

FORGOING OR DISCONTINUING LIFE-SUSTAINING MEDICAL TREATMENT

POLICY

Among the most difficult situations that can occur during Department involvement with a family are those in which a child's health is so severely compromised that a decision must be made about the appropriateness of forgoing or discontinuing life-sustaining medical treatment (LSMT). According to the American Academy of Pediatrics, LSMT encompasses all interventions that may prolong the patient's life, such as cardiopulmonary resuscitation, respiratory and circulatory support, and artificially administered nutrition, hydration and medications. The following describes the process to be followed when a medical provider or the Department believes that the medical situation of a child who is in Department care or custody requires decision-making regarding such interventions, including seeking a judicial action to forgo or discontinue LSMT.

Department regulations (110 CMR 11.12) do not permit the Department to make a decision about whether to forgo or discontinue LSMT, such as by ordering that a child in its custody not be resuscitated. A parent makes this decision when the child is in Department placement due to a Voluntary Placement Agreement or CHINS custody, and a court makes the decision when the child is otherwise in Department custody.

Any Department request for a court order must begin with a written recommendation to the Department by a treating physician that outlines the specific medical interventions that she/he believes should be withheld or withdrawn and the medical rationale. To determine the action it will take, the Department supports a thorough exploration of the child's situation and best interests in several ways by:

- working with the family,
- obtaining a second opinion from a consulting physician with appropriate expertise who is not affiliated with the hospital at which the child is being treated and does not have a direct business or financial relationship with the treating physician (hereinafter referred to as the "second opinion physician"), and
- obtaining a recommendation from the Ethics Committee of the treating hospital.

When the child is in Department non-CHINS court custody, it is the Department's responsibility to gather information from these sources as well as from the family of the affected child, the child herself/himself (when cognitively and emotionally appropriate), other health providers, therapists, educators, caretakers and others who are involved with the child, and formulate a recommendation on whether to pursue a judicial order. The Department's final decision to pursue the judicial order is made by the Commissioner, in consultation with the Deputy Commissioner of Field Operations and General Counsel. When diligent efforts do not result in a second opinion or one that provides sufficient information to support decision-making, the Commissioner will review all available information with the Deputy and General Counsel. The Commissioner will make a decision regarding a recommendation to the court based on the available information. The Department may seek additional perspectives from medical, ethical and legal experts at many junctures throughout the process.

IMPORTANT: *In those rare circumstances when a child's medical situation requires immediate decision-making regarding forgoing or discontinuing LSMT, the Department recognizes that the treating physician must use her/his best medical and ethical judgments on whether ongoing resuscitative efforts are medically indicated for the child, including a child who is in Department custody. It is not the intention of this policy to interfere with or impede a physician who faces such a medical emergency, or to replace the medical community's routine expectations regarding such judgments and how they are made and reviewed.*

Family Roles in the Process

The Department endeavors to inform **both parents** of a situation in which an order to forgo or discontinue LSMT is being considered. The child's legal status affects the parents' and Department's specific roles in decisions regarding forgoing or discontinuing LSMT as described below.

Children in Placement Due to VPA or CHINS Custody. If decisions are required regarding forgoing or discontinuing LSMT for a child who is in placement due to a Voluntary Placement Agreement or CHINS custody, *only* a parent can consent. The Department arranges for parents to be informed as soon as it learns of any situation that requires such a decision to be made, and provides support to the parents. If no parent is available or able to make decisions regarding medical treatment, the Clinical staff must contact the Legal staff to discuss how the situation will be addressed.

Children in Non-CHINS Court Custody. When the child is in Department non-CHINS court custody, parents are informed that the Department, along with other entities (such as the physician, hospital or parents themselves), has authority to proceed with a request to obtain an order regarding forgoing or discontinuing LSMT. Most courts request information about the parent's wishes, regardless of the child's placement circumstances. Parents are encouraged to express their wishes about the request and ask questions. Efforts to inform include contacting incarcerated parents and those who are out of state when contact information is available.

If the Department determines that contacting a parent might pose a danger to the family, a safety plan is developed. The Department is not required to inform a parent that a decision regarding forgoing or discontinuing LSMT is needed if the parent's rights have been terminated. Whether or not the Department does inform the parent depends upon such issues as the child's adoption placement status and whether the parent continues to maintain positive contact with the child. *Please NOTE: A post-termination agreement may exist between the biological parents and the Department that will govern the sharing of information about forgoing or discontinuing LSMT.*

Even when parents have legal interests that directly conflict with the child's (e.g., when the child's health has been compromised by the actions or inactions of the parent), the Department may inform parents that an order to forgo or discontinue LSMT is being considered. This may occur in the context of the parents' legal case, and Department Legal staff should advise the Department how to proceed in these situations. The opportunity for parents to express their wishes may be critical to their emotional adjustment and that of other children in their care. It is possible for many reasons that parents may hold wishes that appear to conflict with the child's best interests; however, they should still be allowed to express these wishes, even if the court may rule against them or they will be unable to participate in court.

Children are considered able to be involved in making judgments about their own orders to forgo or discontinue LSMT, unless the treating medical or mental health providers determine that they are likely to suffer physical or psychological harm as a result of discussing the issue or there is a concern that they are not cognitively competent to adequately consider what is being proposed. If the treating medical providers believe that the child is able and competent to do so without risk of harm, the Department, with the assistance of the medical providers, informs the child that such an order is being considered and allows the child to express her/his wishes. Attorneys for all parties should be notified that such a decision is being contemplated.

For every situation, including those in which parental rights have been terminated but the child has not yet been placed with her/his adoptive family, the Department considers whether it is in the best interests of the child to convene a **family meeting** with the parents, and involving kin if the parents agree, in which the child's treating physician, medical providers, the child herself/himself and her/his caretakers can discuss the child's situation and any recommendations. Any such family meeting must be convened in accordance with the Department's confidentiality requirements.

When discussing LSMT with a family, the Department takes extra care to keep in mind the Department's Core Practice Values. The Department should remain especially sensitive to the cultural or religious background of the family, which may strongly influence their response.

PROCEDURES: OBTAINING A JUDICIAL ORDER TO FORGO OR DISCONTINUE LSMT FOR A CHILD IN DEPARTMENT NON-CHINS COURT CUSTODY

When the health of a child is so severely compromised that consideration of forgoing or discontinuing LSMT is appropriate, either the treating physician or the Department may initiate the discussion. For the **child who is in Department non-CHINS court custody**, the Department requires:

- a written recommendation from the treating physician, using the form the Department provides, that specifies the LSMT she/he proposes to forgo or discontinue and the rationale for the recommendation;
- a written recommendation from a second opinion physician; and
- the recommendation of the treating hospital's Ethics Committee using the form that the Department provides. The treating physician's and second opinion physician's recommendations are provided to the Ethics Committee for their consideration.

The Department Medical Services Unit supports the Area Office staff in obtaining the required information and conveys it to the Deputy Commissioner and General Counsel who review it and develop a recommendation for decision-making by the Commissioner, including that the Department may:

- advocate in court for the recommendation(s) made by the treating and consulting physicians and hospital's Ethics Committee;
- inform the court of its disagreement(s) with the recommendation(s) made by the treating and second opinion physicians and hospital's Ethics Committee;
- develop and present in court a modification of the recommendation(s) of the treating and second opinion physicians and hospital's Ethics Committee; or
- decide not to file a recommendation in court.

*[NOTE: As indicated above, when forgoing or discontinuing LSMT is being considered for a **child who is in Department placement voluntarily or due to CHINS custody**, the parent makes the decision. The Department's role is to support them in this process. However, if the parent is unavailable or unable to make the decision, Department Legal staff should be consulted.]*

Area Office Staff Responsibilities

[NOTE: In the procedures below, the term "manager designee" indicates someone other than a Social Worker or Supervisor who is a member of SEIU Local 509.]

1. **Initial Discussions Regarding a Decision to Forgo or Discontinue LSMT.** At a minimum, the Area Office staff contact the treating physician or medical provider to discuss the child's current medical status. The Area Office staff may also convene a meeting with parents and/or kin (if parents agree and Department confidentiality requirements allow), the treating physician and/or medical provider to discuss the child's current medical status, diagnoses, treatment options, prognoses and recommendations regarding the forgoing or discontinuing of LSMT.
2. **Notification of Department Staff.** As soon as a treating physician or medical provider informs Department Area Office staff, or Department Area Office staff otherwise become aware that the child's physical condition may require decision-making regarding forgoing or discontinuing LSMT, the Area Director/manager designee verbally notifies the **Regional Director/manager designee, Regional Counsel/designee and Medical Services Unit.**
3. **Initial Information Provided to Medical Services Unit.** The Area Director/manager designee communicates the following information to the Medical Services Unit verbally and/or in writing:
 - the child's name, date of birth and the name(s) of the parent(s);
 - the child's current location;
 - name(s) and telephone number(s) of the treating physician and any other medical provider(s);
 - the child's current legal status;
 - the child's medical circumstances and the treating physician's recommendation, including a copy of the completed and signed Physician's Recommendation Form as soon as available;

- whether the parents have been informed and their wishes with regard to the medical provider's recommendations. If a parent cannot be located or is unable to communicate her/his wishes, this should include an explanation of these circumstances and the efforts that were made to obtain information from her/him regarding the recommendations;
 - whether the child has been informed of the request, and if so, the child's wishes with regard to the treating physician's recommendations;
 - the status of arrangements to obtain the second opinion physician's written recommendation; *[NOTE: Procedures for obtaining a second opinion are described below.]*
 - whether a hospital Ethics Committee has reviewed the recommendations from the treating and second opinion physicians regarding forgoing or discontinuing LSMT, and if so, a copy of the completed and signed Ethics Committee Recommendation Form;
 - the name and contact information for any GAL appointed for the child and any report from the GAL regarding forgoing or discontinuing LSMT; and
 - the child's current placement if different from the child's current location.
4. **Required Submissions to Request Judicial Orders for Child in Department Non-CHINS Court Custody.** The Area Director/manager designee arranges for copies of the following to be submitted to the Department Medical Services Unit:
- the Department form completed and signed by the treating physician detailing the child's diagnoses, treatment options, prognoses and the physician's recommendation regarding forgoing or discontinuing LSMT for the child, with any supporting medical information;
 - the Department form completed and signed by the second opinion physician; and
 - the Department form completed and signed by the Ethics Committee of the hospital where the child receives treatment, detailing the Committee's recommendation regarding forgoing or discontinuing LSMT for the child.
5. **Distribution of LSMT Order to Medical and Personal Care Providers.** Upon receipt of an order consented to by either a court or a parent regarding LSMT, Department Area Office staff arrange for copies of the order to be provided to the emergency medical response team in the area in which the child resides, the foster/pre-adoptive parent or residential program (when applicable) and to all professionals involved with the care of the child (including the school, when the child is enrolled), and for a copy to be filed in the child's Department case record.
6. **Documentation of LSMT Orders.** Area Office staff arrange for information about the LSMT order to be documented in dictation and the child's FamilyNet health record.

Legal Staff Responsibilities

1. **Legal Filings.** Department Legal staff will be responsible for filing the applicable motions seeking an order to forgo or discontinue LSMT, if the Commissioner, in consultation with the Deputy Commissioner and General Counsel, determines that such an order is appropriate.
2. **Appointment of GAL.** If not already appointed, Department Legal staff seek court appointment of a GAL.
3. **Review of GAL Report.** Department Legal staff review any available GAL report that considers a Do Not Resuscitate (DNR) or other order to forgo or discontinue LSMT. If a GAL report is not available, the Legal staff discusses recommendations with the GAL and ascertains the GAL's position.
4. **DA Notification.** Department Legal manager/designee notifies the District Attorney if information is obtained that the child's medical situation may be related to criminal activity and there is or previously has been a DA referral made by the Department related to the child's injuries or condition.
5. **Coordination with Medical Facility Legal Staff.** Department Legal staff coordinate communications between the legal staff of the Department and the medical facility, if indicated.
6. **Coordination with Medical Provider and Other Clinicians.** If necessary, Department Legal staff meet with the child's treating physician and other clinicians involved with the child's care.

7. **Distribution of Judicial Orders.** Department Legal staff coordinate with Area Office staff to arrange for copies of any judicial order to be:
 - provided to the Department's Medical Services Unit, the medical facility, the foster/pre-adoptive parent, any other medical provider, school (as needed), emergency medical response team and other caretakers, and
 - placed in the child's Department record.
8. **Documenting Judicial Orders.** Department Legal staff arrange for information about the order to be documented in the child's FamilyNet legal record and place a copy of the order in the legal file for the custody case.

Central Office Staff Responsibilities

1. **Review of Request for Judicial Order to Forgo or Discontinue LSMT for Child in Department Non-CHINS Court Custody.** The Medical Services Unit:
 - assists Area Office staff in obtaining the written recommendations from the treating physician, second opinion physician and treating hospital's Ethics Committee, as needed;
 - reviews for completeness the signed form from the treating physician (including any supporting medical information), the signed form from the second opinion physician, the signed form from the hospital Ethics Committee, and the information from Area Office staff;
 - discusses the situation directly with the treating physician and/or other provider(s) if necessary; and
 - forwards the request to the Deputy Commissioner.
2. **Review by the Deputy Commissioner and General Counsel.** The Deputy Commissioner and General Counsel review the request, in consultation with the treating physician or medical provider and any medical, ethical and/or legal experts if necessary, and develop a recommendation which they communicate to the Commissioner. They may convene a meeting to discuss the information and develop the recommendation.
3. **Review by Commissioner:** The Commissioner makes the final decision regarding any recommendation to be made in court, in consultation with the Deputy Commissioner and General Counsel and/or any medical, ethical or legal experts she/he determines necessary. When diligent efforts do not result in a second opinion or one that provides sufficient information to support decision-making, the Commissioner will review all available information with the Deputy Commissioner and General Counsel. The Commissioner will make a decision regarding a recommendation to the court based on the available information. The final decision is forwarded to the Medical Services Unit.
4. **Communication of Commissioner's Decision.** The Medical Services Unit communicates the decision to the Area Office Clinical staff and Legal staff verbally and in writing.

Obtaining a Second Opinion from a Physician

The Medical Services Unit will assist in identifying physicians qualified to render a second opinion when a child's treating physician recommends decision-making regarding forgoing or discontinuing LSMT. Such a physician will not be affiliated with the hospital where the child receives treatment nor will she/he have a direct business or financial relationship with the treating physician.

Requesting Orders during Non-Business Hours

Recommendations to request an order to forgo or discontinue LSMT are most often *not* emergencies. There are few circumstances in which immediate action is necessary to meet the best interests of the child involved. Most recommendations that are received during non-business hours, including evenings, weekends, and holidays, can wait to be handled by the Area Office staff on the next business day.

If it is not feasible to wait until the next business day, the Area Director/manager designee should contact the Deputy Commissioner for approval to contact Legal staff with the request to obtain an order to forgo or discontinue LSMT. Under emergency circumstances, the Deputy Commissioner may attempt to arrange for a recommendation from a second opinion physician regarding the recommendation to forgo or discontinue LSMT. However, this should occur only in rare circumstances. The Medical Services Unit

should be notified on the next business day regarding the recommendation and any actions that have been taken.

Children who Enter Department Care or Custody with LSMT Orders

When a child whose health has been severely compromised enters Department care or custody with an order regarding forgoing or discontinuing LSMT already in place, the Area Director/manager designee:

- obtains a copy of the order from the parent or physician,
- documents this information in dictation and the child's FamilyNet health and legal records,
- forwards a copy of the order to the Medical Services Unit and
- places the copy of the order in the child's record.

When such a child enters Department placement due to a Voluntary Placement Agreement or CHINS custody, the parent(s)/guardian(s) maintains responsibility for any medical or legal decisions concerning LSMT. When such a child enters placement due to non-CHINS court custody, the Area Director/manager designee notifies the RD/manager designee, Regional Counsel/designee and Medical Services Unit as described in "Area Office Staff Responsibilities," Procedure 2 and Procedure 3, bullets 1 through 7, above. The Medical Services Unit will assist the Area Office in determining whether it will be necessary for the treating physician or anyone else to complete a review of the existing order.

Department Responsibilities When Someone Other than the Department or a Parent Seeks an LSMT Order

In some situations, someone other than the Department or the parent will seek an order regarding forgoing or discontinuing LSMT on behalf of a child in Department care or custody. When this occurs, the Area Office staff document in dictation the information received regarding such actions, arrange for the Medical Services Unit to be notified, and continue to communicate with the child's medical providers as appropriate to the child's legal custody status. The Department enters into legal action as deemed appropriate to meet its responsibilities for acting on behalf of the child's best interests, utilizing the advice of medical, ethical and legal experts, as necessary, to formulate its recommendation to the court.

Implementing the Order

Each situation involving forgoing or discontinuing LSMT is unique. The Department carries out each order according to the directives of the court.

Periodic Reviews of Active LSMT Orders

The child's health status and any order to forgo or discontinue LSMT that is in place are reviewed as part of the Foster Care Review. The Department also provides for an annual review by the Medical Services Unit to determine whether there is reason to re-evaluate the existing order. The Medical Services Unit sends the Physician's Recommendation Form to the Area Director/manager designee. The Area Director/manager designee requests that the child's treating physician complete and sign the form and submit it to the Medical Services Unit with supporting documentation if she/he chooses. The Medical Services Unit may request clarification from the treating physician or consultation from other physicians if necessary to make a decision. If the Medical Services Unit determines that updated recommendations are needed, the procedures described above for review of new proposals to forgo or discontinue LSMT are followed. If no further review is necessary, the Medical Services Unit informs the Area Director/manager designee, sends a copy of the form to the Area Director and files the completed form with the copy of the existing order.

Responding to Changes in the Child's Medical Situation

If a Department manager learns of a change in the medical condition of a child who is in Department custody for whom an order to forgo or discontinue LSMT has been issued, she/he contacts the treating physician for a medical recommendation regarding whether the change in the child's condition warrants a review of the existing order. If the treating physician believes that a review of the existing order is warranted, the Department manager notifies the Medical Services Unit to initiate a review that follows the procedures above for periodic reviews.

Required Reconsideration When Anesthesia or Surgery is Required for Child for Whom a DNR Order is in Place

Anesthesia and surgery introduce additional risks for any patient and often necessitate medical interventions that may be precluded by an existing DNR order (e.g., intubation, mechanical ventilation). When either is considered for a child for whom a Do Not Resuscitate (DNR) order is in place, the American Academy of Pediatrics recommends that a required reconsideration of the order occur. The Department regards these as circumstances in which the child's medical situation has changed. When the child is in Department non-CHINS court custody, the Department follows the procedures above for Annual Reviews to determine whether to seek an amendment of any judicial order for the surgical and immediate post-operative period.

Further Reference

For information regarding the death of a child who is in Department care or custody, including organ donation, autopsy and funeral arrangements, see *Policy #90-002, Responding to a Child Fatality*.