

Withdrawing and Withholding of Life-Sustaining Treatment Policy

POLICY: The decision to withdraw or withhold life-sustaining treatment is always a difficult one and requires medical judgment, a consideration of personal values and much discussion between and among the medical care team, patient, and family. The following guidelines have been developed by Children's Ethics Committee to help all of those involved in such decisions understand the process of making the determination to withdraw or withhold life-sustaining treatment. The guidelines are intended to be a flexible guide, adaptable to individual situations, and are not intended to be rigid standards or a statement of legal requirements. Often times these determinations will be made with full agreement of the medical care team, patient, and family. In such instances, Ethics Consultation and Ethics Committee Review are not necessary.

In the event that the medical care team, patient, or family wishes reassurance or review of their decision, Ethics Consultation and/or Ethics Committee Review are available. At any time that there is an unresolved conflict among the medical care team or between the medical care team and the family regarding the issues of withdrawing and withholding life-sustaining treatment, Ethics Consultation and/or Ethics Committee Review are recommended and are available at the request of any of the parties involved.

PROCEDURE:

1. Determination that a life-sustaining treatment should be withdrawn or withheld

A. Definition

A life-sustaining intervention may, in certain circumstances, be withdrawn or withheld when there is no reasonable medical probability that it would be effective. (For example, continued ventilatory support in a patient with progressive respiratory failure despite maximal respiratory management might reach this point.)

B. Determination to Withdraw or Withhold Treatment

A determination that an intervention should be withdrawn or withheld in a particular Case requires agreement among the attending physician and two other physicians, at least one of whom is not directly involved in the care of the patient. Except in extremely unusual situations, as describe below, the agreement of the parent or legal guardian is also required.

C. Documentation

The required method for documenting that an intervention will be withdrawn or withheld is a note from each physician in the patient's chart stating that the intervention under consideration has no reasonable medical probability of effectiveness. All three physicians (the attending plus two) must write and sign notes. The agreement of the parent or legal guardian must also be documented.

D. Ethical Considerations

There is no ethical obligation to provide treatments that are ineffective. It is not the general policy of Children's to provide such intervention to patients. In general Children's encourages physicians to refrain from using these interventions.

- 1) There is an obligation of a single physician, usually the attending of record, to discuss the withholding or withdrawing of treatment at issue with the patient, parent or legal guardian and to ensure that other members of the patient care team are informed of the determination to withdraw or withhold treatment.
- 2) If the patient, parent or legal guardian concurs with the recommendations of the physicians, treatment may be withdrawn or withheld.
- 3) In the event of a dispute among members of the care team or between the care team and the parent or legal guardian, follow the pragmatic conflict resolution process described below. In cases of unresolved disagreement, court intervention may be invoked, as described below.

- 4) Exceptional reasons may exist for providing continuing treatment for short periods of time in order to provide short term benefit to family members.
- 5) The commitment to provide comfort care should be affirmed in discussions with the patient and family.

E. Conflict Resolution

The preferred sequence of steps for addressing disagreements among parties is:

- 1) Communication among parties
Every effort should be made to resolve conflicts about providing, withdrawing or withholding therapy through respectful discussion among the parties involved in the dispute. Strong consideration should be given to involving Social Work, Child Psychiatry and Pastoral and Spiritual Care in these discussions.
- 2) Ethics Consultation
If disagreement about the provision, withdrawing or withholding of treatment persists, an ethics consultation should be sought. (See appendix A for further detail.)
- 3) Ethics Committee
If disagreement about the provision, withdrawing or withholding treatment continues, the case should be referred to the full Ethics Committee for review. (See appendix A for further detail.)
- 4) Medical Director
Final resolution is the responsibility of the Medical Director. After these consultations, if the Medical Director determines that treatment should be withdrawn or withheld, but a disagreement persists with the parent or legal guardian, the Medical Director may choose to seek court intervention as set forth below.

F. Court Intervention to Withdraw or Withhold Treatment

In extremely rare cases, it may be appropriate to seek a court order to withdraw or withhold treatment even when the parent or legal guardian

disagrees. This section outlines both relevant considerations in making the decision to seek a court order and the process to follow in doing so.

1) Relevant Considerations

- Court intervention to override the wishes of a parent or legal guardian is extraordinary. In any such situation, the burden of proof will rest very heavily on the person or entity who wants to override those wishes, especially if the result is to hasten or fail to prevent the death of a minor patient. Any such decision will require a strong consensus that the parent or legal guardian's wishes are outside acceptable boundaries.
- Court intervention is possible under Washington law when a patient is abused, neglected or dependent. There can be a wide gulf between what clinicians may consider sub-optimal clinical decision-making, and the relevant legal standards of abuse, neglect or dependency. There is no legal mechanism for establishing a patient's "best interests" or promoting it through clinical decision-making.
- Clinicians, parents, the courts and the public mean different things when discussing the "best interests" of a patient. In general, clinicians tend to think there is one "best" course of action for a patient, primarily dictated by the patient's medical condition. Parents, the courts and the public tend to think in terms of a range of choices, many of which may be acceptable at any given time, and no one of which may be clearly "best" for all the issues facing the patient. In particular, these groups may give more weight to non-clinical considerations than do clinicians.
- In any case where a clinician believes that the acts of a parent or legal guardian constitute abuse or neglect, a report to Child Protective Services must be made. Prior to making such a report in cases involving a dispute over withdrawing or withholding treatment, clinicians should follow the suggestions for conflict resolution outlined above.
- In considering court intervention, Children's supports an analysis based on harm: where continuing the treatment at issue creates a

substantial risk of serious harm to the patient, which extends beyond the harm contemplated or expected if the clinician's recommendations are followed, court intervention may be warranted. There must be both a "substantial" risk, and the risk must be of "serious" harm, to warrant an override of the parent or legal guardian. The incremental benefit of the recommended course - not just the total benefit, but the increase in benefit over the course desired by the patient or legal guardian - should be substantial before any consideration of court intervention.

- Court intervention takes time. This time is likely measured in weeks if not months (though it is essentially impossible to predict total time). Clinicians should take this timing into account when considering the natural progression of the disease process and the feasibility of court intervention.

2) Process to Obtain Court Intervention

- When the conflict resolution process does not result in agreement between the care team and the parent or legal guardian, and the Medical Director believes that court intervention is in the best interests of the patient, the Medical Director will notify the President and Chief Executive Officer.
- When requested, the President/CEO will appoint an ad hoc committee to advise whether court intervention is appropriate. The ad hoc committee will include the Medical Director, the Nurse Executive, the General Counsel, and the Chair of the Ethics Committee, or their respective designees.
- The ad hoc committee will meet as soon as possible to consider the matter. The committee may request information or consultation from any employee or member of the Medical Staff. Unless there are compelling reasons not to do so, the ad hoc committee will meet with the legal guardian and solicit the guardian's views.
- The ad hoc committee will make its report and recommendations to the President/CEO as soon as possible. The committee will recommend

either that a) Children's should bring a court petition for appointment of an alternative guardian because the patient is abused, neglected or dependent; or b) Children's should not seek court intervention.

- The final decision whether to seek court intervention rests with the President/CEO

3) Court Intervention

- When the President/CEO determines to seek court intervention for appointment of an alternative guardian, the General Counsel will prepare or cause to be prepared the Petition and other legal documents to initiate the court action. The General Counsel may request supporting affidavits or other assistance from any appropriate children's employee or member of the Medical Staff.
- Children's will assure that the parent or other current legal guardian of the patient has legal counsel in proceedings on any Petition. If the parent or legal guardian is unable to afford counsel, Children's will pay for such counsel.
- The General Counsel will follow all procedural steps necessary to obtain a determination on the Petition at the trial court level, and will report the court's decision to all interested parties including the parent or other legal guardian, the President/CEO, the Medical Director, the Nurse Executive, the Chair of the Ethics Committee, and any involved clinicians.
- The President/CEO will determine whether to appeal any adverse court decision.

2. Ethical and Practical Considerations when Disputes Arise Regarding Withdrawing or Withholding Treatment

A. Ethical Considerations

All treatment decisions should be based on the patient's overall best interest. Best interests are determined by weighing relative benefits and burdens to the patient. Ideally, this weighing is done by the patient's family and the patient in consultation with the medical care team.

B. Necessary Elements of Care

Consistent with the informed consent of the patient, parent or legal guardian, Children's respects the integrity of all caregivers and supports provision of clinically appropriate necessary elements of care as determined by responsible clinicians. Patients, parents and legal guardians do not have the right to tell clinicians how to practice their profession. A clinician may determine that it is only ethical to offer a treatment or intervention on certain conditions. For example, it is reasonable, appropriate and ethical to require pain control following surgery; it is reasonable, appropriate and ethical to require anti-nausea medication as part of chemotherapy. Other determinations of necessary elements of care may be made by the care team. See the following policies on informed consent for more information: "Informed Consent to Operation, Post-operative Care, Anesthesia and Invasive Procedures Performed in the Operating Room or Ambulatory Surgery Area"; "Consent for Care and Treatment"; "Emergency Medical And Surgical Treatment Including Transfusion Of Blood And Blood Products For Minor Patients Without Parental Consent".

C. Staff support, at all levels, is crucial to help staff deal with clinical decisions that are contrary to the ones the staff member would make. Given the gap that sometimes arises between clinicians, perceptions of the ideal course of treatment and the willingness of the courts to intervene, staff may be called on to participate in care that they consider sub-optimal. Beyond upholding the principle that clinicians can define the scope of their care, as described in "Necessary Elements of Care", above, Children's also will give staff members the ability to opt out of care, if possible. It may not be possible to honor all requests to opt out of care in every situation involving withdrawing or withholding life-sustaining care. If sufficient numbers of staff choose to opt out of care, Children's may seek to transfer care to another institution if a transfer can be arranged.

D. Palliative care approaches have much to offer in cases involving difficult decisions and the risk of significant pain for the patient. Bringing in the

palliative care team early in the process makes palliation part of the normal care, not something only considered when therapeutic interventions are abandoned. Cure and pain control are important twin goals of care; they should be explicitly considered and balanced throughout the course of care.