

PROGRAM MEMO

Program Memo: Title 390, Protection and Safety #6-2005

To: Holders of Title 390

From: Todd Reckling, Administrator
Office of Protection and Safety

Signed by: _____, Director
Department of Health and Human Services

_____ (Date)

**Re: CAPTA Required Procedures for Reports of Medical Neglect
Of a Handicapped Infant**

Effective Date: July 15, 2005

Duration: Until revised regulation is issued.

Contact: If you have any questions regarding this program memo, please contact,
Shirley Pickens White at (402) 471-9196

The Keeping Children Safe Act of 2003 amended CAPTA, the Child Abuse Prevention and treatment Act (PL 108-36), and was signed into law on June 25, 2003. This law includes the requirement that the State develop procedures for responding to reports of medical neglect including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions.

Background

The withholding of medically indicated treatment from disabled infants with serious birth defects that are life threatening is a category of neglect that was defined in the amended Child Abuse Prevention and Treatment Act of 1984 (P.L. 98-4576). These situations have been referred to as "Baby-Doe" cases, after a 1982 Indiana court case contesting the parents' rights to withhold medical treatment, food, and water from an infant who was born with a life-threatening but surgically correctable condition that prevented oral feeding.

The 1984 amendments to the Child Abuse Prevention and Treatment Act defined as neglectful: "The failure to provide treatment (including appropriate nutrition, hydration or medication) which, in the judgment of the physician would be most likely to be effective in ameliorating or correcting the life-threatening condition."

The law and the regulations issued by the Department of Health and Human Services require that States receiving Federal funds for CPS programs regard the withholding of medically indicated treatment from these disabled infants with life-threatening conditions as a form of neglect and to actively investigate reported cases. Hospitals are likewise obligated to observe the provisions of the law and to post notices in newborn wards that failure to feed and provide care for disabled infants is a violation of Federal law.

The law does make exception for withholding treatment (other than nutrition, hydration, or medication) to an infant when, in the physician's reasonable medical judgment:

1. The infant is chronically and irreversibly comatose;
2. The provision of such treatment would merely prolong dying, be ineffective in correcting the life-threatening condition, or be futile in terms of the survival of the infant; and
3. The treatment would be virtually futile in terms of the survival of the infant and the treatment itself would in such a situation be inhumane. Food and water must *a/ways* be provided regardless of the extent of disabilities, and "quality of life" cannot be used as a criterion for deciding upon appropriate medical treatment.¹

Definitions: For the purpose of this program memo the following definitions will apply:

- Disabled infant means an infant having a physical or mental impairment that substantially limits or may limit in the future one or more major life activities. Major life activities include functions such as, but not limited to, breathing, seeing, hearing, walking, caring for one's self, performing manual tasks, learning and working.
- Infant means an infant less than one year of age.
- Medical neglect means the failure to provide adequate medical care, and includes, but is not limited to, the withholding of medically indicated treatment from a disabled infant with a life-threatening condition.
- Withholding of medically indicated treatment means the failure to respond to the infant's life threatening conditions by failure to provide treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgement, will be most likely to be effective in ameliorating or correcting all such conditions.

Reasonable medical judgement means a medical judgement that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.

REQUIRED PROCEDURES: The Office of Protection and Safety has developed the following required procedures that must be followed by Protection and Safety staff as set forth in CAPTA:

1. The Intake staff will obtain as much information as possible about the infant's circumstances. Information must include:
 - a. The name and address of the hospital;
 - b. The name and address of the infant and the infant's parents;
 - c. The birth date of the infant;
 - d. The attending physician's name and contact information; and
 - e. The condition of the infant: In particular whether the infant will suffer harm within the immediate future if medical treatment is withheld;
2. The worker will consult with his/her supervisor to determine whether the referral meets the criteria for medical neglect of a medically handicapped infant as defined in Neb. Rev. Stat § 28-710 and 390 NAC 3-005.01;
3. A report alleging withholding of medical treatment from a medically handicapped infant with a life-threatening condition will be considered a Priority 1 and will be assigned immediately;
4. The intake worker will contact Law Enforcement immediately;
5. If the child is in hospital the initial assessment worker will immediately contact the hospital. Otherwise, the attending physician will be contacted to gather medical information, as well as any other documenting material, that will allow for an informal decision to be made on medical care necessary to preserve life. The attending physician will be asked by the worker whether or not they consulted with other medical professionals and whether or not:
 - a. Other medical professionals are in agreement with the course of treatment recommended by the attending physician; and
 - b. If there is an immediate need for court intervention.

Medical information must include: diagnostic and medical records on the condition and treatment of the child as well as any other information that can assist in the determination as to whether appropriate medical care and nutrition are being provided.

6. The initial worker will determine if the parents consented to or refused medical treatment ;
7. The worker and supervisor will forward all information to Shirley Pickens White in Central Office for review with medical officer(s); and
8. Once the case has been reviewed by medical officer(s), the supervisor will be contacted with the results of the review.
9. If after the review of the results if it is felt that the child is not receiving the appropriate care necessary to preserve life, the worker must involve the parents in ensuring that the child's needs are met.

10. If the parents do not consent to medical care and treatment, the worker will contact the county attorney's office for assistance in obtaining an emergency court order granting authorization to provide medical care and treatment.
 - 11, The worker must document all activities performed in compliance with these required procedures on N-Focus.
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