilitate the process.

- Let the family know they will not be abandoned. Sample language has been offered by the American Medical Association's EPEC training,<sup>28</sup> and might include: "We will continue to provide the best medical care possible for your infant. This will include frequent assessments by the nurse, daily visits by the physician, and the visits of the social worker and the chaplain. We will be adjusting medications so that your infant is comfortable. What other support can I offer to you?"
  - Assist the family in obtaining all of the medical information that they want. Tell them that the entire medical team wishes the situation were different. Let them know you will support them every step of the way and that their infant is a valued and loved member of their family.
    - Hold conversations in a quiet, private, and physically comfortable space. Allow a lengthy period of time. Be seated. Give the parents written notes. If indicated, offer to tape-record the conversation for their use later. Offer the family the benefit of having a third party present.
      - Give them your beeper number or telephone number to call you after they have digested the information and have more questions. Offer the ability to have a second opinion and/or an ethics consultation. One might ask: "Who else do you have to support you? Is there anyone you would like me to call, such as a family member, your rabbi, priest, or minister, or someone important to you that could help you at this time, or would you like to speak to one of the chaplains on staff?"

- Come back later with a statement such as “Many parents in your situation have had similar questions, should I share those questions with you?”
- Provide parents time to consult the local regional center that works with children with special needs or their area pediatrician who can provide information on projected abilities and disabilities.
- Offer to introduce them to parents who have been in a similar situation. Many facilities have parent–counselors as part of the paid or volunteer staff. The video created by the Colorado Collective for Medical Decision Making<sup>29</sup> has been helpful in showing parents the responses of other parents.
- When possible, use lay person language to clarify medical terms, and allow a great deal of time for parents to process the information. Strive for nonjudgmental language. Use visual aids to explain the extent of the problem if appropriate.
- The terms “withdrawal of treatment” or “withdrawal of care” should be avoided. Explain that the infant will be continuously cared for by highly trained and dedicated staff and that his/her symptoms will be monitored, and discomfort prevented or aggressively treated.
- Communicate and collaborate with parents at all times. Efforts should be made to clarify mutually derived goals of care for the infant. Do not tell parents that they have a choice between technological support and palliative care if technological support is no longer an appropriate or beneficial form of care. Given such a choice, parents often mistakenly feel that they would be agents of the infant’s death if they do not use all technological interventions. The team’s professional recommendation that the goals of care should be directed toward enhancing comfort rather than trying to unsuccessfully modify the disease process should be clearly stated. Give as many choices as possible about how palliative care should be implemented for their infant. Inform the parents of improved access to the infant for holding, cuddling, kangaroo care, and breastfeeding.
- If the transition in care involves the removal of ventilatory support, explain that the use of ventilators is for the improvement of heart–lung conditions until cure — when cure is a likely outcome. Make clear that using a ventilator to breathe for an infant who is overwhelmed by the underlying disease process, and is dying, is neither beneficial nor recommended. Affirming this with their spiritual leaders and extended family members is also important, as this is a difficult concept for some families to comprehend and may take recurrent discussion.
- Tell the parents that you cannot change the situation but you can support the infant’s short life with comfort and dignity. Explain that discontinuing interventions that cause suffering is a brave and loving action to take for their infant.
- Validate the loss of the dreamed-for healthy infant, but point out the good/memorable features he/she has. Help parents look past any deformities and work to alleviate any blame they may express.
- Encourage parents to be a family as much as possible. Refer to the newborn by name. Assist them to plan what they would like to do while the infant is still alive.

- Encourage them to ask support persons to join them on the unit. Facilitate sibling visitation. Support siblings with child life specialists on staff.
- In daily conversation, avoid terms that express improvement such as “good,” “stable,” “better” in reference to the dying patient so as not to confuse parents. If necessary, use words such as “death,” “die,” and “dying,” and do not speak in euphemisms (e.g., “not doing well” or “passing away”). “There is nothing more we can do” should never be voiced.
- Prepare the family for what may happen as the infant dies. Review what they may see, hear, smell, and feel. Provide information on the estimated length of time it may take until he/she actually dies, from minutes to days, and that palliative care will be continued as long as it is necessary.
- Report to them that not all family members experience grief at the same pace, that differences in coping styles and stages is common, and that each will be supported by staff.
- Introduce families to the chaplain and social worker early in the process. Offer support for extended family. Ask about their desire for infant baptism or other religious services on the unit. Have a hospital chaplain contact their local spiritual advisor in the community.
- Funding palliative care measures remains a concern.<sup>30</sup> When a newborn’s care shifts from highly technological life support to palliative care, it is essential that the written documentation continue to reflect the need for physician management, skilled nursing care, and interdisciplinary support. The physician should note that the infant’s condition warrants intensive nursing monitoring and activities. Charting should reflect that the infant is critically ill and there should be close collaboration with utilization review, coding, and billing staff. Appropriate diagnoses and accurate procedural coding should be used to ensure reimbursement of palliative care measures. Continued advocacy at the federal, state, and local level for hospice/palliative care reimbursement is essential.

## OPTIMAL ENVIRONMENT FOR NEONATAL DEATH

When the decision is made that a newborn infant may be close to death, there are several components to optimizing the care. These include some general principles, such as the following.

- Compassionate, nonjudgmental, consistent staff for each infant, including physicians knowledgeable in palliative care. If consistent staff is not an option in a particular unit, then agreement on the plan of care is essential, with proposed revisions to care discussed with the whole team.
- Nurses and other health care staff educated in providing for the family a meaningful experience while caring for the family’s psychosocial needs including a period of time after the death.
- Parents who are educated in what to expect and who are encouraged to participate in, or even orchestrate, the dying process and environment of their infant in a manner they find meaningful.

- Flexibility of the facility and staff in responding to parental wishes, such as participation of siblings and other family members, and including disires of parents and families who do not wish to be present.
- Institutional policies that allow staff flexibility to respond to parental wishes.
- Providing time to create memories, such as allowing parents to dress, diaper and bathe their infant, feed him/her (if it is possible), take photos, and hold the infant in their arms. If they wish to take the infant outdoors to a peaceful and natural setting, that should be encouraged.
- Siblings should be made comfortable; they may wish to write letters or draw for the infant. Snacks should be available.
- Allowing the family to stay with the infant as long as they need to, including after death occurs.
- The process for treating the dying infant is well described in the literature and by the various bereavement programs. Such processes include such things as having one nurse assigned to be with the family, staying with the infant while the parents take breaks, and collecting mementos that families may wish to take home (e.g., pictures or videos, hand- and footprints, and locks of hair).
- Parents should be assisted in making plans for a memorial service, burial, etc. Some parents might wish to carry or accompany the infant's body to the morgue, or take it to the funeral home themselves. Issues such as autopsy, cremation, burial, and who may transport the body should be discussed, especially if the parents are far from home and wish to take the body back to their home area for burial. In some states, hospitals may release a body to parents after notifying the county department of vital statistics. The family must sign a form for removal of the body. The quality assurance department should be notified. Further discussion of autopsy and organ/tissue donation issues is included.

Specific skills are needed by the staff to provide palliative care. These include:

- a physician leader of the team who is familiar with family-centered care and the tenets of palliative/hospice care;
- a trained nursing staff, clinical social workers, and clergy supportive of this manner of care;
- agreement to cease all invasive care, including cessation of frequent vital signs, monitoring, medical machinery, and artificial feeding;
- removal of all medications other than those to provide comfort or to prevent or treat a troubling symptom, with continued intravenous access for pain medication and anxiolytics;
- maintenance of skin care, participation in discussion on the appropriateness of feeding, and prevention of air hunger;
- use of simple blow-by oxygen or suctioning if needed for comfort;
- continuous observation and gentle assessment by nursing staff as individualized by parent wishes;

- physicians' notes describing the need for ongoing physician observation and nursing staff interventions to provide the needed level of care;
- appropriate palliative care orders on the chart.

### LOCATION FOR PROVISION OF PALLIATIVE CARE

In this research, and that of others, both parents and health care professionals report that the location is not as important as the "mind set" of persons involved in end-of-life care. The attitude of staff, their desire to care for dying newborns and their families, their training in observation, support, and symptom management, and their knowledge of how to apply a bereavement protocol are more important than the physical location of the patient. Many agree that an active NICU may not be the optimal place for a dying newborn. Whether the infant is moved to a room off of the unit (e.g., a family room), onto a general pediatrics ward, or kept on the postpartum floor, the best available physical space with privacy and comfort should be chosen.

In some cases, parents have not wished to leave the NICU where they have bonded with staff and have adjusted to the noise and activity. These families might feel isolated if moved to a private place. Thus, if transition out of the NICU is needed, this should be handled very gently, possibly with care being provided by the same staff so parents can see that the infant will continue to receive staff attention as they did in the unit. If the location in the hospital does change, continuity of care between patient care units is critical and should be seamless among the nurses, physicians, social services, and family.

Some families may wish to take their infant home to die. Discharge to home may be a goal for families who are willing and able to do so and have adequate assistance. Significant planning will be necessary to do this, including setting up the provision of home health care or home hospice support. There are areas of the country where this might be difficult to accommodate due to a lack of resources outside the hospital. However, without being challenged to meet these needs, pediatric hospice services or home palliative care will not evolve. It is essential to establish a relationship with the local hospice provider and work together to establish the needs of the dying newborn or infant prior to sending him/her home.

If families take the infant home, coordination with the emergency medical system personnel may be necessary to prevent undesired intervention. Parents need to be instructed not to call 911 as, in some places, emergency medical technicians are obligated to provide cardio-pulmonary resuscitation. A letter describing the diagnosis, existence of in-hospital Do-Not-Resuscitate order, and hospice care plan for home with the full expectation that the patient will die should be provided to the parents, their primary physician, home health agency/hospice, and perhaps the county emergency medical system coordinator. Generally, hospice nurses are allowed to confirm a patient's death.

## VENTILATOR REMOVAL, PAIN AND SYMPTOM MANAGEMENT

At times, cessation of certain technological supports accompanies the provision of palliative care. The following information addresses: (1) how to prepare the family, staff, and facility for discontinuation of ventilator support, and (2) the process of removing the ventilator in a manner that minimizes discomfort for the infant and the family.

### Preparation

- The entire focus of ventilator removal must be concern for the comfort of the infant in a setting that allows privacy for the family. Providers should assure parents that every attempt to prevent suffering will be taken and that their infant will be treated with dignity and expertise in comfort measures.
  - Parents must be provided time to respond to the critical situation, and encouraged to direct how the process should go.
  - Medical records should reflect the substance of patient care conferences with parents and care orders written should be clear to staff members. Orders to cease mechanical ventilation, forgo cardiopulmonary resuscitation, to cease monitoring vital signs and drawing blood samples should be written in the chart with appropriate signatures and documentation.
    - Parents should be able to gather their significant others and bring in their religious, spiritual, or cultural leader to conduct a ceremony or provide support.
    - Once the decision is made, parent education should include that no further resuscitation efforts will occur. A change of shift for nurses or change of attending physicians should not alter the plan once it is decided upon without discussion and approval of the whole team and family.
      - Consideration for notifying the ethics committee or risk manager about the decision may be appropriate in some facilities.
      - Special permission must be obtained by the medical examiner in the instance of coroner's cases.
      - The sequence of events should be laid out for parents in advance and they may express their preferences about the process.
      - Parents should be helped to understand that not every newborn dies immediately after the ventilator is removed. A contingency plan should be discussed, specifically including where and by whom the infant will be managed under a palliative care regimen (see Process section). When available, the hospice team should be notified in advance if it is thought that the infant may not immediately expire or if the family desires to go home if the infant survives after extubation.
        - It is appropriate to discuss autopsy and organ/tissue donation concurrently with removal of life support discussions. Some parents may wish to address how the body will be handled after death and to indicate that they would like to have the infant buried or cremated; others may allow the body to be taken to pathology.

### Process

- Parents should decide who will be present at the time of extubation. Staff, including the social worker, neonatologist, spiritual advisor, and primary nurse, should be close by and available upon request. Parents can hold a service at the bedside as desired. If parents wish, a nurse or other designee may bless or baptize the baby if no clergy have been invited, or parents may do so themselves.
  - Staff should work out in advance who will be doing what part of removal of technological support such as removal of invasive lines, monitors, and the endotracheal (ET) tube. The actual turning off of the ventilator has often been seen as a physician responsibility.
    - Staff should anticipate and have available medications that may be needed based on the infant's condition. Drugs such as vasopressors and antibiotics should be discontinued. Monitors should be removed and all alarms turned off.
      - Neuromuscular blocking agents (paralytics) should never be introduced when the ventilator is being withdrawn. If the newborn has been on paralytics, these should ideally have been weaned off hours to days earlier. On rare occasions, the ongoing pharmacologic effect of paralytics might be construed as contributory to patient death following removal of the ventilator. In all cases, when paralytics have been recently part of the newborn's care, the medical record should attest to: (1) physician and parent discussion, understanding, and consideration of this fact in view of the decision to remove the ventilator; (2) an affirmation of the intent of such decisions being to relieve suffering associated with burdensome and nonbeneficial care; and (3) the disproportionate burden imposed upon the patient and family of waiting lengthy hours or days for the paralytic effects to diminish.
        - Intravenous access must remain in place to give medication for symptom relief. Infants will need pain relief, relief for labored respirations or perhaps seizure activity. The pharmacy should assist in preparing proper doses of medications in intravenous, suppository, or buccal delivery form. Doses of medication should be sufficient to provide comfort and prevent signs of air hunger. Relevant medications include narcotic and non-narcotic analgesics, medications to relieve air hunger, sedatives, diuretics, hypnotics, anticholinergics, anticonvulsives, and antipyretics. Standard reference resources are available<sup>31–36</sup> and the authors (A.C., B.C.) can provide dosage lists upon request.
          - Prior to removal of the ET tube and disconnecting the ventilator, the alarms on the ventilator should be turned off. The ET tube should be gently suctioned when removed and the mouth gently cleaned. Then the ventilator can be shut off. If possible, the baby should be held in the parent(s)' or a staff member's arms when this takes place.
            - If possible, any tape on the face, or other unnecessary lines, should be removed. If not removed, these lines should be tied off and any open areas covered with gauze pads.
            - Supplemental oxygen is usually not given when a ventilator is withdrawn. Parents may wish to administer oxygen to provide comfort. It may be more appropriate to administer morphine if an

infant exhibits signs of shortness of breath, such as nasal flaring, air hunger, color changes, or grunting, as some clinicians report the possibility of oxygen prolonging the dying process. A suction machine or bulb suction should be available.

- Environmental support should provide for as much of a normal and nurturing environment as possible. Lights can be kept low, especially if color changes are expected. Noise should be kept to a minimum with phones and pagers turned low and staff conversations at a minimum. The infant can be dressed in his/her own clothes, bathed, diapered, and bundled by parents. Parents can bathe the infant, do infant massage, attempt breastfeeding, or engage in kangaroo care. Availability of music playing and rocking chairs is helpful.

- A nurse should gently describe any physical changes that might be taking place and occasionally check to see if there is no heartbeat. The infant should continue to be observed and treated for any signs of dyspnea, discomfort, agitation, or seizures.

- Parents and family members should be able to hold the infant for as long as they need to, which may be for an extended time after death.

- Mementos can be obtained by nurses, such as lock of hair, hand- or footprints in plaster, and photos of family together, if this is culturally appropriate. If the infant has serious anomalies, photos of hands, ears, lips, and feet can be provided. Ear prints and lip prints are possible. Some parents have indicated that mementos of a newborn who died are not acceptable in their culture.

- Parents require care after the infant has died. It is helpful to walk parents out to their cars so they do not have to feel so alone when they leave. Parents can be given a memory box or stuffed animal to avoid walking out with empty arms. Cleaning of the bed space area should not be done until they are gone.

- Occasionally, due to distance or home responsibilities, parents cannot be present or may choose not to participate at all or only in portions of care as described above. The process would be similar, with a staff person holding the infant from the time of extubation until death, and a box of keepsakes retained on the unit in case family desires them later.

#### **WHEN DEATH DOES NOT OCCUR AFTER CESSATION OF AGGRESSIVE SUPPORT**

- A private room somewhere in the hospital is recommended where nurses trained in palliative care are available.

- If the expected time for expiration passes and death does not take place, the infant could be discharged to home for ongoing palliative care services. The parents, NICU staff, and the hospice staff should meet to make plans for home care, including the investigation of what services are offered and what insurance will cover. Continued palliative care/hospice services with home nursing care are essential, including the possibility of ventilator removal at home.

- If the infant is to go home, a procedure for dispensing outpatient medications should be in place. All needed drugs and

directions for use should be sent along with infant so that parents do not have to go to a pharmacy to fill prescriptions. Identifying and communicating with a community health care provider who will continue with the infant's home care needs is essential.

- Some families and health care providers feel dying newborns should be fed, and, if unable to suck, should be tube-fed. Others feel that artificial feeding is inappropriate. Recent research indicates that feeding can be burdensome and that an overload of fluids can impede respirations. In all cases, infants should receive care to keep their mouth and lips moist. Drops of sucrose water have been found to be a comfort agent if the infant can swallow, and they may be absorbed through the buccal membrane.

- Parents who feel they cannot take the infant home should be assisted to find hospice care placement. This might require help from within the extended family or religious community, foster care, or long-term care placement. Some parents might opt to leave their infants in the hospital.

#### **DISCUSSION OF ORGAN AND TISSUE PROCUREMENT AND AUTOPSY**

At some point in the course of care, organ and tissue donation and autopsy will need to be discussed. Prior to discussion with families, the regional organ donation center should be contacted to see if a particular infant qualifies as a potential donor. In some areas, only corneas or heart valves are valuable in an infant under 10 lb; but in different locations, other organs (e.g., heart) or tissues may be appropriate. It is important to know if a newborn has no potential donor use and to communicate this respectfully. Parents often desire the ability to give this gift and may be doubly hurt if they are hoping for the opportunity to help others and are turned down.

The person who discusses organ/tissue procurement must be specially trained. While this usually is initiated by the physician, a nurse, chaplain, or representative from the donor services may conduct the conversation with tact and compassion. The provider should be aware of cultural, traditional, or religious values that would preclude organ donation for a specific family, as many cultures and religions would consider this desecration of the dead infant.

It is suggested that this conversation be clearly "uncoupled" from the discussion on treatment goals to avoid any perceived conflict of interest by the caregivers. Conversation regarding autopsy or organ donation should be clearly documented in the chart so all can see that these discussions have already taken place.

Requests for autopsies are not required in all states, but may be considered appropriate in many instances of infant death. If the medical examiner or coroner is involved in the case, autopsy may be required by law. Some providers feel that asking for an autopsy is important in order to potentially provide parents with some answers regarding their infant's illness and death. The placenta may also be used for testing to provide information. In the discussion, parents may wish to know all or some of the following.

- Autopsy does not cause any pain or suffering to the infant; it is done only after death.
- The body is handled with the ultimate respect.
- Some insurance companies pay for a physician-ordered autopsy.
  - For families who do not wish a complete autopsy, limited tissue studies can be done on some areas of interest and imaging studies can be done rather than dissection.
  - Explanations may include how tissue removed from the body is handled and disposed of and if this tissue can be buried with the infant on request.
  - Genetic testing may be done on blood, skin, and certain tissue biopsies.
    - If a family desires an open viewing of the infant at the funeral or memorial service, the pathologist must be notified as to allow for the least possible disfigurement.
    - Preliminary results may be available from the pathologist within 72 hours, with a written report within 7 to 10 days. Conducting an autopsy may slightly delay release of the body to a funeral home for embalming or cremation. There may be cultural issues requiring release of the body for burial within a certain time frame and these should be observed when possible.
    - Final results are returned in approximately 6 to 8 weeks, at which time the primary physician can meet with the parents, conduct a telephone conference, or communicate by letter to discuss the results.
    - Informational literature about autopsy is available.<sup>18</sup>

### **FAMILY CARE: CULTURAL, SPIRITUAL, AND PRACTICAL FAMILY NEEDS**

The needs of families with a loved one receiving palliative care are the usual ones of any family with a critically ill member. The hospital social worker is an essential component of supportive palliative care. Families may immediately need meal tickets and assistance with parking fees. A phone card to allow them to call extended family would be very helpful. They may also need access to transportation, a place to stay (preferably with the infant), and possibly financial assistance as part of their overall care. They may need day care for the other siblings. Whatever practical support issues that can be met should be met, and those that cannot be met should be explained.

#### **Practical Considerations**

- Parents of multiples in which some lived and one died will need special attention to validate their bereavement as well as to support their love for their living child(ren).
- Time should be permitted for the parents to contact the needed authority in their culture and to plan any necessary ceremony.
- Many ceremonies include the use of incense and/or candles. Special permission may be required from the hospital facility. A

specific location in the hospital away from gases and flammable material will be needed.

#### **Cultural Sensitivity**

Families will benefit from access to culturally sensitive and specific support, and respect toward their spiritual needs. These support needs should be anticipated and provided as much as possible.

- When using a translator, simple words and phrases should be used so that the translator can convey the message exactly as it is given. It is most appropriate to use hospital-trained and certified translators to ensure accuracy.
  - Whenever possible, written materials should be given in the family's primary language, in an easy-to-read format, culturally and linguistically appropriate for the family.
    - There may be various culture-specific practices that should be respected. For some families, eye contact and touch may be expected; for others, this may cause them to be uncomfortable and is not appropriate.
    - There may be special cultural practices when an infant is born with malformations. Various groups may find fault with the mother if this occurs.
    - Staff may need to model holding the very sick infant. While most families will desire to hold their infant, there are those who will not wish to touch the infant as it is dying or after it has died.
    - An autopsy request might be seen as contrary to cultural practices.
      - At times, there may be difficulty working with families who have a basic fear or distrust of authority figures. Whether they come from foreign countries ruled by corrupt or brutal regimes, or from oppressive inner cities locally, some parents will not automatically look to providers for support. Earning their trust is possible, but may take effort. Some ethnic and social groups may view palliative care as a racist or elitist denial of care. Poor unmarried women of all ethnicities may view the cessation of technological intervention as a cost-cutting measure aimed at them as a group. It is hard to know how to counter these views except to have doctors, nurses, or counselors of similar backgrounds help in the counseling and assure mothers in poverty that heroic care is not desired by many who could well afford it, e.g., many neonatal practitioners. Telling parents that many neonatologists and neonatal nurses might prefer palliative care for their own imperiled infants may allow parents to see that this form of care is not being offered as a class- or race-based policy.
      - Culturally sensitive grief counseling and contact with a support group of other parents who have been through this would be helpful.

#### **Spiritual Support**

Caregivers should be aware of the tendency of family members to second-guess their decisions and feel enormous guilt. It is our job to help families work through this. Families will be in a crisis of spirit

and may be asking “Why me? Why my baby? What did I do wrong?”. Reassure parents that these questions are normal parts of grief. Parents may need reassurance, or permission, that they can be both “good parents” and parents who “let go” with selfless and loving intent.

Some parents may believe that withholding or withdrawing technological support is not acceptable in their cultural/religious tradition. For them, the issue needs to be framed a certain way to be acceptable (i.e., the physician may need to say, “Additional technological support is inappropriate and will increase the infant’s suffering. I recommend we increase the palliative care services and work intensively now to support comfort for your infant and you.” Thus, the family does not have to “decide” anything and is allowed to just love and comfort their infant.)

Those practitioners with background in providing end-of-life care for newborns have had extraordinary experiences. Some report a full funeral service with the patient in his casket in a classroom of the hospital, or families on the floor wailing with grief. Others recount a father bathing and dressing his infant before carrying him to the morgue, or a medicine man praying over an infant’s body, or shamans and elders at the bedside, or staff members and the family forming a prayer chain around the infant’s bed and praying and singing together. Each family’s experience will be unique.

## FAMILY FOLLOW-UP CARE

Families who have experienced a neonatal death will likely leave the facility in a shocked state. A member of the staff should be designated to be the follow-up connection with future calendared (planned) calls, and perhaps visits, so that contact is not lost. Families can be best be served by the following.

- Establishing contact with a social worker, chaplain, or grief counselor prior to discharge.
- Receiving an information packet as described and a date for a follow-up discussion with the attending physician (which may be in conjunction with autopsy results).
- Notifying the family’s obstetrician of the death no matter how long after delivery it occurred.
- A home visit by one of the staff or a public health nurse within a few days.
- Primary nurse writing a letter about what the baby was like and how it felt to care for the infant.
- Phone calls weekly, then monthly, then at 6-month intervals if parents agree. Also providing contact on significant days such Mother’s Day, the infant’s due date, or anniversary of death. When making parent contact, remember to ask how all of the family is doing, including fathers, grandparents, and siblings. Each time, ask parents “May I call you again?”.
- With parents’ permission, posting the family’s address in the unit so that staff may send cards.

- Provide staff the opportunity to attend services if desired.
- If parents desire it, introducing parents to another family which has lost a newborn or young infant.
- Facilitate introduction to a support group. Some parents prefer to attend a grief group led by someone they have already met in the facility. Others prefer talking with counselors not associated with the hospital.
- Invite family to a group memorial service held by the hospital for those who have lost pregnancies or infants in the past year.
- Keep in mind that subsequent pregnancy may be difficult and offer support at that time; include genetic counseling if indicated.
- Keep snapshots and mementos on the unit if parents do not wish to take them at the time, as some parents may reconsider later.

Some facilities report that parents have appreciated purchasing an “in memoriam” plaque with the infant’s name on it. In this way, parents will have a special place to return to with a memorial to their child. Some parents may also desire to return to the unit and volunteer time or services and offer support for other families.

It is important for staff to realize, however, that not all families will have bonded during a problematic pregnancy and/or with an ill infant, and some may not desire support or contact after the infant dies.

## ONGOING STAFF SUPPORT

The work of providing end-of-life care for newborns and their families is very intense. It is essential that all staff participating in this form of care have both ongoing support and critical incident debriefings from outside experts. Staff needing support must not be limited to the nursing staff, and must include physicians and all health care and ancillary personnel who have interacted with the infant or family. There are many colleagues within the clinical setting that may be called upon for help, such as psychologists, ethics consultants, psychiatry staff, employee assistance personnel, social workers, mental health counselors, hospice bereavement staff, and spiritual care providers. Suggested support includes:

- Facilitated meetings of the multidisciplinary team during the process are needed, especially if some of the team members are reluctant to change to this mode of care.
- Debriefings after every infant’s death and after any critical incident will be helpful for the staff.
- Meetings or counseling sessions should be part of regular work hours and not held on voluntary or unpaid time.
- Planning sessions, allowing for incorporation of lessons learned and for future palliative care cases, may allow staff to have a stake in improving the care and accepting it as they shape the manner in which it is provided.
- It is important to include residents, medical students, and nursing students in the provision of palliative care to model behavior they will incorporate in future actions.

- This type of caregiving should be voluntary, and nurses or physicians who do not wish to be involved should be able to take other assignments.
- Clarity in physician orders is essential for cohesion in the caregiving process. A closely working team allows patient care to go smoothly and lessens individual moral distress.
- Moral support for the nurses and physicians directly caring for the dying newborn is required from peers as well as the unit director, other neonatologists, chaplain, and nursing house supervisor.
- Nursing staff scheduling should be flexible and allow for overtime to continue with the family or orient another nurse to take over.
- If they wish, the primary nurse and physician should be called if not present at the actual time of the infant's dying. With permission by the parents, they should be allowed to attend the funeral if desired and to take time off afterwards if needed.

## SUMMARY

Physicians have reported a need for ethical guidelines in caring for newborns who may need to have technological support withheld or withdrawn. This protocol will assist providers who may not have had formal ethical/clinical training for withdrawing or withholding life-sustaining interventions from dying or critically ill newborns. Incorporating the palliative care model in professional newborn care is essential. This protocol can allow for consistency in the approach to caring for newborns with life-limiting conditions and provide a model useful for teaching palliative care to medical and nursing trainees.

## APPENDIX

### Establishing the panel

A varied and well-rounded multidisciplinary panel was compiled to explore the needs of family and staff. Data were solicited to describe how physicians, nurses, health care professionals, and facilities have successfully provided or wish to provide palliative care, where, under what circumstances, with what type of staff and resource support, and with what institutional or legal consultation, and also how parents who experienced the birth of a very ill or dying child described appropriate infant and family needs. The multidisciplinary focus addressed the caution of Linstone and Turoff<sup>36</sup> that the group should be representative of those who have a stake in the issue and not just professionals. Hospice experts joined the study after the first round.

First line participants were recruited either as interested parties from the American Academy of Pediatrics, National Perinatal Association, Society for Pediatric Research, and the American Society for Bioethics and Humanities, or from responses to a web page announcing the study. The Internet and e-mail were used to gather data from throughout the US and abroad. The 101 participants

included 30 physicians [neonatologists (21), pediatricians (3), maternal fetal specialists (2), obstetricians (2), adult intensivist (1), hospice specialist (1)], 41 nurses [perinatal educators/researchers (10), obstetric (9), neonatal (9), hospice specialists (6), pediatric (3), administrators (2), nurse anesthetist (1), therapist (1)], 9 parents, 5 ethicists, 3 neonatal social workers, 3 health attorneys, 3 health administrators, 2 psychologists/child life specialists, 4 European neonatal providers, 1 neonatal pharmacist, 1 neonatal educator respiratory therapy, and 1 funeral home director.

### Delphi methodology

Delphi methodology<sup>37</sup> was originally developed by Rand to collect accurate, extensive, and timely data on the potential for a Soviet air strike in the 1950s. The method<sup>38</sup> allows for the generation of critical ideas, and the structured collection of information from parties in multiple areas of the world with multiple expertise to develop consensus on difficult world problems. This methodology allows for conceptualization of different structures for examining a problem and allows that different individuals may perceive the same problem differently.<sup>37</sup> The procedure aims at improving decision making by distilling vast amounts of information for which there is evidence but not yet policy or scientifically proven knowledge.

Prior to the advent of personal computers, this was done by serial mailings that allowed for input, continuous review of data, and feedback until a large group could reach policy development consensus. Presently, such a study can be conducted with the use of multiple e-mail communications. Participants were sent four sequential e-mail questionnaires over 18 months' time soliciting response; the responses underwent investigator analysis, the package sent out again, and follow-up responses from participants analyzed until consensus was reached.

The Delphi methodology was chosen for the purpose of including public discussion and fostering national and international collaboration. The strengths of the Delphi methodology are that it allows all parties with a stake in the topic to be heard in an anonymous fashion with no power differentials between professional and lay persons; allows for asynchronous responses to allow response to areas of interest with the ability to add more thoughts if they arise and to refrain from giving an opinion on topics that are not in scope of expertise; allows agreement on areas to be accepted and allows focus on areas of disagreement in continued round; and allows a topic to be thoroughly developed through individual panelist input and then collective wisdom of group. The limitations of the method are related to e-mail and Internet format, i.e., not all potential participants were able to handle the required computer skills, and to time commitment, as participants must feel continued tension and interest to continue with project whose length was over 18 months in time.

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