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VERMONT ADVANCE CARE PLANNING: FACILITATOR TRAINING

CHALLENGING SITUATIONS

SESSION 4

MARCH 24, 2026

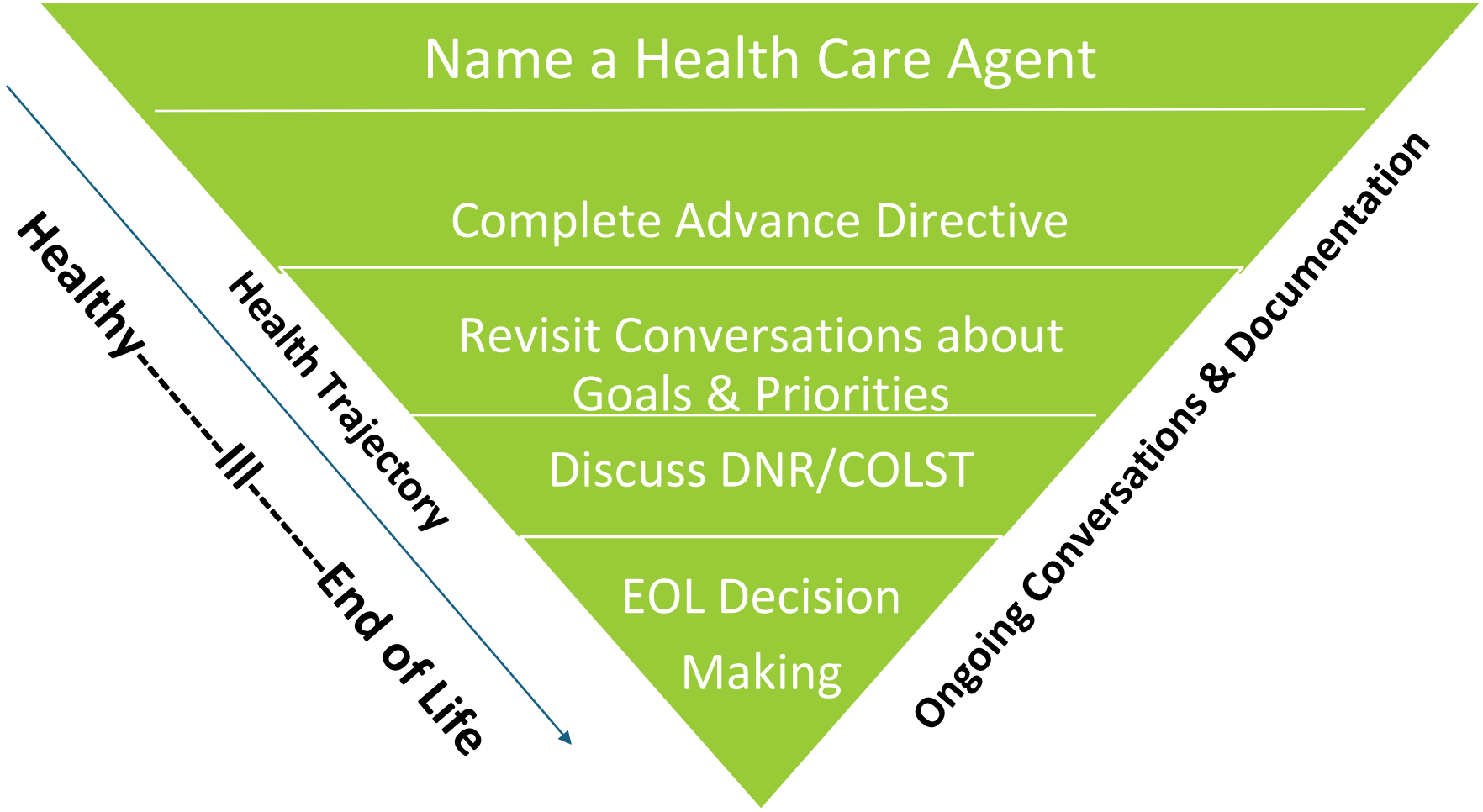
Learning Goals & Objectives

Appreciate the relationship between decision-making capacity, informed consent and competence

Support individuals with ACP documentation there are disease-specific concerns

Describe situations when use of the Vermont Ulysses Clause may be appropriate

ACP Continuum



Shigeko Izumi, PhD, RN, FPCN1 and Erik K. Fromme, MD, MCR, FPCN. Jour*nal of Palliative Medicine*. Vol 20; No.7, 2017

Advance Directives vs. DNR/COLST Orders

Advance Directives

Preference-based documents *completed by a capacitated individuals* to guide **future** medical decisions.

DNR/COLST Orders

Portable medical order *completed by a clinician;* outcome of shared a decision-making process; requires informed consent; intended to guide **current** treatment decisions.

Case Scenario 1

67 year old with past history of alcohol use disorder (AUD); has not had a drink in the last 5 years

Recently unhoused; now living in an assisted living setting

Suffers from hypertension, hyperlipidemia and COPD; remains a heavy smoker

Completion of an AD has been recommended

SASH RN has been visiting and has noted significant memory impairment; unclear if it’s related to prior AUD or some kind of dementia

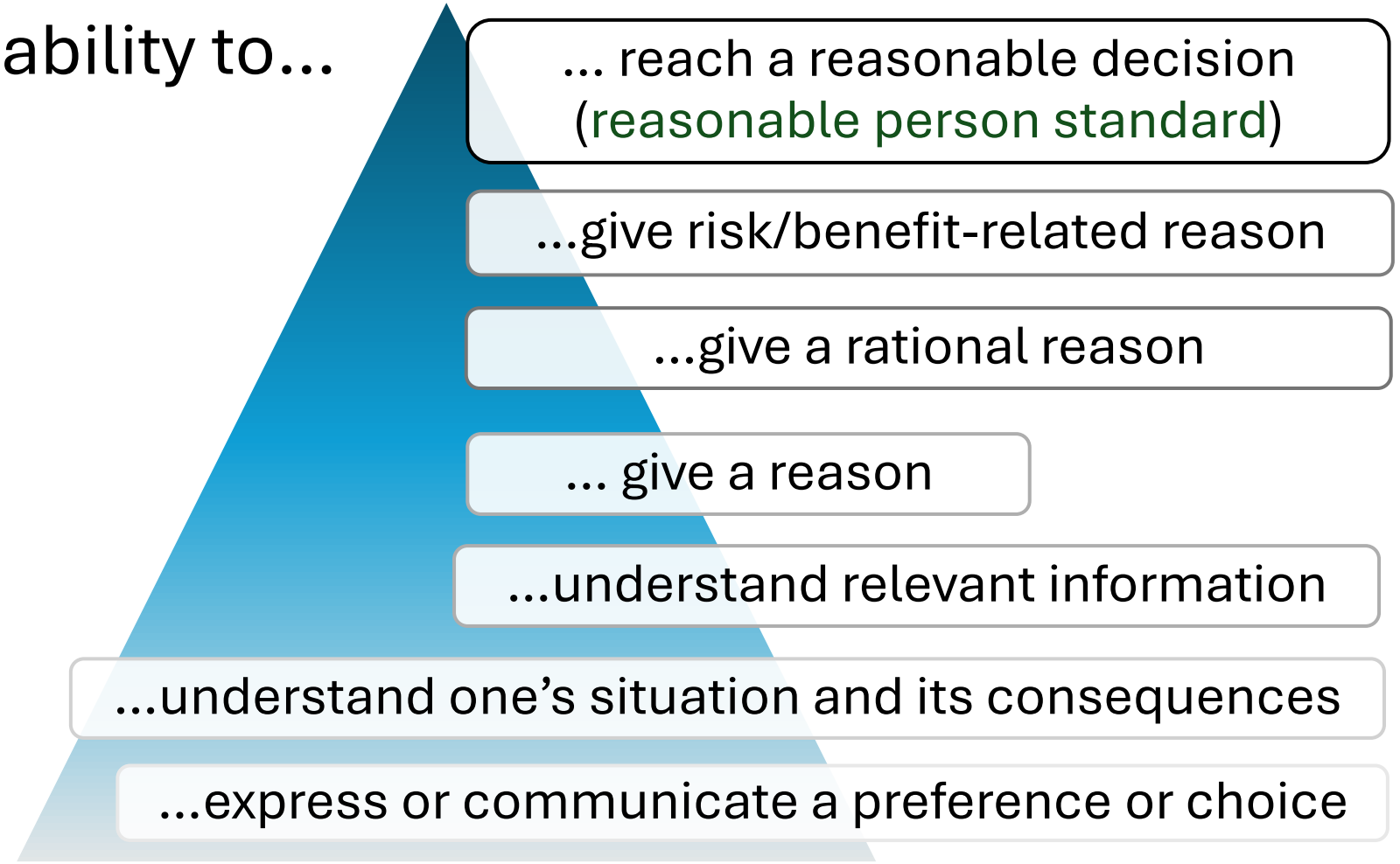
Concern about completing ACP docs when there is evidence of short-term memory loss

Capacity

- Presumed
- Decision specific
- Uncertainty managed in the direction of the presumption
- Cognitive (understanding) and functional (ability)
- ≠ Competence

Levels of Decision-Making Capacity

The ability to…



Capacity Applied

Patients with intact decision-making capacity decide which/how much treatment to accept or refuse

Our role is to educate, to partner, and respect when adult patients make adult choices (even if unwise or unsafe)

Case Scenario 1 – Take Aways

Memory loss does not automatically equal lack of decision-making capacity
The less complex and less risky the decision—the less capacity is needed
Higher the risk, higher the complexity – more capacity required
Naming of a health care agent is generally low risk, low complexity
Promote to make decisions and complete documents appropriate to level of decisional capacity.

Case Scenario 2

- 72 y.o. with newly diagnosed heart failure, chronic kidney disease, T2DM, and peripheral vascular disease
- Exacerbation of HF, hospitalized for 3 weeks; in and out of ICU
- Spouse struggles and get anxious in hospitals
- Has adult children who live locally.
- Advised to think about doing some advance care planning
- Meets with ACP facilitator and shares that the primary goal is to “do everything” to live as long as possible, no matter what.

Advance Care Planning

What's your approach?

Which form might you use and why?

What aspects of naming a health care agent might be important to consider?

How might you discuss a preference to "do everything"?

Realistic Expectations

- Consider the ACP tool wisely – when are values and goals more helpful than a menu of treatment options
- Support thoughtful choice of Health Care Agent
- Set the stage for realistic expectations and more discussion
- Nuance and/or inconsistency *is navigable* in an advance directive and should be expected
- Not all combinations of treatments work
- Medical reasonability/appropriateness CAN/MAY supersede preferences
- DNR/COLST is not merely a tool for documenting code status and using it as such is problematic

Case Scenario 3

85 y.o. with a history of Alzheimer's dementia, COPD, peripheral vascular disease

Presented to hospital with hip fracture following a fall

Received surgical repair of hip fracture; hospital course complicated by heart attack and sepsis.

2022 Advance Directive that says “do everything”; Agent now deceased; no family

Guardianship through OPG in 2024

Team looking to institute DNR/DNI orders prior to discharge

Surrogate Authority

Health Care Agent

- No limits; all decisions patient could make if capacitated
- Substituted judgement first; then best interest

Guardian

- Authority determined by court order
- No default authority for foregoing LST, for treatment over objection or change of residence over objection

Informal Surrogate

- No hierarchy, statute largely silent
- Framework for consent for hospice and DNR/COLST

Decision-Making with a Guardian

- If there was an AD prior to guardianship, obligation to look at and follow the instructions of the individual (to the degree possible).

- If no AD, the person and their guardian (along with other people who are important to the individual) should discuss and determine preferences and treatment at end-of-life.
  - Include the individual's clinician when possible

When Prior Court Approval is Needed

- Guardian has to seek prior approval from the Court:
  - When the person under guardianship objects to the decision;
  - When the court had previously ordered that the decision would not be made without a hearing;
  - **Before withholding/withdrawing life sustaining treatment, other than antibiotics, (unless under an advance directive), except in an emergency*; or**
  - **Before consenting to a DNR order (unless pursuant to an advance directive), except in an emergency**.**

** when a decision needs to be made before a court decision could be made*

*** when the clinician certifies in writing that the patient is likely to experience cardiopulmonary arrest before a court order can be obtained.*

NOTE: Title 14 Guardianship – Probate Court (Private & Elders with Public Guardian)

Prior Approval by DAIL Ethics Committee

For persons with developmental disabilities who are under public guardianship:

- Any decision to withhold or withdraw medical treatment for an irreversible or terminal condition shall be reviewed by the DAIL Ethics Committee.

NOTE: Title 18 Guardianships

Case Scenario 4

- 65 year old man, active and in good health
- Stops by a community table asking for help with an AD
- Says he is healthy now, but cared for his mom with progressive Dementia through death a few years ago
- “It was awful. I don’t want to go through that”
- Has heard about something called a “dementia directive”
- Wants to know if having one of those will ensure he doesn’t experience what his Mom did.

STATEMENT OF TREATMENT PREFERENCES
THE DARTMOUTH DEMENTIA DIRECTIVE

DDD V 39 – 11/25/2022

THE DARTMOUTH DEMENTIA DIRECTIVE

An advance care document for dementia care planning

CHOICES FOR CARE IF I HAVE DEMENTIA AND LACK DECISIONAL CAPACITY:			
MEDICAL INTERVENTIONS	**MILD DEMENTIA**	**MODERATE DEMENTIA**	**SEVERE DEMENTIA**
	Initial One Below	*Initial One Below*	*Initial One Below*
FULL TREATMENT: I want to remain alive for as long as possible, and I want to undergo all medical treatments and other interventions to prolong my life, including antibiotics, the use of CPR, or a ventilator, if necessary.			
LIMITED TREATMENT: I want to receive treatment to prolong life, or to see if I get better, but if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures (e.g. CPR, ventilator).			
COMFORT- FOCUSED TREATMENT ONLY: I want to receive only "comfort" care focused on relieving current suffering (e.g. pain or anxiety). I do not want care that would prolong my life. I want antibiotics only if these are necessary for my comfort.			
DPOA-HC SHOULD DECIDE: I do not wish to express any choices for medical interventions now. I wish my DPOA-HC to make these decisions in consultation with my healthcare providers.			

ADDITIONAL COMMENTS REGARDING TREATMENT PREFERENCES FOR MEDICAL INTERVENTIONS, INCLUDING DIRECTIONS TO MY DPOA-HC, MY FAMILY, AND/OR HEALTH CARE PROVIDERS
[ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

CHOICES FOR CARE IF I HAVE DEMENTIA AND LACK DECISIONAL CAPACITY, CONT.:			
LOCATION OF CARE	**MILD DEMENTIA**	**MODERATE DEMENTIA**	**SEVERE DEMENTIA**
	Initial One Below	*Initial One Below*	*Initial One Below*
HOSPITAL OR INPATIENT HOSPICE: I am willing to be admitted to a hospital or an inpatient hospice facility, or to receive hospice care at home.			
HOSPICE BUT NOT REGULAR HOSPITAL CARE: I would be willing to be admitted to a hospital for inpatient hospice care, but otherwise I do **not** want to be admitted **to** a hospital. I am willing to receive hospice care at home.			
NO HOSPITAL OR INPATIENT HOSPICE ADMISSION: I do not want to be admitted to a hospital or inpatient hospice facility unless my comfort cannot be maintained in the environment in which I am residing at the time. I would be willing to receive hospice care at home.			
DPOA-HC SHOULD DECIDE: I do not wish to express any location of care choices now. I wish my DPOA-HC to make these decisions in consultation with my healthcare providers.			

ADDITIONAL COMMENTS REGARDING TREATMENT PREFERENCES FOR LOCATION OF CARE, INCLUDING DIRECTIONS TO MY DPOA-HC, MY FAMILY, AND/OR HEALTH CARE PROVIDERS
[ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

CHOICES FOR CARE IF I HAVE DEMENTIA AND LACK DECISIONAL CAPACITY, CONT.:			
NUTRITION AND HYDRATION	**MILD DEMENTIA**	**MODERATE DEMENTIA**	**SEVERE DEMENTIA**
	Initial One Below	*Initial One Below*	*Initial One Below*
FULL NUTRITIONAL SUPPORT: I want to receive any form of nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings, tube feedings or intravenous nutrition.			
LIMITED NUTRITIONAL SUPPORT: I would accept assisted feedings until I no longer willingly open my mouth or otherwise indicate that I do not want to continue to receive nutrition. At that point, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. However, I do not want tube feeding or intravenous nutrition, but I would accept intravenous fluid replacement for dehydration or other reversible medical condition.			
NO NUTRITIONAL SUPPORT: I want to receive no nutrition if I cannot feed myself. I do not want to be offered food or fluids in any form if I cannot feed myself. However, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips.			
DPOA-HC SHOULD DECIDE: I do not wish to express any nutrition or hydration choices now. I wish my DPOA-HC to make these decisions in consultation with my health care providers.			

ADDITIONAL COMMENTS REGARDING TREATMENT PREFERENCES FOR NUTRITION AND HYDRATION, INCLUDING DIRECTIONS TO MY DPOA-HC, MY FAMILY, AND/OR HEALTH CARE PROVIDERS
[ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

Ulysses Clause

Waiver of Right to Request or Object to Future Treatment
(18 V.S.A. § 9707)

(h)(1) An advance directive executed in accordance with section 9703 of this title may contain **a provision permitting the agent, in the event that the principal lacks capacity, to authorize or withhold health care over the principal's objection.**

Ulysses Clause Provision Requirements 18 VSA § 9707(h)

- Requires naming of a health care agent who must sign and accept responsibility.
- Must **specify the treatments to which it applies** and include an **explicit statement that the person desires or does not desire the proposed treatments even over their objection.**
- Acknowledgment the person is knowingly and voluntarily waiving the right to refuse or receive treatment at a time of incapacity.
- Clinician has to sign and affirm they had an inform consent conversation with the patient about the specific treatments covered in the provision.
- Explainer needs to sign (ombudsman, mental health representative, VT licensed attorney or Probate Court designee) affirming they have explained the provision and there is no undue influence or duress on part of the person.

Long Form – Part 6 Page 1

NAME _____ DOB _____ DATE _____

PART 6: WAIVER OF RIGHT TO REQUEST OR OBJECT TO FUTURE TREATMENT

I hereby give my agent the authority to consent to or refuse the following treatment(s) over my objection if I am determined by two clinicians to lack capacity to make healthcare decisions at the time such treatment is considered:

1. **I *do* want** the following treatment to be provided, even over my objection, at the time the treatment is offered: _____

   I do *not* want the following treatment, even over my request for that treatment, at the time the treatment is offered: _____

2. I give permission for my agent to agree to have me admitted to a designated hospital or treatment facility even over my objection.

   _____ Yes _____ No

3. I give my agent permission to agree that my release from a voluntary admission for mental health treatment may be delayed even over my objection for up to four days so that a decision can be made regarding whether I meet criteria to be involuntarily committed.

   _____ Yes _____ No

4. I hereby affirm that I am knowingly and voluntarily waiving the right to refuse or request specified treatment at a time of incapacity, and that I understand that my doctor and one other clinician will determine whether or not I have capacity to make health care decisions at that time. I know that I can revoke this part of my Advance Directive only when I have the capacity to do so, as determined by my doctor and at least one other clinician.

Signed: _____ , Principal Date: _____

(Continued next page)

Specific Treatments

Voluntary Admission

Waiver of Right

Signature of Principal

NAME _____ DOB _____ DATE _____

Acknowledgements

Acknowledgement by Agent — I hereby accept the responsibility of consenting to or refusing the treatments specified above, even if to do so would be against the principal's expressed wishes at the time treatment is considered.

Signed: *(Agent)* _____ and *(Alternate)* _____

Print names:

Phone:

Date:

Acknowledgement of principal's clinician — I affirm that the principal appears to understand the benefits, risks, and alternatives to the health care specified above that is being consented to or refused by the principal.

Signed: _____ Title:

Facility: Date:

Please print name:

Acknowledgement by persons who explain Part 6 — I, as the designated person to explain Part 6, affirm that I am an ombudsman, mental health patient representative, an attorney licensed to practice in Vermont, or a probate court designee and that I have:

- Explained the nature and effect of this Waiver of the Right to Request or Object to Treatment to the principal, and
- The principal appears both to understand the nature and effect of this provision and to be free from duress or undue influence.
- If the principal is in a hospital at the time of signing, that I am not affiliated with that hospital, and
- I am not related to the principal, a reciprocal beneficiary, or the principal's clergy or a person who has exhibited special care and concern for the principal.

Signed: _____

Position: Date:

Part 6 - Page 2

Agent Acknowledgements

Clinician Acknowledgement

Explainer Acknowledgement

Utility & Limits of a Ulysses Clause

Situations where a Ulysses Clause may be helpful

- Psychiatric illness as part of Psychiatric AD
- Dementia with behavioral disturbance as addendum to Medical AD
- Permission for Covert Medications
- Operationalizing “do-not-spoon feed” preferences in a Medical AD

Limitations of Ulysses Clause

- Specific treatment focus
- Doesn’t give broad authority to override incapacitated refusals in any context
- Can’t address incapacitated revocation of health care agent
- Doesn’t appear to solve the “medical hold” problem

THANK YOU

Any Questions?

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