VERMONT

OFFICE OF PUBLIC GUARDIAN
END-OF-LIFE CARE DECISION MAKING

GUIDELINES
2016

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I. Introduction

The role of the Office of Public Guardian is to protect and promote the health of all people we serve and seek treatment which will best promote the individual's overall well-being and functioning. These guidelines support the role of the Public Guardian when seeking health care to make treatment decisions that will:

A. Be respectful of the dignity and integrity of the individual.

B. Optimize health and wellness and maintain function as long as possible.

C. Consider the desires of the individual, his/her family, and other people who have a significant role in his/her life.

D. Promote the individual's comfort and peace of mind.

The consideration of these four goals becomes the ultimate concern in end-of-life decisions.

II. Definitions

A. "Advance Care Planning" means an ongoing process of discussing, understanding, planning and documenting the individual's goals, values and wishes for specific treatments based on the individual's medical condition, personal preferences (to the degree known) and/or best interest.

B. "End-of-Life decision" means a decision to authorize or withhold medical treatment when there is a reasonable expectation that the individual may die within a year.

C. "Irreversible condition" means a condition that cannot be cured or eliminated.

D. "Terminal condition" *means an incurable condition and irreversible disease which would, within reasonable medical judgment, result in death within six months*. (Title 18, § 5281 (10))

E. "Advance Directive" is a document that describes an individual's treatment choices for life support measures and other end of life instructions. An advance directive *means a written record executed pursuant to section 9703, which may include appointment of an agent, identification of a preferred primary care clinician, instructions on health care desires or treatment goals, an anatomical gift as defined in subdivision 5238(1), disposition of remains, and funeral goods and services. The term includes documents designated under prior law as a durable power of attorney for health care or a terminal care document* (Title 18, 231, §9701 (1)). Advance directives which existed before guardianship remain in effect unless the Probate Court orders a review.

F. "Do-not-resuscitate order" or "DNR order" is a doctor's order that documents the decision to not attempt resuscitation in case an individual's heart were to stop or he/she were to stop breathing. A DNR order *means a written order of the patient's clinician directing health care providers not to attempt resuscitation.* (T18, 231 Section 9701 (8)) *A DNR order precludes efforts to resuscitate only in the event of cardiopulmonary arrest and does not affect other therapeutic interventions that may be appropriate for the patient.* (Title 18, 231, § 9708 (l))

G. "Clinician orders for life-sustaining treatment" or "COLST" *means a clinician's order or orders for treatment such as intubation, mechanical ventilation, transfer to hospital, antibiotics, artificially administered nutrition, or another medical intervention. A COLST is designed for use in outpatient settings and health care facilities and may include a Do not Resuscitate (DNR) and/or Do not Intubate (DNI) order that meets the requirements of Section 9708.* (Title 18, 231, § 9701 (6)). A DNR/DNI order for individuals under public guardianship requires the completion of a COLST.

III. Role of the Public Guardian

A public guardian (appointed by either Family or Probate Court) with medical decision-making authority bears primary responsibility for advance care planning and decisions regarding initiation, continuation or abatement of life-sustaining treatment. Clinical care and treatment should be inclusive of the individual's preference. Proactive discussions with the individual (to the degree that s/he is able), caregiver(s), family members and clinician(s), anticipating likely future health care needs, and documenting decisions in an appropriate manner, can decrease crisis decision-making, and optimize the individual's autonomy and improve quality of care.

A public guardian considering a decision to withhold or abate medical treatment for an irreversible and/or terminal condition for a person with developmental disabilities is required to present the case to the Department of Disabilities, Aging and Independent Living (DAIL) Ethics Committee using the process described later in this guideline. A public guardian acting under a Title 14 guardianship order must obtain approval for any major decision regarding treatment from the appointing court. (Title 14, 111, § 3075)

See section VI and VII regarding how to prepare for reviews by the Ethics Committee and Probate Court.

IV. Advance Care Planning

The process of advance care planning is important for addressing future health care decisions that an individual is likely to face based on his/her current health situation, progressing medical condition(s) and/or advancing age. Planning for health care needs in advance of a health care crisis improves the quality of care for individuals at the end of life by aligning the individual's goals, values and priorities (when known) with available treatments options.

For an individual whose path to the end of their life is more certain, either due to emergent medical issues, chronic health problems or advanced age, these conversations may focus more on specific treatment options (e.g., resuscitation, intubation, tube feedings, transfer to hospital, antibiotics, etc.). Consideration of the benefits of any proposed treatment relative to the burdens associated with that treatment should be discussed.

In any event, the following principles guide 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 is a good idea for the family and team to explicitly explore advance care planning before the need for critical decision making occurs.

C. Advance care planning is a dynamic process that changes as the individual's situation changes. The discussion should be revisited periodically [as recommended in each individual's guardianship plan] or when an individual's health condition changes. Options that seem reasonable for someone in good health may seem less reasonable when the individual's health declines.

D. These discussions should be documented to serve as a guide to future critical health care decision making. [See resources at the end of this guideline.]

E. Advance directive documents may be helpful tools for advance care planning with seriously ill people, but they cannot be formally filed by a public guardian and do not constitute a DNR/DNI order for people under public guardianship. Instead, a COLST form must be completed in cases where the individual's disease trajectory is predictable, and limitations are appropriate in order to avoid harm without proportional benefit. (A DNR/COLST may also be completed to verify an individual's full code status.) Please refer to process described below in Section V.

V. End of Life Decision Making Process

When a person under guardianship is clearly approaching the end of life, and/or when the answer to the question, "Would you be surprised if this person passed away in the next year?" is, "No", advance care planning should be used to identify end of life treatment goals. In making end of

life decisions for an individual with an irreversible and/or terminal condition, a guardian, together with the team, which is supporting the individual, will follow the guidance below.

A. Obtain a written medical opinion from the individual's physician as to whether the individual's condition is irreversible and/or terminal, and, if so, the physician's recommendation regarding life sustaining treatment for this individual. If the medical opinion concerning the individual's condition is not clear, or if it is a Title 14 guardianship, obtain a 2nd medical opinion.

B. Determine the goals of end-of-life care, including life sustaining treatment options for the individual (e.g., maximize quality of life, avoid hospitalization, keep individual at home, prolong life as long as possible).

C. Discuss the options for medical procedures or treatment and the possibility of limiting treatment with the individual, his or her friends and support workers, family members, and others who know the individual well. Involve someone who is knowledgeable or experienced in palliative care medicine, if one is available. The primary focus of these discussions is to assist the guardian to determine what the preferences, goals and values of the individual would be if he or she were in a position to decide. If unable to ascertain the individual's preferences, consider what would be in the individual's best interest (i.e., what most people would want in a similar situation).

D. The decision to withhold medical treatment for an irreversible condition may be pursued when the burden of treatment outweighs the benefits of treatment to the individual. If this appears to be the case and the person has a developmental disability, the public guardian will present the person's situation to the Ethics Committee. Title 14 requests for elders will be presented to the Probate Court.

E. Please keep in mind that, *No decision to withhold or abate medical treatment will be made based solely on the age, economic level or the level of disability of the individual under guardianship.* (Title 14, § 3075 (f)(3))

VI. The DAIL Ethics Committee

A. Composition

The DAIL 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 elders. The make-up of the Committee shall include people from a variety of backgrounds such as ethics, medical, faith-based, disability and clinical and offer a balanced, thoughtful and informed perspective on end-of-life decision making issues.

The Chair of the Committee is assigned by the Director of the Developmental Disabilities Services Division (DDSD). The committee is managed by a staff member of the DDSD. The other members are not employees of DAIL although DAIL employees may attend the meetings. Membership of the Committee is approved by the Director of the Office of Public Guardian (OPG) at DDSD.

B. Role of the Ethics Committee

The function of the Ethics Committee is to review and make recommendations to OPG regarding end-of-life decisions. However, the role of the Committee is advisory and does not involve making diagnoses or treatment decisions outside of what medical professionals have advised. Final responsibility for any end-of-life decision for individuals with Title 18 guardianship lies with the Office of Public Guardian. If the Ethics Committee disagrees with a decision by a Public Guardian, the Director of OPG shall notify the Director of the Developmental Disabilities Services Division of the disagreement.

1. Decisions for Individuals under Public Guardianship:

    a. Any decisions by a Public Guardian to withhold or abate life-sustaining treatment for an individual with a developmental disability must be reviewed by the Ethics Committee (in person or by phone). Where prior review by the Ethics Committee is not possible (see Section VI.D.), review must be sought at a future 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.

    b. Any decisions by a Public Guardian to withhold or abate life-sustaining treatment for an elder under Title 14 guardianship may be reviewed by the Ethics Committee in circumstances where the guardian is struggling with decision-making prior to seeking approval by the Probate Court. The director of the Office of Public Guardianship is responsible for deciding whether to request an emergency meeting of the Ethics Committee.

2. Role in Policy Development: The Ethics Committee may advise DDSD in the development of policy concerning health care decisions about people with developmental disabilities and age-related health issues.

C. Confidentiality

All Ethics Committee members are required to sign Notice of Non-Disclosure agreements. 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., personal identifying information will be redacted prior to distribution and copies shredded after use).

D. Frequency of meetings

The Ethics Committee meets every other month or when needed. Emergency meetings may be by conference call.

E. Preparation for a Case Presentation at Ethics Committee

Information about the individual who is being presented to the Ethics Committee needs to be sent out to committee members prior to the review date. This written case review, briefly outlining the information described below, needs to be submitted to the Director of OPG one week prior to the presentation (or as soon as possible). Include only that information that is felt to be relevant to the specific case. The Director of OPG will review the materials to ensure the necessary information is included.

1. Name of the individual(s) presenting the case. Include names of other members of the individual's team who will participate in the discussion.

2. Reason for case review by the Ethics Committee
   a. Why is the case being brought to the committee?
   b. What are the specific questions that the committee needs to consider?

3. Description of the person (use initials only) and brief history
   a. Photograph of the person being reviewed, if possible
   b. Demographics and history: age, place of residence, background information
   c. Current situation: significant others (family, friends, staff), how they spend their time, where they work, etc.
   d. Relevant personal information: joys, fears, interests, abilities

4. Medical status
   a. General medical issues and list of medications
   b. Chronology of medical events leading up to present situation
   c. Diagnosis
   d. Prognosis
   e. Treatment options and recommendations

5. Goals of treatment for this individual and other issues to consider
   a. Comfort level of the person: Are they symptomatic? How do they respond to pain, hospitalization, enforced inactivity, etc.?
   b. Communication style: ability of the person to communicate (expression and comprehension)
   c. Person's understanding of, and input into, treatment options.
   d. Perspective and values of significant others (family, friends, staff, private guardian)
   e. What action has the guardian and/or treatment team already taken?
   f. What future actions are the guardian and/or treatment team considering?
   g. What is important to this person in the time he/she has left?
   h. What would this person consider to be "worse than death"?
   i. What would they be willing and able to tolerate to increase the amount of time they have left?

F. Required medical documentation. Include relevant documentation from the attending physician(s) and other medical specialist(s) as described in the *Guide for Physicians in Providing Medical Documentation for End-of-Life Decision-Making to the Office of Public Guardian*. The physician's letter(s) should include a description of medical status, a determination that the person has an irreversible and/or terminal condition, and the

physician's recommendation regarding life sustaining treatment for this individual. One physician letter is required for Title 18 guardianships if it is clear that the person's condition is irreversible and/or terminal; two physician letters are required if it is not clear. See Section VII for Title 14 Probate Court requirements.

G. The Meeting

Meetings are generally held at the Waterbury State Office Complex. In person attendance is preferred but participation via conference call is available as needed. Meetings typically last two hours, though individual presentations vary depending on the complexity of a case. Guardians will be notified with the approximate time of their presentation. The Guardian should arrive 30 minutes early but are welcome to attend the entire meeting.

The meeting is convened and facilitated by the designated Chair of the Ethics Committee. The Guardian provides a brief overview of the case and describes the questions for consideration by the committee. There is in-depth discussion about the case with questions asked by Committee members to obtain sufficient information in order to provide a recommendation. The Chair of the Ethics Committee summarizes the discussion and proposes recommendations of the committee. Each member indicates their position and consensus is sought.

H. Post Meeting

Minutes will be sent out to all participants of the meeting and committee members. Documentation usually outlines key issues discussed, questions and concerns, recommendations, and follow-up. The recommendations of the committee are advisory. The presenter may be asked to bring the case back to a future meeting in follow-up to recommendations made by the committee, or the Director may choose to report back to the committee on behalf of a Public Guardian.

VII. Probate Court – Title 14 Request for DNR/COLST and Notification of Death

A. Request for DNR/COLST

If medical guardianship is ordered under Title 14, the guardian is generally required to obtain prior written approval from the probate court before withholding or withdrawing life-sustaining treatment other than antibiotics, unless there are pre-existing advance directives, or it is impractical due to time constraints (see Section VIII).

If an individual completed advance directives before guardianship was established, they should be followed unless they have been revoked by the Probate Court. The guardian should request guidance from the court regarding this situation as soon as advance directives are discovered.

When the guardian has completed the end-of-life decision making process described in Section V, the guardian must submit a written request for court approval for a DNR/DNI

order (in the form of a letter) to the Probate Court. The written request should include the information described above (see Section VI.F), or, at minimum, include the following:

1. Description of the person and medical situation.
2. Description of process used to arrive at decision to request DNR and individual's involvement, preferences, values.
3. Description of opinions of other interested parties, especially family members.
4. Attach supporting documents from the individual's physician describing medical opinion and the likely outcome of attempts to resuscitate the individual. Because the Probate Courts vary in their requirements, the guardian should inquire about the Court's expectations. Some courts accept one physician's letter, while others expect one or more physicians to be on the phone during the hearing or even present in the court room.

B. Notification of Death

After an individual dies, the guardian must notify the Probate Court by phone or in writing and send a copy of the Death Certificate to the court.

VIII. Decisions When Prior-Review by Ethics Committee or Probate Court is not Possible

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 or review by the Probate Court. The Director of the Office of Public Guardian and the Chair of the Ethics Committee or Senior DDSD staff shall determine when the following conditions are met:

A. The decision is clear, and it is considered to be impractical to convene a timely Ethics Committee meeting or Probate Court hearing, and

B. Clear medical opinion (preferably written[1]) indicates the individual has an irreversible and/or terminal condition and specifies that life-saving attempts are not indicated given the individual's current health situation.

In addition, the public guardian shall seek agreement from the rest of the individual's team and from known family members involved in the individual's life and who are available to give input. Ultimately it is the guardian who makes the final decision.

The guardian shall present the case at a future Ethics Committee meeting, even if the person has died.

In Title 14 guardianship, if the person under guardianship is likely to experience cardiopulmonary arrest before court approval can be obtained, the guardian shall immediately notify the court of the need for a decision by phone, shall obtain the clinician's certification prior to consenting to the do-not-resuscitate order, and shall file the clinician's certification with the court after consent has been given. (Title 14, 111, § 3075 (g1) (D))

[1] When it is not possible to get a written medical opinion in the event of an emergency, a verbal agreement from a doctor will suffice but a written statement from the doctor will be required for the post-decision review by the Ethics Committee

IX. Resources:

Instructions for Clinicians Completing Vermont DNR/COLST Form
Vermont Ethics Network, Vermont Ethics Network, 61 Elm Street, Montpelier, VT 05602 Tel: (802) 828-2909, Fax: (802) 828-2646, www.vtethicsnetwork.org
http://www.vtethicsnetwork.org/forms/dnr_colst_instructions%20and%20Form%2009.pdf

Thinking Ahead: My Way, My Choice, My Life at the End. Coalition for Compassionate Care of California, 1331 Garden Highway, Suite 100, Sacramento, CA 95833, 916-489-2222, www.coalitionccc.org.
http://coalitionccc.org/wp-content/uploads/2014/01/Thinking-Ahead-English-web.pdf

Thinking Ahead Matters: Supporting and Improving Healthcare Decision-Making and End-Of-Life Planning for People with Intellectual and Developmental Disabilities. Coalition for Compassionate Care of California, 1331 Garden Highway, Suite 100, Sacramento, CA 95833, 916-489-2222, January 2015. www.coalitionccc.org.
http://coalitionccc.org/wp-content/uploads/2015/10/thinking_ahead_matters_final.pdf

People Planning Ahead: Communicating Healthcare and End-of-Life Wishes, Leigh Ann Creaney Kingsbury, AAIDD, 2009