



## FACILITATION GUIDE FOR PROGRAM 5

### **CONDITION: CRITICAL HEALTH CARE IN THE UNITED STATES**

#### **A Series of Education Programs on Health Care Ethics**

#### **Ethics Program 5: Born Too Soon, “Neonatal Care in the 21st Century”**

##### SECTION I

Narrative Video with Expert Commentary

##### SECTION II

Discussion Questions for the Program

##### SECTION III

Projects or Assignments for the Program

##### SECTION IV

Individual Learning Model Information



## SECTION I

### Narrative Video with Expert Commentary

#### NARRATIVE VIDEO

The 30-minute video examines ethical dilemmas that arise in the high technology world of caring for babies in neonatal intensive care units. The video considers the various options for aggressive medical treatment of premature and vulnerable newborns. And the program examines the legal and social context of this care, such as dealing with Baby Doe regulations or society sharing the burden of expensive treatment and ongoing care. Finally, the program examines the important relationship between parents and professionals in making tough decisions about life and death in the neonatal intensive care unit. The ethical debate in the video is presented in four sections.

1. Health care technology for babies in neonatal intensive care
2. Aggressive medical treatment for babies in neonatal intensive care
3. The legal and social context of caring for babies in neonatal intensive care
4. The relationship between parents and professionals in neonatal intensive care

#### EXPERT COMMENTARY

The video includes expert commentary by internationally recognized figures on the ethical dilemmas that arise in neonatal intensive care, including, Dr. Baruch Brody, Dr. Norman Fost, and Professor Laurie Zoloth.

#### LEARNING OBJECTIVES

The 30-minute video enables participants to foster discussion at the end of each section as well as at the end of the program. Participants will be able to:

- understand some of the expectations and limits of health care technology in neonatal intensive care
- understand the dilemmas around aggressive treatment in neonatal intensive care
- understand the legal/social context of caring for babies in neonatal intensive care
- understand the relationship between parents and professionals for decision making in neonatal intensive care

#### STRUCTURE OF THE EDUCATION SESSION

The facilitator should explain the learning objectives, show the video, and then engage the participants in discussion and/or assign follow-up projects.



## SECTION II

### Discussion Questions for the Program

#### I HEALTH CARE TECHNOLOGY FOR BABIES IN NEONATAL INTENSIVE CARE

- What expectation is there for survival of premature babies in neonatal intensive care?
- What limits are there for the survival of premature babies in neonatal intensive care?

##### Answers

#### II AGGRESSIVE MEDICAL TREATMENT FOR BABIES IN NEONATAL INTENSIVE CARE

- Is there an impulse in medicine to over-treatment or under-treatment in neonatal intensive care?
- What is the role of the infant's interest, such as burdens and benefits, in neonatal intensive care?

##### Answers

#### III THE LEGAL AND SOCIAL CONTEXT OF CARING FOR BABIES IN NEONATAL INTENSIVE CARE

- What impact did the Baby Doe Regulations have on neonatal intensive care?
- What significance should be given to the suffering of families during care for their infants in neonatal intensive care?

##### Answers

#### IV THE RELATIONSHIP BETWEEN PARENTS AND PROFESSIONALS IN NEONATAL INTENSIVE CARE

- What role should parents have in making decisions about neonatal intensive care?
- What role should financial cost play in neonatal intensive care?

##### Answers



## SECTION III

### Project or Assignments for the Program

These projects or assignments could be distributed among participants for them to expand on the answers in the discussion section by further review of the video.

#### I HEALTH CARE TECHNOLOGY FOR BABIES IN NEONATAL INTENSIVE CARE

- Explain what expectations there are for survival of premature babies in neonatal intensive care.
- Explain what limits there are for the survival of premature babies in neonatal intensive care.

#### II AGGRESSIVE MEDICAL TREATMENT FOR BABIES IN NEONATAL INTENSIVE CARE

- Explain the impulse in medicine to over-treatment or under-treatment in neonatal intensive care.
- Explain the role of the infant's interest, such as burdens and benefits, in neonatal intensive care.

#### III THE LEGAL AND SOCIAL CONTEXT OF CARING FOR BABIES IN NEONATAL INTENSIVE CARE

- Explain the impact that the Baby Doe Regulations had on neonatal intensive care.
- Explain what significance should be given to the suffering of families during care for their infants in neonatal intensive care.

#### IV THE RELATIONSHIP BETWEEN PARENTS AND PROFESSIONALS IN NEONATAL INTENSIVE CARE

- Explain the role that parents should have in making decisions about neonatal intensive care.
- Explain the role that financial cost should play in neonatal intensive care.



## SECTION IV

### Individual Learning Model

The Individual Learning Model complements the Group Learning Model by providing individual students with interactive independent study. This self-learning multimedia tool contains quizzes, on-screen readings, and videos for the entire DIA Learning Ethics Series.

#### INDIVIDUAL LEARNING MODEL

The Individual Learning Model is a chaptered, Web-based program available as Full Course or Selected Topics. It offers the following items:

- 60-minute narrative video with expert commentary
- Up to 12 chaptered curriculum topics, each including:
  - 5-minute narrative video components
  - On-screen reading components
  - On-screen quiz components
- Pre-test and post-quiz learning outcome measurement
- Real-Time Score-tracking
- Automated Certification by recognized accrediting bodies

#### COURSEWORK

The Catholic Version of the Individual Learning Model for Ethics Program 5 includes the following coursework:

- Chapter 1. Ethics in the Neonatal Intensive Care Unit
- Chapter 2. Ethical Issues Regarding the Resuscitation of Neonates
- Chapter 3. Ethical Issues Concerning Decisions to Withhold or Withdraw Care in Neonates
- Chapter 4. Decision-Making in the NICU: Providing Aggressive Treatment
- Chapter 5. Ethical, Legal, and Policy Concerns in the NICU
- Chapter 6. Ethical Issues Concerning Parents' Decision-Making Authority in the NICU
- Chapter 7. Parents' and Professionals' Attitudes on Neonatal Intensive Care
- Chapter 8. Ethical Issues Concerning Surrogate Decision-Making in the NICU
- Chapter 9. Team-Based Decision-Making in the NICU: Collaboration Among Physicians, Nurses, and Parents
- Chapter 10. The Ethics of Pain Management and Palliative Care in the NICU Setting
- Chapter 11. Social Responsibility Related to Neonatal Intensive Care
- Chapter 12. Professional Ethics Standards: Neonatal Intensive Care



## QUESTIONS & ANSWERS

### Discussion Questions for the Program

The suggested “answers” simply indicate some items from the video that relate to the question. The facilitator should encourage a broad range of responses from the video and beyond.

#### I HEALTH CARE TECHNOLOGY FOR BABIES IN NEONATAL INTENSIVE CARE

- **What expectation is there for survival of premature babies in neonatal intensive care?**

For the doctors and nurses in neonatal intensive care the treatment of sick babies is aimed at increasing their odds of survival and their ability to grow up and lead so-called normal lives. The commitment to these ailing infants is an intense, passion-filled endeavor. Studies point out that survival rates among premature babies have improved. That’s the good news, filled with accounts of the miracle babies who survive the long odds and have what are called good outcomes.

- **What limits are there for the survival of premature babies in neonatal intensive care?**

There are limits for the survival of babies in neonatal intensive care. Not all the babies do well, especially those born on the extreme margins of viability around 24 weeks gestation, or possibly 23 weeks, and some would argue maybe as early as 22 weeks. There is a real limit in terms of the ability of very, premature babies to be supported outside the womb. And that limit is mainly due to the development of the lungs. But, for every day, hour, and minute a premature baby can stay inside the womb, the chances for a good outcome and the possibility of a normal life improve dramatically.

#### II AGGRESSIVE MEDICAL TREATMENT FOR BABIES IN NEONATAL INTENSIVE CARE

- **Is there an impulse in medicine to over-treatment or under-treatment in neonatal intensive care?**

In the high tech world of neonatal intensive care, the biggest questions center on when to treat and when not to treat very sick babies. Doctors consistently struggle with exactly how aggressive they should be in treating the fragile babies entrusted to their care. The impulse in medicine is heavily biased toward over treatment rather than under treatment, partly because of the ever-present proviso that medical treatment can always be withdrawn.

- **What is the role of the infant’s interest, such as burdens and benefits, in neonatal intensive care?**

In medicine, the best interests of the patient stand out as paramount in treatment decisions. Words like benefits, burdens, and futility often become part of the decision making process. A central issue is whether to use or stop the technology based upon the baby’s or the child’s best interests to be kept alive. Many questions must be considered, such as the balance between burdens and benefits of treatment, what is the process of decision-making about treatment, and how should the parents be involved.



## QUESTIONS & ANSWERS

### Discussion Questions for the Program

#### III THE LEGAL AND SOCIAL CONTEXT OF CARING FOR BABIES IN NEONATAL INTENSIVE CARE

- **What impact did the Baby Doe Regulations have on neonatal intensive care?**

In the early 1980s, there was a highly publicized case of parents who wanted to let their Down Syndrome child die rather than be treated. The controversial case led to changes in the law. President Reagan and Surgeon General C. Everett Koop led the way to enact what is called the Baby Doe law, which prevented parents from refusing for their disabled children medical treatment that otherwise would have been approved if the children were not disabled. These regulations had a dramatic effect. On the one hand, the regulations led to treating Down Syndrome and spinal bifida babies from whom treatment often had been withheld. On the other hand, doctors began over treating babies who really should not have been treated, for example some extremely premature babies with very poor prognoses. That is, doctors acted as if the regulation required them to treat every baby whatever its condition.

- **What significance should be given to the suffering of families during care for their infants in neonatal intensive care?**

Parents and families share the burden of suffering when their babies are in neonatal intensive care. Some parents can question the use of heroic efforts to keep alive their premature, disabled children who are on the edge of viability. Parents can question such efforts because of the pain and suffering they see in their children that can become too much to bear. Also many families with premature and disabled children forge stronger family bonds, finding a mission in life to care for such severely damaged children.

#### IV THE RELATIONSHIP BETWEEN PARENTS AND PROFESSIONALS IN NEONATAL INTENSIVE CARE

- **What role should parents have in making decisions about neonatal intensive care?**

In the past parents often were not given a role in the decision making process. Today, there is a greater awareness that parents should play a critical role in determining difficult life and death questions in neonatal intensive care. And in hospitals across the country, ethics committees serve as an impartial third party when the hospital staff cannot agree among themselves or with the wishes of the parents. But parental rights do have some boundaries in medical decision-making. For example, a parent who is a Jehovah Witness is not allowed to refuse a blood transfusion for a child, though they can refuse it for themselves as adults. In other words, society is willing to honor parental decision but within a certain range.

- **What role should financial cost play in neonatal intensive care?**

As medical costs soar higher and higher and as hospital competition increases costs can become an important issue in neonatal intensive care. Neonatology can be a high-dollar enterprise. The pressures for parents can challenge their families, their marriage, and their finances. For some, insurance covers the large majority of medical bills. For others who do not have insurance, they may need to rely on Medicaid. And some ethicists argue that whenever a lot of money is being spent in medicine we should look at it carefully to inquire whether this is where our resources should go, though neonatal intensive care has established an impressive record.