

**OFFICE OF PUBLIC GUARDIAN
POLICY ON CRITICAL HEALTH CARE DECISIONS
1996
Updated: 2007**

I. Introduction

The role of the Office of Public Guardian is to protect and promote the health of all people we serve and to provide and seek treatment which will best promote the individual's overall well-being and functioning.

The role of Office of Public Guardian staff is to seek health care and make treatment decisions which will:

- A. Preserve life and maintain function.
- B. Consider the desires of the individual, his/her family, and his/her significant others.
- C. Be respectful of the dignity and integrity of the individual.
- D. Promote the individual's comfort and peace of mind.

The balance among these goals becomes a major concern in critical health care decisions.

II. Definitions

- A. "Critical health care decision" means a decision to authorize or withhold medical treatment which raises significant ethical considerations.
- B. "Terminal condition" means an incurable condition which, regardless of the application of life-saving procedures, will, within reasonable medical judgment, produce death, and where application of life sustaining procedures would only postpone the moment of death.
- C. "Irreversible condition" means a condition which is incurable. A decision to withhold medical treatment for an irreversible condition may be made when the burden of treatment outweighs the benefits of treatment to the person.

III. Role of the Guardian

All individuals who are unable to give consent to medical treatment should have a responsible person who is available to authorize medical treatment. For people who are not able to make decisions for themselves, this may be a family member who is actively involved with the individual, a health care agent, a private guardian (appointed by Probate Court), or a public guardian (appointed by either Family or Probate Court). A guardian with medical decision-making authority bears primary responsibility for decisions regarding initiation, continuation, or abatement of life-sustaining treatment.

A private or public guardian who has been appointed by a Vermont Probate Court must clear any major decision regarding treatment with the Probate Court.

Court approval is not required for medical treatment decisions by public guardians appointed by a Vermont Family Court; instead, Title 18, Section 9310 (a)(4) requires that “any decision to withhold or abate medical treatment for an irreversible or terminal condition shall be reviewed by the department’s ethics committee.”

IV. Planning Ahead for Critical Health Care Decisions

The need for end of life decision making will be a reality for most people regardless of their current state of health or disability. These decisions, while never easy, can be easier if pro-active advance care planning has occurred well before the time comes for the making of the specific critical health care decision. Depending on the stage of life of the individual and his or her health status, this planning can take different forms. For someone who is relatively young and healthy, this can look like documenting a casual conversation around the meaning of an individual’s comment of “I would never want that” when they see a story about a critically ill person in the media. For someone whose path to the end of their life is clearer, either due to chronic health problems or advanced age, these conversations may be more directive about the person’s interest in specific treatment options in specific circumstances. In any event, certain principles guide all of this planning.

- A. The individual needs to be involved in these ongoing conversations to the extent that he or she can.
- B. The individual’s care team and family play an important role in preparing for and carrying out critical health care decisions. As a result, even when the individual can participate only in a limited way, it can be a good idea for the family and team to explicitly address end of life planning before the need for critical decision making occurs.
- C. Planning for critical decisions is a dynamic process that changes as the individual’s situation changes. Options that seem reasonable for someone in good health may seem less reasonable when the person’s health declines.
- D. These plans should be documented to serve as a guide to future decision making.

V. Making Critical Health Care Decisions

In making critical care decisions for a patient with a persistent terminal condition or an irreversible condition, a guardian, together with the team which is supporting the individual, shall follow these steps:

- A. Before accepting a medical opinion that a patient's condition is terminal or irreversible, obtain a least one independent second medical opinion that supports the conclusion regarding the patient's condition. (There may be an exception in extraordinary situations where the diagnosis, prognosis, and treatment options are unquestionable, and further evaluation would be intrusive to the patient.)

If the second physician is of the opinion that the individual may recover with treatment, the guardian shall proceed on the basis of the opinion unless the guardian does not feel the second opinion is reliable, in which case yet another opinion should be sought.

- B. Discuss the options with the individual, his or her family, his or her religious representative, friends and support workers who know the individual well. The primary focus of these discussions is to assist the guardian to determine what the preferences of the individual would be if he or she were in a position to decide.
- C. Determine the goals of health care for this individual. In those situations where the patient's condition is terminal or irreversible, the primary goal of care may be to promote the comfort, dignity, and peace of mind of the individual.

No decision to withhold or abate medical treatment will be made based solely on the age or the level of disability of the person.

VI. The Ethics Committee

A. Composition

The Ethics Committee is a diverse group of people who have a personal or professional interest in the well being of people with developmental disabilities and/or people who are aging. The Chair of the Committee is a staff member of the Department of Disabilities, Aging and Independent Living (DAIL). The other members are not employees of DAIL although DAIL employees may attend the meetings. Members of the Committee are appointed by the Deputy Commissioner of the Division of Disability and Aging Services.

B. Role of the Ethics Committee

The function of the Ethics Committee is to review and give advice regarding critical health care decisions.

1. Any decisions by a Public Guardian to withhold or abate life-sustaining treatment for a person with a developmental disability **must** be reviewed by the Ethics Committee. Where prior review is not possible (see section VI.C.), review should be sought at the next meeting of the Ethics Committee. The director of the Office of Public Guardianship is responsible for deciding whether to request an emergency meeting of the Ethics Committee.

A decision by a Public Guardian appointed by the Probate Court to withhold or abate life-sustaining treatment **may** be reviewed by the Ethics Committee if it presents complex or difficult issues and Ethics Committee review would be helpful to the person, the court or the team.

2. The Committee is available to assist any interested person who is concerned with the ethical aspects of a critical care decision for a person who receives services through DDAS. An “interested person” must know the individual personally.
3. The Ethics Committee may advise DDAS in the development of policy concerning health care decisions about people with developmental disabilities and people who are aging

C. Emergency Decision

There are times when decisions to limit or withhold medical treatment may be made on an emergency basis prior to presentation to the Ethics Committee.

- I. Conditions where the decision is clear and post-decision review by the committee is deemed sufficient based upon:
 - a. Clear and consistent medical opinion from two independent medical sources,
 - b. Approval of the Director of the Office of Public Guardianship,
 - c. Strong agreement of the person’s team, **and**
 - d. Agreement by all known family members involved in the person’s life.
- II. Conditions where it is not possible to convene a timely emergency Ethics Committee meeting and where there is:
 - a. Determination of the Director of the Office of Public Guardianship and the Chair of the Ethics Committee that waiting to convene an Ethics Committee meeting is a greater burden upon the person than requiring treatment,
 - b. Strong agreement of the person’s team, **and**
 - c. Agreement by all known family members involved in the person’s life.

D. Frequency of meetings

The Ethics Committee meets bimonthly or when needed. Emergency meetings may be by conference call.

E. Confidentiality

Proceedings of the Ethics Committee are confidential. Any participants in the Ethics Committee process shall maintain the confidentiality of information specifically pertaining to an individual. All protected health information that is used in the course of reviewing Ethics Committee cases will be treated as confidential material (e.g., de-identified prior to distribution, extra copies shredded after use).

F. Advisory role

The role of the Ethics Committee is advisory. Final responsibility for any critical health care decision lies with the Office of Public Guardian.

If the Ethics Committee disagrees with a decision by a Public Guardian, the Chair of the Ethics Committee shall notify the Commissioner of the Department of Disabilities, Aging and Independent Living of the disagreement.