Tangled Terminology:
Avoiding the Ethical Pitfalls of Misnomers in Decision-Making Language

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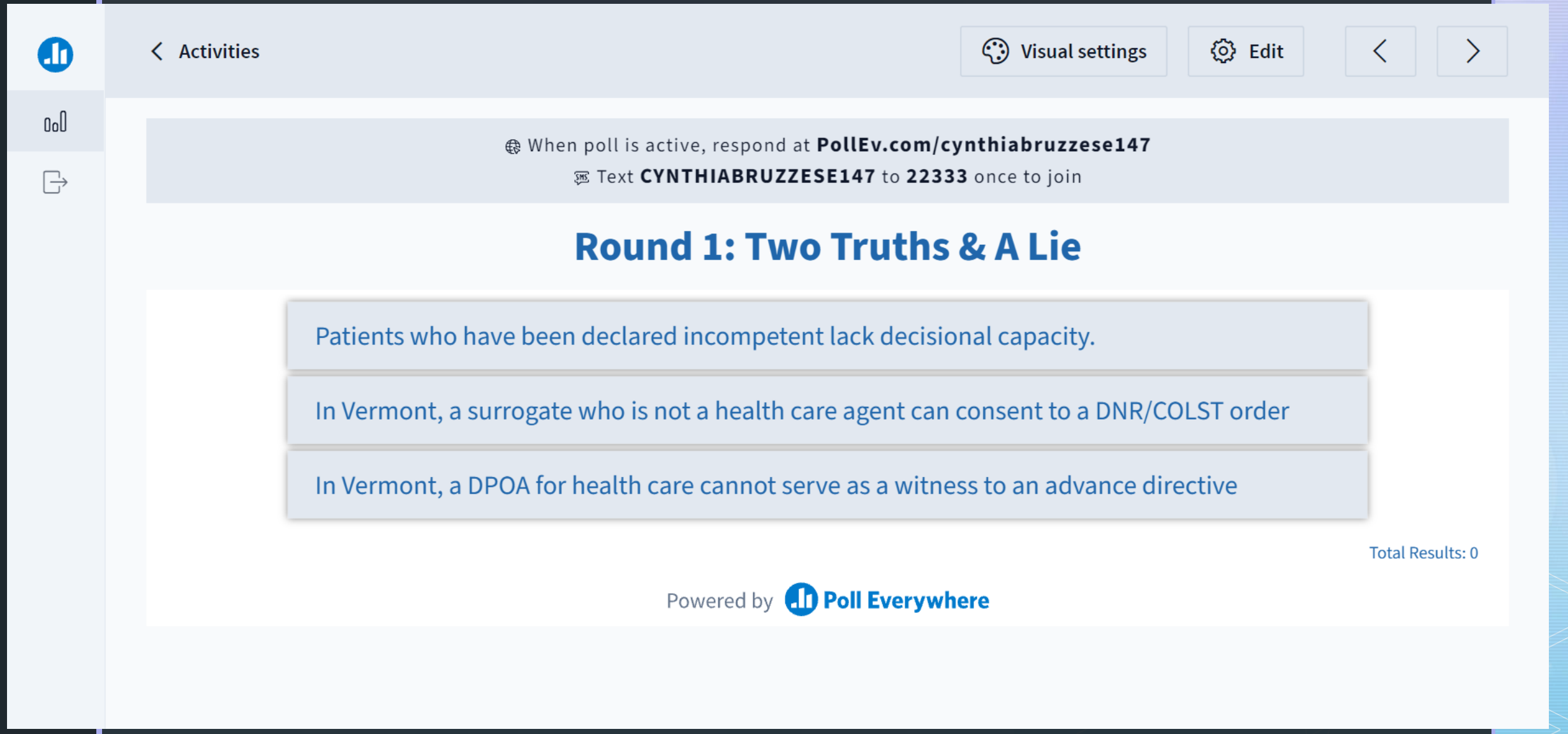
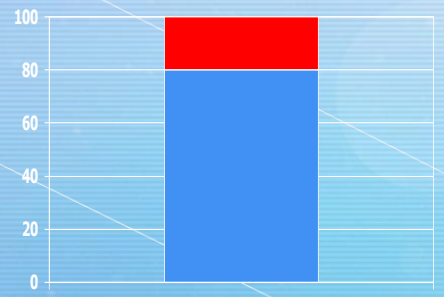
Let's Play a Game



Common Misnomers

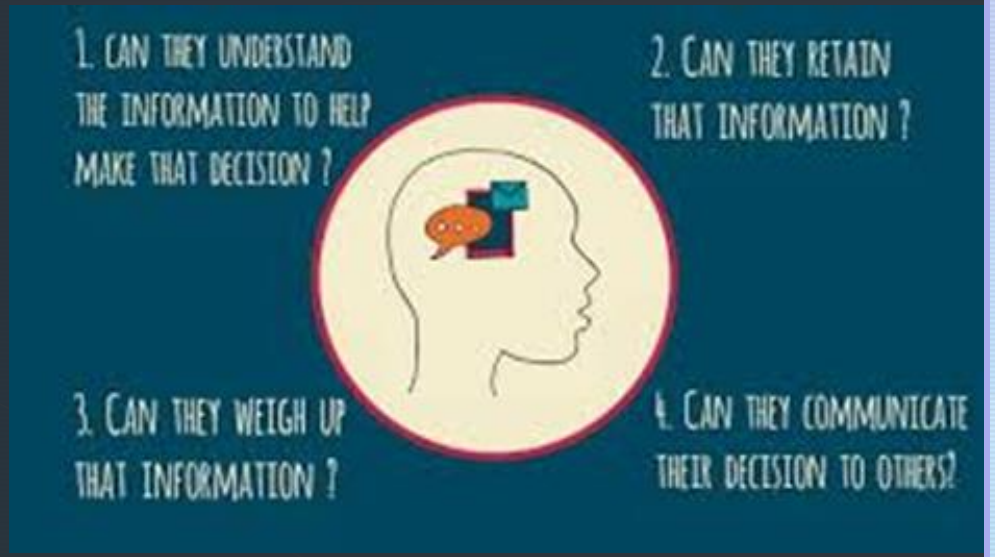
- Ability to engage in decision-making
- Surrogates

Competence vs. Capacity



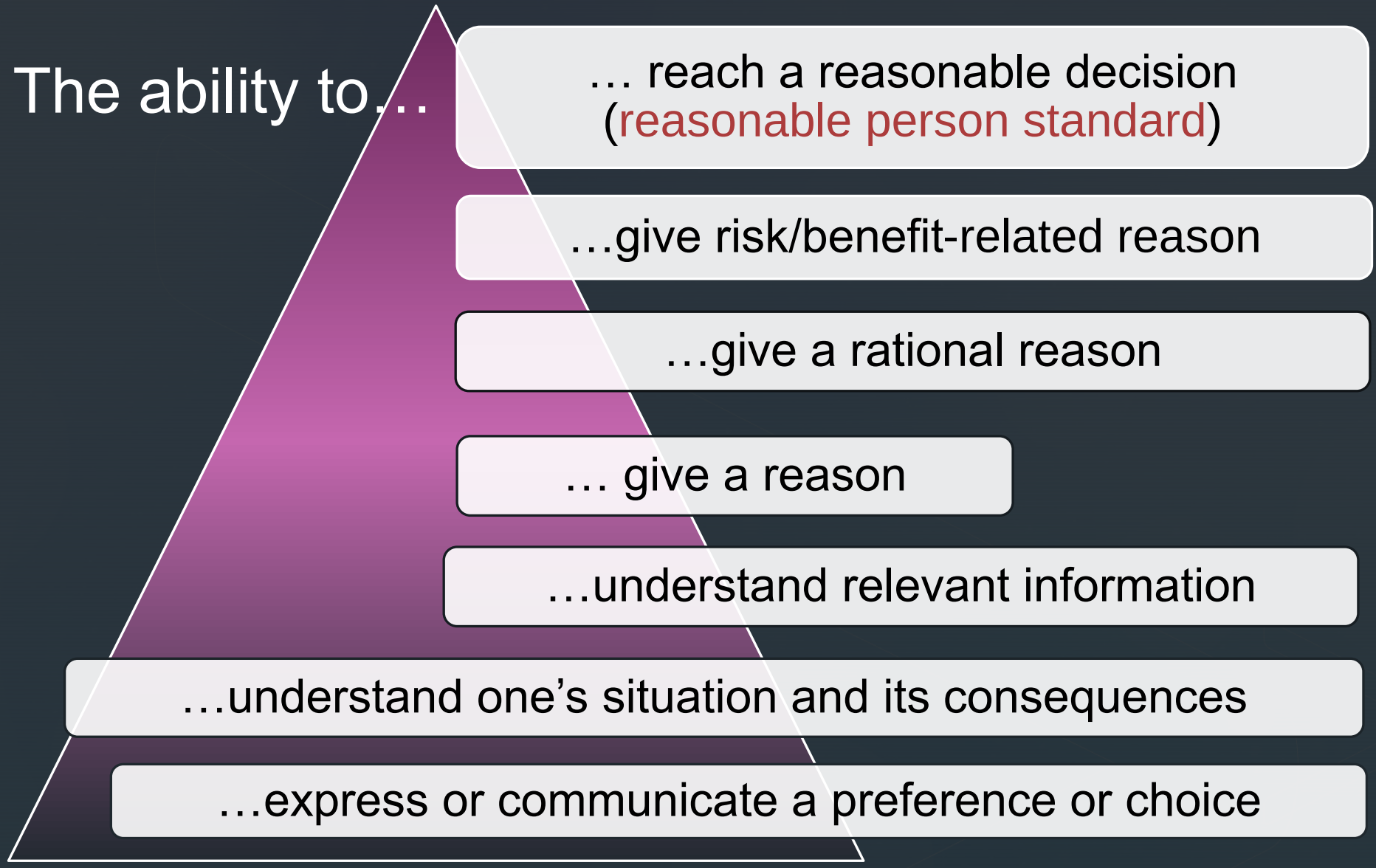
Informed Consent

- Understand and communicate
- Appreciation of/for the decision
- Reason through risks, benefits and alternatives
- Freedom from coercion or undue influence, voluntary



THESE ARE THE 4 BASIC ELEMENTS OF INFORMED CONSENT

Levels of Capacity



Ethical Significance & Potential Pitfalls

Autonomy & Respect for Persons

- Promote patients (even those declared incompetent by a court) to make as many decisions as their capacity allows and to do so in the least restrictive manner possible.
- Patients with **and without** capacity retain the right to refuse.

- Identify the wrong surrogate
- Convey power to a surrogate inappropriately
- May fail to obtain assent/dissent
- Assume permissibility or authority to consent treatment over objection

Back to our game….

Surrogate Decision-Makers

FORMAL

- **Health Care Agent**
  - Proxy
  - DPOA-HC
- **Guardian**
  - Private
  - Public

INFORMAL

- Family, friends or other persons with a known close relationship to the patient

Standard: Substituted Judgement then Best Interest

Surrogate Consent for DNR/COLST

Title 18 : Health

Chapter 231 : Advance Directives For Health Care, Disposition Of Remains, And Surrogate Decision Making

Subchapter 002 : Surrogate Consent

(Cite as: 18 V.S.A. § 9731)

§ 9731. Informed consent by surrogate for DNR/COLST order

Ethical Significance & Potential Pitfalls

- Power and scope of authority differs depending on type of surrogate decision-maker and the decision.
- Guardianship is not always the answer and may not solve the problem we are seeking to solve.
- We may end up complicating EOL decision-making

Let’s Play Another Round of Our Game

Common Misnomers

- Tools
- Process

Advance Directive vs. DNR/COLST

ADVANCE DIRECTIVE

Preference-based document *completed by a capacitated patient* to guide **future** medical decisions.

- Typically nuanced document requiring discussion, context and interpretation.
- Only a person with decisional capacity can complete/update one.

DNR/COLST

Outcome of shared a decision-making process; medical order c*ompleted by a clinician,* requires informed consent, and is intended to guide **current** treatment decisions.

- Based on patient's *current medical condition* **and** their *goals and values*.
- Consent can be provided by someone other than the patient.

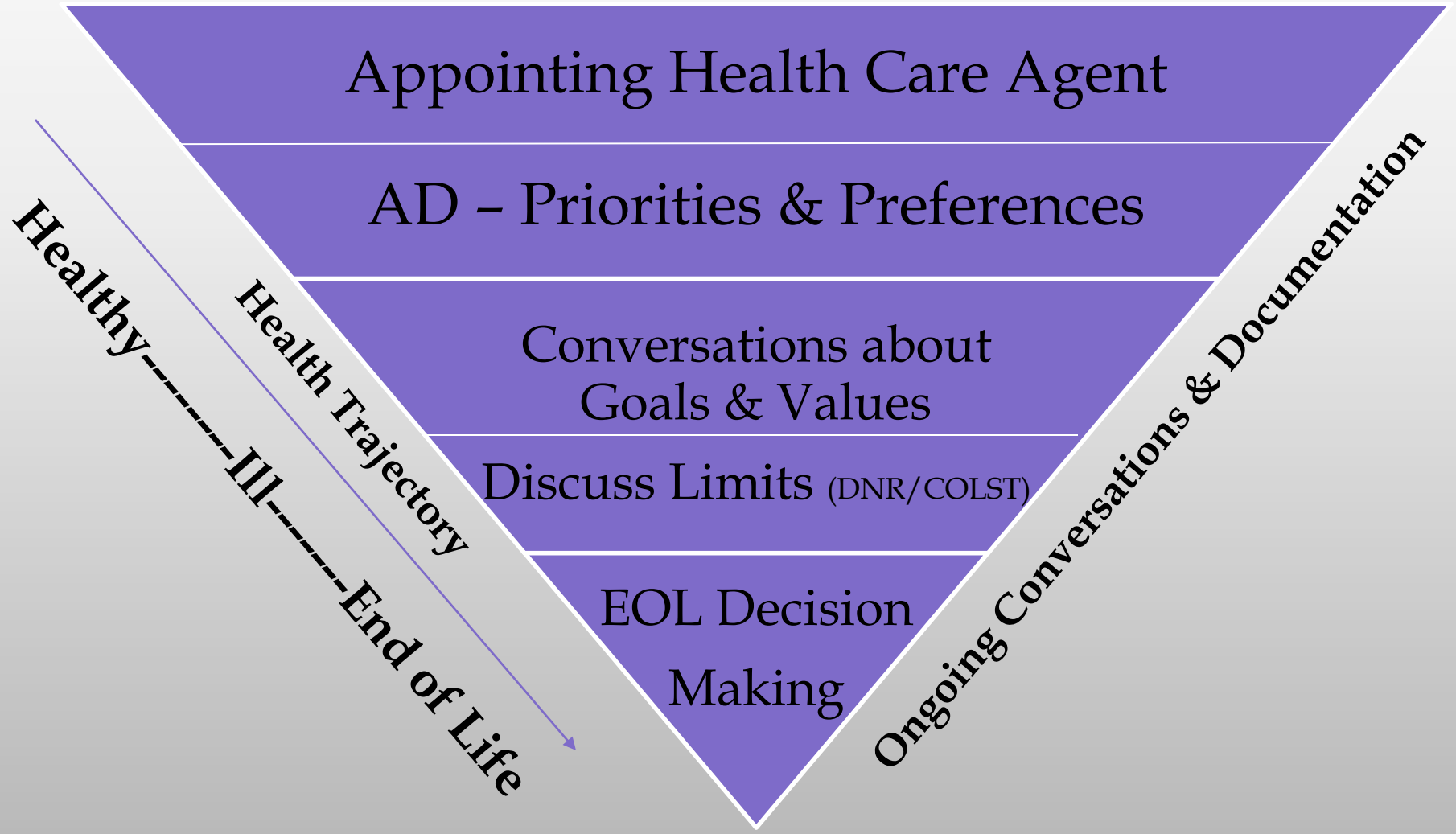
Back to Round 2:

Advance Care Planning (ACP)

An ongoing process of discussing, understanding, planning and potentially documenting an individual's goals, values and wishes for future

health care

ACP Continuum



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

Execution of Advance Directives

Misinformation

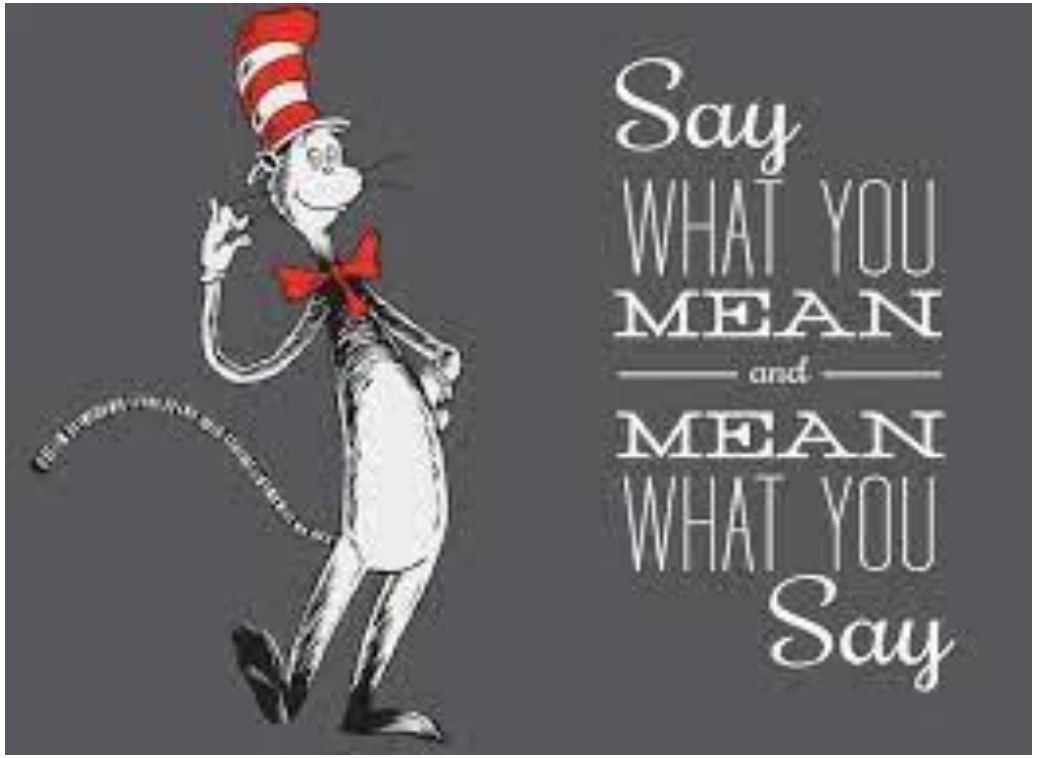
- Witnesses CANNOT be the patient's agent, spouse, parent, adult sibling, adult children or grandchildren
- Health care providers may serve as a witness
- No notary requirement and notary can't take the place of having 2 witnesses

Misnomers

- ACP and ADs are not the same
- Witnesses and Explainers have different responsibilities
  - Explainers can serve as one of the two required witnesses

Ethical Significance & Potential Pitfalls

- Patient autonomy & self determination
- Artificial barriers to completion of AD documents
- Delays to timely decisions, particularly at EOL
- Missed opportunity to ensure alignment of care and treatment with patient goals and values


Say
WHAT YOU
MEAN
and
MEAN
WHAT YOU
Say


WORDS
MATTER!

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