VNSNY HOSPICE & PALLIATIVE CARE
POLICY and PROCEDURE

TITLE: VSED: Responding to a Patient's Desire to Voluntarily Stop Eating and Drinking
APPLIES TO: Hospice
PREPARED BY: Hospice Administration and the Hospice Ethics Committee

PURPOSE: VNSNY Hospice & Palliative Care (VNSNY Hospice Care) recognizes the right of patients with decision-making capacity to exercise their autonomy by making decisions regarding their health care at the end of life, including decisions to voluntarily stop eating and drinking (VSED). This policy and procedure document provides guidelines on how to respond to a patient who expresses a desire to VSED.

DEFINITION: VSED is the decision by a patient to voluntarily stop eating food and drinking liquids so that death can be hastened. It is distinct from (1) a natural reduction in the patient's appetite and interest in food or water that occurs as death becomes imminent, and (2) the refusal of artificial hydration and nutrition. An alternate definition is that VSED is a situation in which "a patient who is otherwise physically capable of taking nourishment makes an active decision to discontinue all oral intake and then is 'allowed to die' gradually, primarily of dehydration or some intervening complication" (Quill, Lo and Brock, 1997).
Oral intake of food and/or liquids is not considered a life-sustaining treatment under applicable laws, and, therefore, a decision to VSED is not considered a decision to withdraw or withhold life-sustaining treatment.

POLICY: It is central to the philosophy of VNSNY Hospice Care that its staff shall identify, assess, and respond to each patient's suffering and symptom distress in a manner consistent with the patient's wishes and best practice standards. If death is not imminent from an underlying terminal condition, VSED can hasten death. For this reason, some patients of VNSNY Hospice Care may verbalize a desire to VSED with the intent to hasten their death. A choice to voluntarily stop eating and drinking is a patient-centered decision that is legally and ethically distinct from aid-in- dying and euthanasia. Because this action is considered to fall within the well-settled right of capable patients to refuse any unwanted intervention, VSED is an ethical and legal option in New York and all other states. In cases where patients with decision-making capacity clearly express their wish to engage the VSED process, VNSNY Hospice staff shall provide continued care and support to such patients and their families, in

accordance with procedures outlined below. In cases where the patient lacks decision-making capacity, VSED cannot be initiated. Hospice team should aggressively work with patient and caregivers to alleviate patient distress. Caregivers can be educated about appropriate feeding adjustments to accommodate disease progression. VSED does not apply to artificial nutrition and hydration (for more information see the policy Withdrawing and Withholding Life Sustaining Treatment)

PROCEDURE

1. Once a patient has expressed his/her desire to VSED, the patient's desire, and reasons for that desire, should be explored by the interdisciplinary team (IDT). For patients whose insufficiently relieved suffering or symptom distress are contributing to the request for VSED, members of the IDT should ensure that all reasonable efforts to alleviate physical, spiritual or emotional suffering have been offered to the patient, and that attempts to address such distress and suffering have been documented.

2. A patient's decision-making capacity should be assessed and documented as outlined in the Hospice policy entitled, "Decisional Capacity".

3. The Hospice IDT should then use best efforts to meet within three (3) days of the patient's expressed desire to discuss the patient. At a minimum, a clinician from each of the core hospice care disciplines should participate in this discussion and consider the following:
    a. whether the patient has decision-making capacity, as assessed in (2) above;
    b. whether the patient's desires are *rational*;
        i. A rational desire to voluntarily hasten death by stopping eating and drinking is defined as follows:
            1. the patient has a realistic assessment of his/her health status and prognosis, and an accurate understanding of the likely outcome of engaging in VSED;
            2. the cognitive process leading to the decision is unimpaired by mental illness, severe and reversible emotional distress, or delirium; and
            3. the motivational basis of his/her decision would be understandable to the majority of uninvolved observers from his/her community or social group. (Note: "understandable" means "able to be *comprehended*," and does not imply or require that such observers would *agree* with such a decision.)
    c. whether the patient's choice is *voluntary*;
        i. To determine whether a decision is voluntary, the following factors should be considered:
            1. The patient's choice is not made subject to (a) coercion from third parties or (b) lack of disclosure or understanding of relevant information.

2. Best efforts have been made to control pain and/or suffering so that the patient is not experiencing duress.
3. Where possible, the patient is able to explain the reasons for his or her choice and how the choice is consistent with those reasons.

d. whether there is documentation of the patient's wishes regarding life-sustaining treatment and other related decisions. If there is not documentation, the patient's wishes shall be explored and documented before the patient loses capacity to make and articulate those decisions as part of the VSED process;
e. whether psychosocial and spiritual interventions, as assessed and identified by the social worker and spiritual counselor, have been explained and offered to the patient; and
f. whether the patient's support system, (i.e., the patient's involved family, friends, health care agent or surrogate, family employed substitute, and/or home health aide ("Support System")), if any, has been fully engaged in the patient's care to the extent practicable and permitted by the patient, and understands (with the patient's permission) the patient's decision and its likely outcome.

4. If the IDT concurs that the patient has decision-making capacity, the decision to engage VSED is rational and voluntary, and the patient's physical, emotional and spiritual needs are being supported by the team and the patient's Support System, then the patient's Social Worker/COC and/or hospice team manager should notify the attending physician of the patient's decision and the IDT's willingness to support the decision. If the patient's attending physician is unavailable or unwilling to support the patient's decision, the Hospice Medical Director shall be notified and an alternate physician selected, in collaboration with the patient, to direct the patient's medical care.

5. The Social Worker/COC should have an informed discussion with the patient and his/her Support System about the process of voluntarily stopping eating and drinking, the likely effect of the process on the patient's experience and expected prognosis, the various ways the IDT will support the patient through the process, and how the Support System shall support the patient. This conversation shall ensure that the patient understands that he/she may change his/her mind at any point in the process. The patient and the Support System should be informed about what to expect as the patient continues through the process of stopping all oral intake and how changes in the process (e.g., the patient choosing to occasionally eat or take sips of water) may alter the patient's experience and prognosis. This conversation must be documented in the patient's medical record.

6. The willingness of the patient's Support System to support the patient through the VSED process should be assessed, confirmed, and documented. The Support System does not need to agree with the patient's decision but should remain informed, subject to the consent of the patient to do so. If the Support System

interferes with the patient's execution of his or her wishes, the IDT should discuss promptly referring the matter to the Ethics Committee.

7. As loss of decision-making capacity is an expected part of the VSED process, a plan for healthcare decisions once the patient loses decision-making capacity should be agreed upon by the patient and health care agent or surrogate, and the plan should be thoroughly documented in the patient's medical record. Patients should be encouraged to discuss their preferences with their health care agent or surrogate. If the patient's wishes regarding VSED deviate significantly from wishes expressed in an earlier advance directive, patients should be encouraged to complete a new advance directive, subject to the provisions of applicable New York State law. **See,** *Advance Directives*.

8. Note that, **the *expressed care wishes of a capable patient survive the loss of capacity and must be honored by caregivers***. This means that, after the patient has lost decision-making capacity and the health care agent or surrogate assumes decision making on behalf of the patient, a prior decision by the patient when capable, including the withdrawing or withholding of life-sustaining treatment, which was expressed to a registered professional nurse, nurse practitioner, physician, physician assistant, psychologist or licensed clinical social worker in the presence of another witness, ***must be honored*** *by the attending physician*. The physician shall record the patient's prior decision in the patient's medical record and his/her reliance on that prior decision. The physician shall make diligent efforts to notify the Surrogate prior to implementing any decision and document such attempts in the record.

9. Patients shall be encouraged to sign a DNR order before beginning VSED, following a discussion about the reasons why the order is recommended.

10. VNSNY Hospice staff shall provide appropriate support and symptom management for the patient and his/her family once the patient has decided to begin VSED. This includes providing palliation for any symptoms associated with the cessation of eating and drinking, as well as providing ongoing emotional and spiritual support to the patient and the family.

11. If, after a patient has begun VSED, the patient requests food or drink, then food or drink should be offered. If the patient continues to request food or drink, then the nurse should meet with the patient to discuss whether the patient wants to continue with his/her plan to engage the VSED process. If the patient does not want to continue with VSED, the overall plan must be reevaluated. Regardless of whether the patient continues to have decision-making capacity, the IDT team shall honor the patient's request to resume eating and drinking.

12. VNSNY Hospice care shall offer bereavement support and services to the family after the death of the patient.

13. No VNSNY Hospice staff member shall be required to provide any care or treatment that violates his or her fundamental moral precepts. Because VNSNY Hospice staff must not abandon patients who VSED, staff who are not comfortable with a patient's decision must ensure a prompt and orderly transfer of the patient to another staff member who is willing to continue providing care for the patient and family.

STANDARDS:

Community Health Accreditation Program, HI.5
Medicare Conditions of Participation for Hospice Care, CFR 42 §418.52(c)
New York Family Health Care Decision Act (NY Public Health Law Article 29-CC)

REFERENCES:

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Medicare Conditions of Participation for Hospice Care, Code of Federal Regulations (CFR) 42 §418.52(c), October 1, 2010.

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SEE RELATED HOSPICE POLICIES:
Advance Directives, Decisional Capacity, Identifying A Surrogate, Patient Rights and Responsibilities, Psychosocial Services

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